

The Sun

Newsletter

Summer 2022

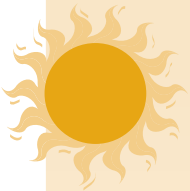
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On speaking with a fellow human being,
by JMK Behavior's founding team member, Jodi Karabin
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Adulting



Our mission

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

Growing up to be a capable, responsible member of the community can be a difficult and confusing process. Many of us look to our role models for direction. But if they don't exhibit appropriate behavior, we could become stymied in our adulting process.

Roadblocks to adulting also include situations that are out of our control. The Great Resignation, for example, has depleted the number of available job coaches and direct support professionals (DSPs), so people with autism spectrum disorder (ASD) and new jobs have had to postpone their starting dates.

For some currently enjoying supported employment, patronizing coworkers feel like a roadblock. Historically, people with ASD were thought to have below-average IQs, but studies show that "...ASD was less strongly associated with intellectual disability than traditionally held" (<https://pubmed.ncbi.nlm.nih.gov/21272389/>).

Being nonverbal also does not equate with a low IQ. For example, Temple Grandin, Ph.D.—a university professor, consulting designer of livestock-handling

equipment, and best-selling author as well as an expert on animal behavior and a renowned autism advocate—did not talk until she was 3 1/2 years old, notes her website: "She was fortunate to get early speech therapy" in the 1950s (<https://www.templegrandin.com/>).

In this issue of *The Sun*, seven individuals with ASD and a range of verbal skills share how they feel about adulting and its varied roadblocks:

- Clifford Brooks is a Pulitzer Prize-nominated poet-author.—**p. 3**
- Lauren Shepler is a married writer, researcher, and storyteller.—**p. 4**
- James Turner III works as a legislative assistant in the Missouri House of Representatives and as a statehouse reporter for *The Missouri Times*.—**p. 5**
- Tyler Manelski, Paul Miller, and Andrew Simpson participate in Autism Delaware's adult services program known as Productive Opportunities for Work and RecreationSM (or POW&RSM, for short).—**p. 6–8**
- Matt Sticinski is waiting for a job coach so he can begin his new job.—**p. 9**

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The McNesby Act and another push by autism advocates

Even when Delaware's autism advocates successfully push through legislation that will provide much-needed support to individuals and families affected by autism spectrum disorder (ASD), the advocacy continues. Take, for example, the passage and enactment in 2019 of the Michael McNesby Full Funding for Adults with I/DD Act. ("I/DD" is an abbreviation for intellectual and developmental disabilities, a designation that includes ASD.)

The McNesby Act promised funding for the workers who support adults with I/DD. At Autism Delaware, these workers are called direct support professionals (or DSPs), and they provide the basic needs of daily life in the homes of people with ASD who require individualized care. DSPs also serve as job coaches who enable people with ASD to work meaningful jobs and to enjoy social and wellness activities, all in their communities. In other words, DSPs are essential to full and inclusive lives for people with ASD.

Unfortunately, the Michael McNesby Full Funding for Adults with I/DD Act had not been fully funded. As a result, support workers were receiving the minimum wage for their essential contribution. Like other I/DD agencies, Autism Delaware had been constrained by state and federal reimbursement rates, so we pushed for the ability to pay all DSPs a family-sustaining wage.

The COVID-19 pandemic magnified this issue as it drove many DSPs away.

DSP vacancies are at an all-time high, and the lack of care is having a devastating impact on Delawareans with I/DD and their families.

In April, Delawareans with ASD and their families again shared their personal stories with their state legislators on Smart Cookie Day and advocated for full funding of the McNesby act.

In late May, the Delaware General Assembly's joint finance committee (JFC) announced that it was adding funds to the state's budget for fiscal year 2023 for the specific purpose of adhering to the promise of the McNesby Act by fully funding it.

And on June 28, Del. Governor John Carney signed the FY2023 budget that includes full funding! In an interview with WMDT, Del. Senator Laura Sturgeon (D-Dist. 4) said "We finally fully funded the McNesby Act. That is money that helps support people with intellectual disabilities. It's something that this general assembly made a commitment to several years back" (<https://www.wmdt.com/2022/06/gov-carney-signs-fy23-budget-as-lawmakers-prepare-to-wrap-up-legislation-session/>).

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Brendan O'Neill
President
Board of Directors

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Q&A with Clifford Brooks

What do you think being an adult looks like, and what training or schooling did you go through?

Being an adult means taking responsibility for your actions and the way you respond. I am not broken or ill-equipped. Once, I felt that way, and then I realized the gifts autism brings if we understand the mindset. I built my company, the Southern Collective Experience, and wrote three books to build a life that makes sense to me and absent the irritations no one wants.

What do you like to do, and what did you do to become good at it?

I love to write. I was nominated for a Pulitzer. I love my job. I love not dealing with toxic people. I love exercise and reading. I became good at it by practice and an innate disinterest in what other people think. I love knowing that my instincts about not worrying about most social norms allow me to live in peace.

Dream big. Autism allows us a focus and stubbornness to see our vision to fruition.

What do you dislike doing, and how did you learn to manage it?

I digest sensory input through shock waves. Strong smells, bright lights, close talkers, the feel of clothing, shrill voices, yelling, and people in general. The way I deal with it is through the creation of my company. That eliminates most irritations.

I take care of my laundry. I ask people politely to step back when I can smell their breath. I don't deal with anyone who doesn't improve my cool. I calm myself with meditation and discipline.

Where do you currently stand in your effort to become an adult, and what type of support do you enjoy?

I am empowered. The most annoying deal now is hearing that I don't look autistic. I find that those who do are always on the hit list of those who don't. I find jealous ignorance like that hilarious. I deal with stimming. I twitch and bark. I talk to myself in bursts. I calm myself so I don't do it in public. I do not agree with making my issues a common problem because I refuse to learn coping skills.

We ask folks to help us be comfortable. Let's return the favor.

I don't make my condition someone else's problem. As an adult, I note now what blessings autism brings me. I have a wonderful therapist. I don't get involved with differing autism organizations' turf wars. As an adult, I love who I am and thank God for my unique mind. I never blame autism for bad behavior. I am content alone. However, recently I've met a woman who innately understands me.

Never, ever settle.

What support do you need to meet your adulting goal, what is getting in your way, and how are you managing to get it?

I maintain my good health practices. I work on my Adulting with Autism courses on Teachable. I don't make excuses or fall prey to self-pity.

I dedicate myself to taking control of my life and creating a safe space only those I trust may enter.

I write new books. I waste no time with those who lash out at me due to my ability to create at a level appealing to a wider audience.



Clifford Brooks is the poet-author of three books, *Athena Departs: Gospel of a Man Apart*, *Exiles of Eden*, and *The Draw of Broken Eyes & Whirling Metaphysics*—which was nominated for a Pulitzer Prize. The 47-year-old Georgia native is also the founder of the [Southern Collective Experience](#), the host of [Dante's Old South](#) on NPR (WUTC 88.1FM), and editor-in-chief of [The Blue Mountain Review](#), a journal that features fiction, poetry, creative nonfiction, art, and interviews with current creative intellectuals. An autism advocate, Brooks shares what he's learned about living a creative life and adulting with autism on [Teachable](#), an online course and coaching platform.

What is “adulthood”?

by Lauren Shepler

Is it reaching physical maturity or legal age?

Is it a life event, such as moving out, joining the military, obtaining a job, purchasing a car or home, or creating a family?

Is it based on character traits, such as being responsible, trustworthy, and respectful?

Physically and by law, I am an adult. I can vote and run for certain government offices.

I’ve held jobs, even while experiencing stress—and sometimes, unsuccessfully.

I can drive, but traveling to certain places is overwhelming.

I’m married, and I lived with my parents up until then.

People sometimes misunderstand my intentions. I try to be a good person, with the knowledge there is always room for improvement.

I also find certain terminology quite confusing, especially that in government, banking, and the medical field.

And aspects of friendships are still a mystery.

Adults have varying life experiences, culture, knowledge, abilities, and different obstacles, which result in different accomplishments,

making milestones unique to the individual.

I have come to learn my adulthood is unique to my own challenges and life experiences. I received my autism diagnosis at 30 years old. During my teens and twenties, I encountered bullying and challenges in making friends, dating, driving, balancing school and work with activities and responsibilities, and navigating society—in part because I didn’t know about my autism. Once I learned about my autism and co-occurring anxiety, I started to celebrate milestones, such as driving on the interstate and going to a professional soccer game or on a date. This helped give me confidence. Additionally, I started learning about my strengths, challenges, and my rights and the ways I could ask for support. People may have similar experiences, yet our sense of these experiences is different, and this difference works to shape what each “adulthood” is.

Throughout my years of life as an individual with autism and anxiety, I’ve experienced pressure to conform to societal expectations. But as I learn and experience new things, I think less about societal expectations and,



Lauren Shepler is a disability advocate, researcher, and writer. She shared her writing as a storyteller at the 2016 Columbus (Ohio) Arts Festival.

rather, what helps me move forward. I’ve learned that family, faith, therapy, particular hobbies, plain language, slowing down to monitor my emotions and body, certain workplace accommodations, all help me function as a better daughter, spouse, coworker, and person.

“Do the best you can with what you know and what you have” is a sentence I once heard. This is appropriate for my adult experience.

Intro to adulting

What does it mean to become an adult, by Connections Academy, part of Pearson Education, Inc.—
<https://www.connectionsacademy.com/support/resources/article/what-does-it-mean-to-become-an-adult>

8 Ways to Be an Adult, by John Kim, LMFT, on the Psychology Today website—
<https://www.psychologytoday.com/nz/blog/the-angry-therapist/201702/8-ways-be-adult>

Living on Your Own: The complete guide to setting up your money, your space, and your life, by Pierre A. Lehu, Quill Driver Books—<https://quilldriverbooks.com/>

What I dislike doing, and how I learned to manage it

by James Turner III

As an adult on the autism spectrum, I often do things outside my comfort zone. Of course, being uncomfortable with tasks isn't something exclusive to people on the spectrum; however, given our neurological makeup, endeavors that may be considered simple for neurotypical people can be much more daunting for us.

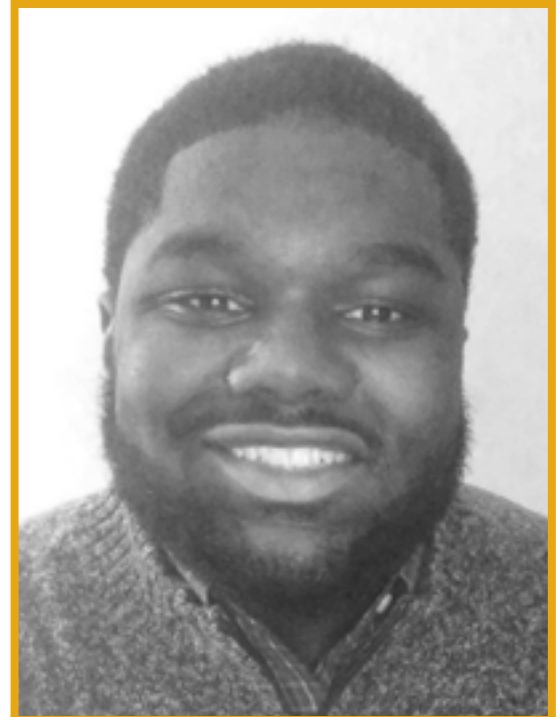
For me, answering random phone calls and calling people has been a part of my responsibilities at work. I've had to brace myself often when I had to make or initiate phone calls with unfamiliar people. I can do it in a limited capacity, but the more frequently I have to do it, the worse my anxiety becomes. Phone calls make me so uncomfortable that I prefer electronic communication or even face-to-face interactions.

One thing that motivates me is my sense of obligation. Because I agreed to do something that elicits discomfort, I at least have to try to

follow through. It's important to remember: The goal of overcoming my anxiety and being successful in my career may be challenging, but I'm making progress.

Another thing that is hard for me is advocating for myself. When I ask for what I need, I feel awkward or people may not respond appropriately. My anxiety has often caused me to neglect my needs or procrastinate asking for help.

Overcoming a feeling of awkwardness and anxiety requires asking myself important questions: "Is it worth going without what you need? What will happen if you don't get what you need?" Then, I consider the consequences I've faced in the past when I hadn't received the help I needed. And I realize it's worth the discomfort to ask for what I need. I've often felt better afterward because either I'll be accommodated or a level of uncertainty will be alleviated so I can work on moving towards another solution.



While working toward a bachelor's degree in political science and government from the University of Missouri, St. Louis, James Turner III began work as a legislative assistant in the Missouri House of Representatives and as a statehouse reporter for *The Missouri Times*. As a member of The Associated Students of the University of Missouri, Turner has also served as a lobbyist and chapter president.

Delaware college and university job and internship programs

Delaware College of Art and Design: <https://dcad.uloop.com/jobs/index.php/internships>

Delaware State University: <https://www.desu.edu/student-life/career-services/student-services/internship>

Goldey-Beacom College: <https://info.parkerdewey.com/gbc>

Strayer University: <https://careercenter.strayer.edu/>

University of Delaware Job & Internship Search

• **undergraduates:** <https://www.udel.edu/students/career-center/students/job-search/>

• **graduate students and postdocs:** <https://www.udel.edu/students/career-center/graduatestudents/>

Wesleyan College: <https://www.wesleyan.edu/career-center/students/jobs-and-internships/index.html>; <https://www.wesleyan.edu/career-center/students/jobs-and-internships/cardinal-internships.html>

Wilmington University: <https://www.wilmu.edu/coel/internships.aspx>

Tyler Manelski's story

by **Carla Koss with translation**
by **Tyler's sister, Gracynn Burnes**

Now that Tyler Manelski is out of high school, he feels a newfound independence as well as the responsibilities of being an adult.

"I'm more confident," begins the 23-year-old, "and better at recognizing mistakes I made in the past and today. I had a bit of a temper, resulting in me feeling frustrated throughout my schooling. My previous behavior is not something I am proud of, and I do wish I had applied more effort in school.

"I will say," adds Tyler, "getting to this point mentally hasn't been easy. I recognize that I made mistakes, learned, persevered. And here I am."

Currently, Tyler participates in Autism Delaware's adult employment program known as Productive Opportunities for Work and RecreationSM (or POW&RSM, for short). With a POW&R employment services manager for support, Tyler works part time in the commissary at Delaware Park Casino, delivering food and alcohol to the casino's restaurants and bars.

Recently, Tyler was presented with a job opportunity at Nemours Children's Hospital: "To do the same work, but it's full time now, so more opportunity."

With more work opportunity comes the hope for living on his own.

"I move in July 15th," says an enthusiastic Tyler. "This is a big step. I'm nervous and a part of me doesn't even feel ready, but I am excited to journey to this new change in my life. I have been waiting for this moment for a while now.

"I am assured that my resources are adequate to fit my needs," continues Tyler. "Eventually, I may need help financially, like with my rent or electric bill, but I want to try on my own first."

Reflecting back on his life so far, Tyler shows his disbelief through his words: "This is crazy now that I think about it. I can't believe I made it this far. And I am grateful for those who helped me get here."



Clip Art

Got a story to share?

Autism DelawareSM would like to hear how you or a loved one is either learning to adult with autism or are currently putting your skills into practice. Your story will be placed as a blog on the Autism Delaware website.

Send your story as a Word doc, plus a high-resolution color photo and contact information, to Carla.Koss@delautism.org.

From making countless mistakes to following instructions perfectly

by Paul Miller

Over the years, I have learned to engage more with my peers and speak up for myself. I have been participating in office activities and events, such as the Art Gala and Nintendo gaming matches. In competitive activities with friends, I've learned to curb my emotions and not lash out if I lose or be a jerk if I win.

Learning office etiquette was difficult for me because I had never worked in an office before and had only a vague understanding of how people act in business. I've learned from countless mistakes, and I now go out of my way to teach new members of our branch how to do our line of work.

A particular example of my growth happened on the last day of a previous job I had. One of the supervisors was angry with me because they [sic] believed that I had not followed instructions when I actually had. After this supervisor brought it up with my boss, the two of them spoke to me about it. I told them that I had followed what the supervisor had instructed and that the other employees heard the directions the same way I had. After confirming what I said, the supervisor admitted they had made a mistake and apologized.

In my present job, I have the support that recognizes my contribution and potential.



Paul Miller works as a solar panel application processor with Green Power Connection at The Precisionists, Inc. (TPI).

Hone your business and personal development skills



Clip Art

6 Business Skills You Need and How to Improve Them can be found on the Indeed job site at <https://www.indeed.com/career-advice/career-development/business-skills>.

Also on the Indeed job site: *9 Ways To Improve Your Personal Development Skills*: <https://www.indeed.com/career-advice/career-development/improve-your-personal-development-skills>.

This is likely the No. 1 thing affecting your job performance (adapted from *Bring Your Brain to Work: Using Cognitive Science to Get a Job, Do It Well, and Advance Your Career*, by Art Markman) is reprinted with permission from Harvard Business Review Press and can be found at <https://www.fastcompany.com/90361698/how-you-should-approach-learning-at-work>.

Defining “an independent adult”

by **Andrew Simpson**

To me, an independent adult is someone who can be depended on by others (rather than being dependent); someone with a home, a car, and maybe a family of his own; someone who can handle his own finances and work situation.

I have struggled with my finances, so I work to fix them every day by paying off my debts and adjusting my budget to address new challenges. I

can do this because I have a well-paying job working on something I love to do: IT software, especially programming. The company I work for not only pays well above minimum wage but also lets me work at my own pace.

Most of what I know about computers is self-taught. I took an interest in this early on and built up a large amount of experience by watching and doing. Anyone can learn anything simply by googling it and looking it up on YouTube.

Usually, working at a computer requires people to sit still for long periods of time, but my limbs will begin to shake when I sit too long. Thankfully, I work at a place that understands and lets me move around for three minutes at a time. This is because I have proven that I can go above and beyond expectations with work when allowed to do things at my own pace.

As an adult with autism, I face two other challenges on the road to a full and independent life. One is being taken seriously. Many people will look at me—and see a child. I need to put a lot of effort into proving that I am a mature, capable adult deserving of respect.

Many people will look at me—and see a child. I need to put a lot of effort into proving that I am a mature, capable adult deserving of respect.

The second challenge has been getting a driver’s license. To take the DMV’s driving test, I need a vehicle, but

to get a car, I need a license! Fortunately, I found a driving program that will train me and provide a vehicle. So, now, I need enough spare money in my budget to pay for the program.

Yes, becoming an independent adult on the spectrum can be a challenge. However, it is not impossible. It takes persistence, effort—and a bit of understanding from the people around you.



Andrew Simpson is an IT contractor at The Precisionists, Inc., in Delaware and an aspiring game developer.

Bridging the communication gap

A Neurotypical’s Guide to an Autistic Communication Style, by Yulika Forman, Ph.D., LMHC: <https://www.linkedin.com/pulse/neurotypicals-guide-autistic-communication-style-forman-phd-lmhc>

Tips for Talking to Adults on the Autism Spectrum, by Margaret Walsh, M.A., BCBA: <https://www.mayinstitute.org/news/acl/asd-and-dd-adult-focused/tips-for-talking-to-adults-on-the-autism-spectrum/>

Neurotypicals: Listen to Our Words, Not Our Tone, on the Autistic Science Person website: <https://autisticscienceperson.com/2021/01/09/neurotypicals-listen-to-our-words-not-our-tone/>

Goals
Work, travel, friends!

When Matt Sticinski was about to graduate from Christiana High School, a job was set up for him through ServiceSource Delaware, but because of the COVID-19 pandemic and the Great Resignation, the agency was short a job coach for the 21-year-old. He'd been transitioning to adulthood since he was 14; now, he waits.

What is your new job?

"Book store."

How did you train for it?

"Data entry and collected books at school library. School work: math work sheet and reading: Good about that. Like reading books."

What else did you learn that will help at work?

"How to have a conversation. I say 'Hi,' 'Nice to meet you, too. How's your day?' 'What'd you do last night?' Have a conversation. Learn about them. Share at same time."



Do you have any other plans in addition to working?

"Want to travel overseas." According to Matt's mom, Virginia, she and her husband met Europeans in Croatia who said Slovenia is "Europe's best-kept secret." The whole family hopes to visit in 2023.

What do you like to do at home?

Matt enjoys playing video games, notes Virginia, but he loves being around people: "He's very social, prefers being in the company of others."

"See [school] friends," explains Matt. "Will wait for them."

"You don't have to wait for them to call," adds Virginia. "Get their phone numbers so you can call them."

"That's nice," smiles Matt.

The McNesby Act and another push by autism advocates

Continued from p. 2

Our state legislators and governor understand the need for a care-giving workforce that's paid a family-sustaining wage for their physically and emotionally demanding work. But what about tomorrow? And what about the financial demands for FY2024? Or FY2025?

And here's another crucial piece of information: The number of Delaware students with an educational classification of autism gets bigger every school year. In 1991, there were 152. There were 2,357 in the 2018-19 school year (before the pandemic shut down our classrooms).

What happens to these children when they turn 21 and age out of the educational program? How many will need a DSP to coach them through the new job jitters and support them in their desired work as well as in their volunteer and social activities in the community? Will more legislation be required to support each individual with ASD so each has the opportunity to learn, grow, and live a full life as an included and valued member of the community?

I admit, I have been an avid proponent of the McNesby Act. I have witnessed firsthand how my daughter's struggles with ASD are exacerbated without the predictable daily routine and consistent care she received from several beloved Autism Delaware DSPs. Lorraine requires skilled personal care from the moment she wakes up in the morning until she goes to bed at night. She cannot talk, use sign language, or read. Her care is further complicated by type 1 diabetes. Plus, due to the pandemic, Lorraine lost her volunteer job that she had held for 17 years.

Actually, I am an avid proponent of any legislation that will improve the lives of people and families affected by ASD. Please join me and Autism Delaware's advocacy grassroots effort. We could use your ideas, skills, and energy when we make another push on behalf of our loved ones on the autism spectrum.

For more information, visit <https://www.autismdelaware.org/get-involved/advocate/>.

Assuring the continuation of programs and services

by Brian Hall, M.S.W.

We are facing significant challenges to some of our services, and we have placed indoor, in-person events on pause during the pandemic out of concern for the safety of our community. But we are still serving people and families affected by autism spectrum disorder (ASD) across the First State, every day—and we have been throughout the pandemic.

Our first priority, from the start of the pandemic to today, is to provide the best family support and adult services that we can. To achieve this goal, our dedicated staff in family support went above and beyond to learn to use telehealth tools and implement virtual support services. And our heroic direct service professionals (DSPs) undertook a training program to help businesses and participants understand how to use COVID-19 safety protocols in the workplace to protect themselves from infection.

Their efforts have paid off. Our family support program has offered services without interruption since the pandemic started, staff members have been able to expand services in the last year, and they remain open for new contacts and referrals!

Autism Delaware hopes to adequately staff all programs and services.

To apply, visit <https://www.autismdelaware.org/about/work-with-us/>.

While our adult service program lost many staff members to the Great Resignation and many community partners to business closures, the program has maintained outstanding support for the current roster of participants but in reduced levels across the state. However, we don't have enough personnel to service everyone on our vocational and supportive living rosters. We are doing all we can to attract personnel, including raising hourly wages and providing signing bonuses.

Our struggles are no different than those of other service providers in our nation and across our state. In fact, Delaware service providers face personnel challenges that are so significant and widespread that the Division of Developmental Disabilities Services (DDDS) has documented the issue.

Serving people and families affected by ASD since 1998—and through the COVID-19 pandemic

- Family support services
 - Autism Care Team (ACT) program
 - Family navigation
- Adult services
 - Community-based vocational services (Productive Opportunities for Work and RecreationSM, or POW&RSM, for short)
 - Personalized supported living services
- Awareness
 - Website and online resource guide
 - Social media
 - Quarterly newsletter (*The Sun*)
- Advocacy: For details on this spring's advocacy push, turn to page 2.

I am so proud of every staff member who continues to give it their all for the individuals and families in our care. But these days, we are frequently saying no or asking families to be patient with us. This is so hard for us! I don't have the answers. I don't know when we will offer the array of activities that have been offered in the past, like camps, ball games, and train rides. We know that community activities are important for all members of the family, but in the last couple of years, COVID has presented a danger to participants in all of our programs. So our reintroduction of some of our programming has been slow and cautious.

Please understand, COVID-19 has been a significant challenge not only to people and families affected by ASD but also to our staff members. Like you, our existing staff faced a sudden shutdown, having to jerry-rig safety measures while keeping their homes running as smoothly as possible, and many found themselves struggling with issues like child care and supporting their children with virtual schooling.

Politically inspired voices are claiming that restrictions are no longer necessary. But we at Autism Delaware follow the science and will remain cautious as opportunities for community engagement begin to increase. Once we put best practice in place, we will feel confident in our ability to maintain health and safety for our clients and our staff.

Please be assured: We want to get back to better than normal. We are working on it and will let you know as soon as we're able.

Meet Alex, the Autism Delaware bear

Keeping acceptance and inclusion going in Alex Eldreth's name

The statewide introduction of Alex, the Autism Delaware bear, was among the planned activities to celebrate Autism Acceptance and Inclusion Month in April.

With one in 44 children being diagnosed with autism spectrum disorder, most people are now aware of ASD, so Autism Delaware joined the advocacy movement for autism acceptance and inclusion.

The brainchild of Autism Delaware communications and marketing manager Lisa Walenceus—with a lot of energy and input from Autism Delaware volunteer and community engagement specialist Susan Campbell—this teddy bear represents universal acceptance and inclusion as advocated by Alex Eldreth, who served as Autism Delaware's policy and community outreach director from April 2014 until his unexpected death in November 2017.

As Autism Delaware's key contact person on all advocacy issues, Alex put to work his hard-earned experience advocating on behalf of foster children and the mental health, LGBTQ, and MS communities. In his first six months at Autism Delaware,

Alex joined forces with other advocates to assist in plans to change state systems for the better. He also grew a grassroots effort to advocate for legislation designed to improve the lives of people and families affected by autism, and he continued to identify potential legislative issues, all while promoting Autism Delaware's mission. For Alex, helping people and families affected by autism fit well with his drive for universal acceptance and inclusion.

His push for advocacy became his rallying call to families: "What makes advocacy successful?" he'd ask. "Grassroots participation!"

And the families came! On Smart Cookie Day at Legislative Hall, they shared their stories of daily life with loved ones on the spectrum and advocated for their loved ones' needs.

For the entire story, including the passage of the Alex Eldreth Autism Education Law, visit <https://www.autismdelaware.org/news-and-info/meet-alex-and-the-bear-named-for-him/>.



Donning his personalized hard hat, Alex, the Autism Delaware bear, began his Earth Day celebration on April 22 by visiting the new site of the Middletown Family YMCA. Joining Autism Delaware's social media campaign, Alex also reminded us that autism inclusion means creating workplaces where people's differences are accommodated and truly valued.



On April 20, Delaware Governor John Carney signed a proclamation stating that April is officially Autism Acceptance and Inclusion Month in the First State. Among the contingent from Autism Delaware was Hope Pearce. As a participant in Autism Delaware's adult services program, Hope works for a Sussex County chocolatier. She presented Gov. Carney with some of her work, hand-dipped chocolate-covered strawberries, before introducing the governor to Alex, the Autism Delaware bear.

On speaking with a fellow human being

by Jodi Karabin, LPC, BCBA, NCC, CADC, founding team member of JMK Behavior in Wilmington

I feel I should have known better in primary school, but my friends and I stared at the students with disabilities and asked each other “What is wrong with them?” It wasn’t until graduate school that I first learned about autism. In an elective on autism’s diagnosis and treatment, I gained a basic clinical understanding of the social and communication differences associated with the developmental disorder.

It was a starting point: I had one course in autism, the criteria to diagnose, and a list of standard strategies. I was off to train the world!

This daydream came to a screeching halt. *Why?*

Because I didn’t know how to communicate effectively with the individuals I was supporting. I was trying so hard to speak “correctly” that I missed my reason for having the conversation. I was not present with the person or, quite frankly, taking in anything the person said. I got frustrated, tried again, role-played countless times, and still found myself asking: “Was my pitch up?” “Was I condescending?” “Have I offended people?” “Why is it so hard?!”

And then, one day, I finally figured out the problem: It was me. It’s humbling to admit, but I was incredibly uncomfortable being around individuals identified with autism. *Ouch!* I had been ignorant and arrogant. I walked in with book knowledge and thought I was set. The entire focus of my interaction was based on which strategy I should use and working my plan of treatment. I was so caught up in my how-to list that I forgot I was speaking with a real person, a fellow human being.

Diagnosis and evidence-based practices inform treatment, but they don’t define a person or produce magical interventions. What turned on the proverbial light bulb for me was changing my cultural us-and-them mentality—and learning that I have challenges, too: some, the same; some, different. Now, I respect the range of ways that people have for receiving, processing, and expressing information.

Given that everybody is different, I asked a colleague to weigh in on this topic. Skye Pardini, BCBA, told me how she uses academics plus experience if she needs to adjust her communication style when speaking with someone with autism.



Clip Art

“I try to read the person,” noted Skye, “just as I would in any social encounter, and then provide a comfortable situation for all parties involved. I consider myself someone with social anxiety, like many people with autism, so I know identifying a mutual topic of interest can help set everyone at ease.

“If I have knowledge of the individual’s

communication skills prior to interacting,” continued Skye, “I will use this information to promote positive interaction, like providing longer pauses in conversation to allow adequate time for the individual to process the information.

“I also look for social cues from the individual so I can gauge if I need to make changes. For instance, is the person moving away from me because my volume may be making him or her uncomfortable? Or am I asking too many questions, making it challenging for the person to listen and respond?

“I think all communication would be more effective,” summed up Skye, “if we paid more attention to the person we are speaking to and less attention to what we want to say next.”

Jodi Karabin’s recommended resource

5 Tips for Working with Adults on the Autism Spectrum, by Brittany Cerny, M.Ed.

<https://www.appliedbehavioranalysisprograms.com/lists/5-tips-working-adults-autism-spectrum/>