PLUS: UNITED STATES MILITARY SECTION

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MAGAZINE
OCTOBER 2023
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IN THIS ISSUE:

LIFE TRANSITIONS

PLUS:

TIPS to HELP YOUR CHILD THRIVE in SCHOOL THIS YEAR

ALSO • DOMINIC CERTO:

FINDING YOUR PLACE

AND • BELLA'S STORY

MADE of MILESTONES

EMPLOYMENT & TRANSITION:

VIEWING THE WORLD with AUTiSM

Matthew Kenslow

EP MAGAZINE
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52
YEARS
CELEBRATES

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EMPLOYMENT & TRANSITION

EP SPECIAL SECTION • THRIVE AT SCHOOL •

ON OUR COVER

Matthew Kenslow says "I believe that Autism has given me a different lens with which to view the world." Read his uplifting story and much more in our Annual Employment and Transition Issue. *Coverage begins on page 12.*

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Moving Forward

Matthew Kenslow's story is at the center of our theme this month, yet he is just one of the inspiring people in this issue.

Matthew Kenslow is a young person living with Autism. He deftly describes his condition in this month's cover story, writing "I view Autism as having an enhancer plugged into my brain, enhancing my perception in life, making things either very easy or very hard." He recounts the various challenges that he has faced while growing up, and celebrates his most recent achievement – starting a fulfilling job as a substitute school teacher.

Matthew's story is at the center of our Employment and Transition theme this month. Yet he is just one of the inspiring people in this issue. 17-year-old Bella Aguilar, who struggled through years of seizures and setbacks due to drug resistant epilepsy, has responded remarkably well to VNS Therapy™ and will begin college next year. Jessica Jankus was born with multiple developmental delays. As her parents approached their seventies, they found an accessible group residence for her, and she has adapted well to the transition.

> "Young people with disabilities often face distinct challenges in their pursuit of an independent lifestyle."

The transition to adulthood normally involves pursuing an occupation in order to live an independent lifestyle. Young people with disabilities often face distinct challenges in this regard. Our contributors this month have valuable advice and resources that can help families make progress on this front. "Guiding Secondary Students with Disabilities toward Successful Employment: A Collaborative Approach," by Jenn Adams, and "Self-Esteem, Accomplishment and Purpose: Making Competitive Integrated Employment Work by Arturo Cazares offer solid guidance on the topic.

Two informative pieces make up "An EP Special Section:Thrive at School." Georgie Normand's article, "Can Dyslexia Be Cured? What the Latest Neuroscience Tells Us About the Prognosis," discusses the latest advances in science and technology, while Dr. Rebecca Jackson's contribution," Tips to Help Your Child Thrive this Year in School," offers practical advice to parents who work hard to help their child succeed in the classroom.

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Faye Simon

Editor In Chief

THE EDITOR IN CHIEF'S DESK

Faye Simon is a certified pre-K–8 teacher with a wide range of educational experience. She has worked in deaf/blind and infant stimulation programs, taught K–2 in public schools, and was a Head Teacher and Parent Coordinator for Head Start. She is Founder and President of the volunteer-run IES Brain Research Foundation. As EP's Editor In Chief, Faye sources and edits articles, creates partnerships with businesses and not-for-profit organizations, and develops relationships with EP's writers, corporate partners, readers and staff.

Information and Support for the Special Needs Community

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WHAT'S HAPPENING

UNITED BECOMES FIRST U.S. AIRLINE TO ADD BRAILLE TO AIRCRAFT CABIN INTERIORS

New tactile signage will help people with visual disabilities better identify row numbers, seat assignments and lavatory locations independently

United Airlines became the first U.S. airline to add Braille to aircraft interiors, helping millions of travelers with visual disabilities more easily navigate the cabin independently. According to the Department of Transportation, about 27 million people with disabilities traveled by air in 2019.

The airline currently has equipped about a dozen aircraft with Braille markings for individual rows and seat numbers as well as inside and outside the lavatories. United expects to outfit its entire mainline fleet with Braille by the end of 2026.

FRIENDLY SKIES: Braille markings identify an aircraft lavatory.

"Finding your seat on a plane or getting to the restroom is something most of us take for granted, but for millions of our customers, it can be a challenge to do independently," said Linda Jojo, Executive Vice President, Chief Customer Officer for United. "By adding more tactile signage throughout our interiors, we're making the flying experience more inclusive and accessible, and that's good for everyone."

In addition to adding Braille, United is working with the National Federation of the Blind (NFB), the American Council of the Blind (ACB) and other disability advocacy groups to explore the use of other tactile navigational aids throughout the cabin such as raised letters, numbers and arrows.

"We applaud United for taking an important step toward making its aircraft more accessible to blind passengers," said NFB President Mark Riccobono. "The flight experience is often frustrating for a number of reasons, one of which is the amount of information that is available exclusively through printed signs and other visual indicators. We hope to continue working with United to explore additional ways to make flying more accessible and less stressful for blind passengers."

"United is taking additional steps to create an accessible airline passenger experience through braille signage," said ACB Interim Executive Director Dan Spoone. "We appreciate the airline's continued exploration of additional in-flight navigational aids like large print and tactile indicators, and we encourage all airlines to follow United's lead in making air travel more inclusive for the blind and low vision community."

Visit **www.united.com** to learn more.

PHOTO COURTESY UNITED AIRLINES

WHAT'S HAPPENING

HAVE YOUR OR YOUR FAMILY LOST MEDICAID HEALTH COVERAGE? HERE'S WHAT YOU NEED TO KNOW

BY SAMANTHA LISS

The nation's health insurance system is undergoing tremendous upheaval as an estimated 8.2 million people will need to find new coverage since pandemic protections for Medicaid enrollees came to an end this spring.

MIND THE GAP: The most important step in retianing your Medicaid is to fill out, sign, and return your Medicaid renewal packet.

That's leaving many patients confused about how to get new medical insurance.

"It's an overwhelming task," said Taffy Morrison, who is working to connect Louisiana residents to new coverage through the nonprofit Southwest Louisiana Area Health Education Center. But Morrison reminds people: "Don't panic. There is help."

For many of those kicked off Medicaid, a state-federal health insurance program that covers people with low incomes and disabilities, new insurance will come from their employers. Others may need to turn to the Affordable Care Act online marketplaces to replace their coverage.

Elevance insurance officials told investors in mid-July they were seeing signs of movement from Medicaid to exchange plans as states ramp up reviews of who still qualifies for the public insurance program. The company, formerly called Anthem, reported 18.2% growth in its exchange plans from

COVER ME : PLANNING AHEAD TO AVOID GAPS IN HEALTHCARE COVERAGE

NAVIGATING THE PATH TO INSURANCE COVERAGE

The most important step: Fill out, sign, and return your Medicaid renewal packet. If you no longer qualify for Medicaid, that denial triggers a special enrollment period for you to find another source of coverage. You typically have 60 days before the loss of your Medicaid coverage to enroll in a new plan; the packets should arrive ahead of losing any coverage, so that should serve as a warning that a change in your benefits may be coming.

You also have 60 days from when you report the loss of coverage, not the date when you actually lost it, to enroll in a new plan. That clock starts when you submit a new application via **healthcare.gov**, according to federal guidelines. To avoid gaps in coverage, plan ahead. Most marketplace coverage begins the first day of the following month.

POTENTIAL COVERAGE OPTIONS FOR YOU AND YOUR FAMILY

Enroll in insurance through your job. Losing Medicaid triggers a special sign-up window for you to enroll in your employer's insurance, if available.

Enroll in an Affordable Care Act plan. If employer-based coverage is not available or affordable, you and your family may be eligible for a discounted plan on the exchange. If your portion of the monthly premium for the lowest-cost family plan exceeds 9.12% of your household income, your family members would qualify for an exchange plan that offers financial assistance.

Workplace insurance may be affordable for a father, for example, but not for the rest of the family. "In that situation, Dad should enroll in the employer-sponsored insurance plan and then they should go to the marketplace for the rest of the family," said Geoffrey Oliver, a navigator who leads Connecting Kids to Coverage, a program of Legal Services of Eastern Missouri.

YOUR KIDS MAY STILL BE ELIGIBLE FOR MEDICAID

Even if parents or guardians no longer qualify for Medicaid coverage, their children might. In some places, kids can qualify for the Children's Health Insurance Program, known as CHIP, with an annual household income of up to 400% of the federal poverty level, which equates to an income of $120,000 for a family of four. See **https://aspe.hhs.gov/topics/poverty-economic-mobility/poverty-guidelines**

BEFORE YOU TURN 19 AND LOSE CHIP COVERAGE

Some young adults will age out of CHIP coverage at age 19. For them, especially those with chronic health conditions, it's important to take advantage of the special enrollment period for an Affordable Care Act plan before losing public coverage.

If you turn 19 in the middle of the month — say, September — you should choose an exchange plan in August because most marketplace coverage begins the first day of the following month. This ensures you will not experience a gap in coverage when CHIP coverage expires.

PHOTO COURTESY DIGITALVISION/GETTY IMAGES

the year before, with its marketplace plans now covering at least 949,000 people.

To prevent gaps in insurance coverage, some states, such as California and Rhode Island, will automatically enroll people who lose Medicaid in such marketplace plans. But elsewhere, Morrison and workers at similar nonprofit health groups nationwide are helping people navigate the difficult administrative process of finding the right plan. Known as "navigators" or "assisters" and publicly funded, they work with patients free of charge.

Consumers should be wary of anyone charging to assist them in finding coverage — or pushing a particular plan. Misleading marketing has led some people to plans that aren't actually insurance, such as health care sharing ministries, which don't necessarily cover members' medical bills.

The dramatic reshuffling of insurance coverage comes with the end of federal covid-19 pandemic protections. States were barred from kicking enrollees off Medicaid during the pandemic to ensure people had access to health care. As a result, the program swelled by 30% from February 2020 to December 2022 to cover about 92 million people, including children who receive coverage under CHIP, the Children's Health Insurance Program. Now, for the first time since 2020, states have resumed checking whether enrollees remain eligible.

The first batch of numbers are rolling in. So far, more than 4 million people have lost coverage in 42 states and the District of Columbia. And in June alone, more than 50,000 of them lived in Louisiana, according to state data. Of the more than 151,000 beneficiaries' files the state reviewed in a single month, nearly 13,000 people no longer qualified for Medicaid but roughly 38,000 additional people lost coverage because they did not submit a renewal packet for the state to determine whether they still qualified.

Morrison's group of 50 navigators across the state will now try to make a dent in those numbers as coverage losses are expected to grow.

Patient advocates in Louisiana and elsewhere agree on one crucial first step Medicaid enrollees must take regardless of eligibility status: They must fill out and return their Medicaid renewal packets.

"That Medicaid paperwork, it's beneficial for everybody to finish it up," said Geoffrey Oliver, who leads Connecting Kids to Coverage, a program of Legal Services of Eastern Missouri that helps families navigate the enrollment process.

If people return the forms and are found to be ineligible, states pass along their information to online insurance exchanges such as **healthcare.gov**. The exchanges will follow up with people and share health plan options, functioning as another tap on the shoulder to prevent people from becoming uninsured.

People shouldn't assume they can't afford marketplace plans, insurance experts say. Many can enroll in low- to no-cost coverage. Roughly 2.7 million people are likely to be eligible for discounted plans, federal estimates show, representing about one-third of all those expected to be ineligible for Medicaid. Of those, about 1.7 million will qualify for zero-premium plans.

Another reason to fill out the packet: Even if adults in a household no longer qualify for Medicaid coverage, or now have employer coverage, children may still be eligible for public plans.

A message plastered on a billboard in Randolph County, Missouri, reminds people about Medicaid renewal in big, bold letters: "Don't miss this letter." About 34% of people living in the central Missouri county are covered by Medicaid, according to a tracker maintained by Washington University in St. Louis.

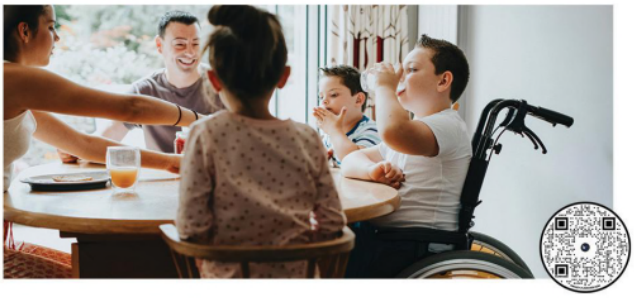
If people throughout the country fail to turn in the renewal packet, they run the risk of falling through the cracks, said Adrianna McIntyre, an assistant professor of health policy at Harvard. Being uninsured can lead people to postpone preventive care – and cause them to end up in debilitating medical debt if emergencies happen.

Most of the millions cut from Medicaid so far lost their benefits because they didn't complete the paperwork, not that they were deemed ineligible, according to KFF. And patient advocates worry enrollees may never have received the packet. Many recipients have likely moved and changed addresses but have not updated their contact information with states. Advocates fear those issues may be felt harder in places such as Louisiana, where many people have been displaced by floods and hurricanes in the past three years.

In some states, Medicaid recipients can check their eligibility status online. Elsewhere, they can ask free navigators, such as Morrison, for help checking on their packets.

ABOUT THE AUTHOR:

Samantha Liss, Midwest Correspondent, is an award-winning journalist who has covered the business of health care for the past decade. Her reporting at the St. Louis Post-Dispatch prompted dialysis provider DaVita to stop steering Medicaid patients into higher-paying private plans. Her work also helped spur a 2018 Missouri bill intended to protect patients from surprise medical bills. She is a proud native of the Midwest and based in St. Louis. She is a graduate of the Missouri School of Journalism.



WHAT'S HAPPENING

NIH-FUNDED STUDY SHOWS SMARTPHONE APP CAN IDENTIFY AUTISM SYMPTOMS IN TODDLERS

Improving accuracy of screening would reduce disparities in early diagnosis and intervention.

A STITCH IN TIME: The SenseToKnow app records and analyzes children's responses to short movies designed to elicit a range of behavioral patterns.

A tablet-based screening application for autism spectrum disorder (ASD) may improve early detection, suggests a study funded by the National Institutes of Health. Early detection is critical for access to early interventions that can have major long-term positive effects on symptoms and later skills. The app showed 87.8% sensitivity for detecting ASD, meaning it correctly identified most children with the condition. Its specificity – the percentage of children without ASD who screened negative – was 80.8%. By accurately identifying toddlers who warrant further investigation for ASD, the app may help healthcare providers ensure that children and families receive the support they need.

Healthcare providers typically screen toddlers for ASD using a parent questionnaire. However, studies have found that the accuracy of such questionnaires tends to be lower in primary care settings compared to research settings, particularly among girls and children of color. This can widen disparities in early diagnosis and intervention.

> ***"SenseToKnow's ability to reliably detect children diagnosed with ASD was consistent across toddlers of different sex, race and ethnicity."***

To address the need for more accurate ASD screening tools, researchers developed the SenseToKnow app, which records and analyzes children's responses to short movies designed to elicit a range of behavioral patterns. The app can track many early signs of ASD, including differences in social attention, facial expressions, head movements, response to name, blink rates and motor skills. The work was led by Geraldine Dawson, Ph.D., and Guillermo Sapiro, Ph.D., of the Autism Center of Excellence at Duke University, Durham, North Carolina.

Healthcare providers used SenseToKnow to screen toddlers ages 17 months to 3 years during a well-child visit. Of the 475 toddlers enrolled in the study, 49 were subsequently diagnosed with ASD and 98 were diagnosed with developmental delays without ASD. The app's ability to reliably detect children diagnosed with ASD was consistent across toddlers of different sex, race and ethnicity. Overall, participants who screened positive for ASD using the app had a 40.6% probability of subsequently being diagnosed with the condition. In comparison, only about 15% of children who screen positive using the standard parent questionnaire are later diagnosed with ASD. Combining the app with the standard questionnaire boosted the probability of a positive screen resulting in later diagnosis to 63.4%.

According to the authors, the study is a step forward in developing ASD screening tools that can reduce disparities in access to early diagnosis and intervention. They also note the importance of ensuring that children with a positive screening result are linked to appropriate referrals and services.

The study was funded by NIH's Eunice Kennedy Shriver National Institute of Child Health and Human Development (NICHD). Additional support was provided by NIH's National Institute of Mental Health and other organizations.

For more information, contact Alice Kau, Ph.D., program director in NICHD's Intellectual and Developmental Disabilities Branch at **nichdpress@mail.nih.gov** •

Reference

Perochon S et al. Early detection of autism using digital behavioral phenotyping. Nature Medicine DOI: 10.1038/s41591-023-02574-3(link is external) (2023)

ABOUT ABOUT THE EUNICE KENNEDY SHRIVER NICHD:

The National Institute of Child Health and Human Development (NICHD) leads research and training to understand human development, improve reproductive health, enhance the lives of children and adolescents, and optimize abilities for all. For more information, visit **www.nichd.nih.gov**.

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WHAT'S NEW AUTUMN ARRIVALS

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The Little Orchard is a cooperative game for children. The players have to pick up all the cherries before the crow can steal them from the tree. With good memory and a little bit of deduction, the game can be won, but if you forget which tiles have the crow on the other side, watch out! He'll eat all your cherries! This game stimulates memory, recognizing and naming colors and developing and experiencing the "we" concept. The fruit pieces are large, designed for smaller hands, and included is one sturdy basket for children to share. This cooperative game is designed to foster social skills, develop color recognition skills, and teach counting by ones, and to encourage a healthy attitude towards working together and listening!

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COLLEGE IS POSSIBLE

FOR STUDENTS WITH INTELLECTUAL DISABILITY

THINK COLLEGE CAN HELP!

BY MEG GRIGAL, PH.D.

Back to school for parents and family members of high school students with intellectual disabilities means grappling with transition planning. Figuring out the future can be challenging. Sometimes the options don't seem that appealing. One future path that might be worth exploring is college.

Did you know there are over 8000 students with intellectual disability (ID) who have attended college in the US? These students have taken college classes, joined clubs, gotten internships and jobs, and made friends on their college campus. More and more colleges and universities are creating inclusive postsecondary education (IPSE) programs enrolling students with ID.

Currently there are 324 inclusive postsecondary education programs in the United States and 153 of those are approved to offer access to federal student aid. Think College wants students with intellectual disability to have the same access to college as other students. We believe the option should be available to anyone who wants to go. A college education leads to good jobs, strong social connections, and an independent adult life. Our goal at Think College is to expand expectations and increase opportunities for students with ID, to go to college, get a credential, and get a job and life they love!

One obstacle to making college dreams come true can be a lack of awareness. Too often, families may hear college is unrealistic, or their educators may not know about the IPSE programs in their state. Think College is trying to change that. We have developed multiple places for educators and parents to learn more about what's out there.

THE "THINK HIGHER. THINK COLLEGE." CAMPAIGN.

To help spread the word that college is possible, we have created a new campaign, called Think Higher, Think College. The "Think Higher. Think College." campaign is building awareness and expanding access to college for students with intellectual disability. Our goals are to increase knowledge of inclusive college options and share information about the benefits and outcomes of students with intellectual disability attending college. We have a great 4-minute video you can share with your child and their educators to plant the seed of growing college dreams. There are also many free resources for parents, students, and teachers available at **https://thinkhighered.net**.

I HAVE SO MANY QUESTIONS!!

Parents and family members have lots of questions when starting a conversation about college. What makes a good IPSE program? How can we help our child prepare for college? How can we pay for it? These are questions we hear every day, so we have the answers to these and many other questions on our website. Below is a sample of the type of information you can find at **https://thinkcollege.net**

HOW TO APPLY

When students are applying to attend a college program for students with ID, there is typically a different admissions process than the one used by degree-seeking students. Unlike students who are applying to college through the standard admissions process, students will NOT need a regular high school diploma or SAT or ACT scores. They WILL need documentation of disability and support needs. Check the website of programs you are interested in to learn more about specific requirements

CAN I AFFORD IT?

College is expensive, and paying for it is never easy. The good news is, that students with intellectual disability can be eligible for financial aid, even if they don't have a HS diploma. Students can also now save for college through the use of an ABLE account. Others may get support from a community agency, such as Vocational Rehabilitation, or receive scholarships to help cover costs. To get more information visit our family resources page at **https://thinkcollege.net/family-resources**

THIS IS GREAT, BUT I THINK I NEED TO TALK TO SOMEONE

Well, you're in luck. We also have a HELP DESK with a team of folks happy to talk with you or send you answers to your specific questions. Just shoot us an email at **thinkcollegeTA@gmail.com** and we will get you the information you need.

WHAT KIND OF PROGRAMS ARE AVAILABLE AND WHERE ARE THEY?

Think College has a college search tool for students and families to see and compare inclusive postsecondary education programs around the country. Users can search for colleges by location, program features, school type, and get basic information about each program's acceptance rate, cost, and programs of study. But, online searches only tell you so much. It is really important to call or visit to get more information. Think College created a college search guide to help families and students ask the right questions and figure out what is important to them. To learn more visit: **https://thinkcollege.net/college-search**

THINK COLLEGE, THINK EMPLOYMENT

This October, as we celebrate National Disability Employment Awareness Month, we can also celebrate the strong connection between postsecondary education and employment outcomes.

ABOUT THINK COLLEGE

www.thinkcollege.net

Think College is a national technical assistance, research, and evaluation center dedicated to developing, expanding, and improving higher education options for students with intellectual disability. It is housed at the Institute for Community Inclusion at the University of Massachusetts Boston. Think College has multiple federally funded projects including the National Coordinating Center, the Inclusive Higher Education Network, Future Quest Island: Explorations, and Transition Leadership. Together, these projects strive to improve postsecondary outcomes for students with intellectual disability. Think College staff provide free assistance to students and families, secondary and higher education professionals, community providers, and policy makers to via our website, national help desk, and accessible resources. **https://thinkcollege.net**

Students with intellectual disability who attend postsecondary education, experience remarkable outcomes: 60-65% find competitive, integrated employment, compared to the overall 18-19% national rate and 51% earn higher wages than those who did not access postsecondary education.

The statistics paint a clear picture: higher education can be a game-changer for individuals with intellectual disabilities. It's a pathway to independence, better employment opportunities, and improved quality of life. National Disability Employment Awareness Month is not just a time to reflect on the progress we've made; it's an opportunity to envision a future where every individual has equal access to education and employment opportunities.

Join us in celebrating this month of awareness and empowerment and take the first step to learn more at https://thinkhighered.net. If you feel inspired, share some of our Think College resources with another parent, with a teacher, or with your child. You may just make someone's college dream come true! •

Funding information statement: Think College projects are funded by grants from the US Department of Education, Office of Postsecondary Education (Grant #P407B200001 and Grant #P407C210001).

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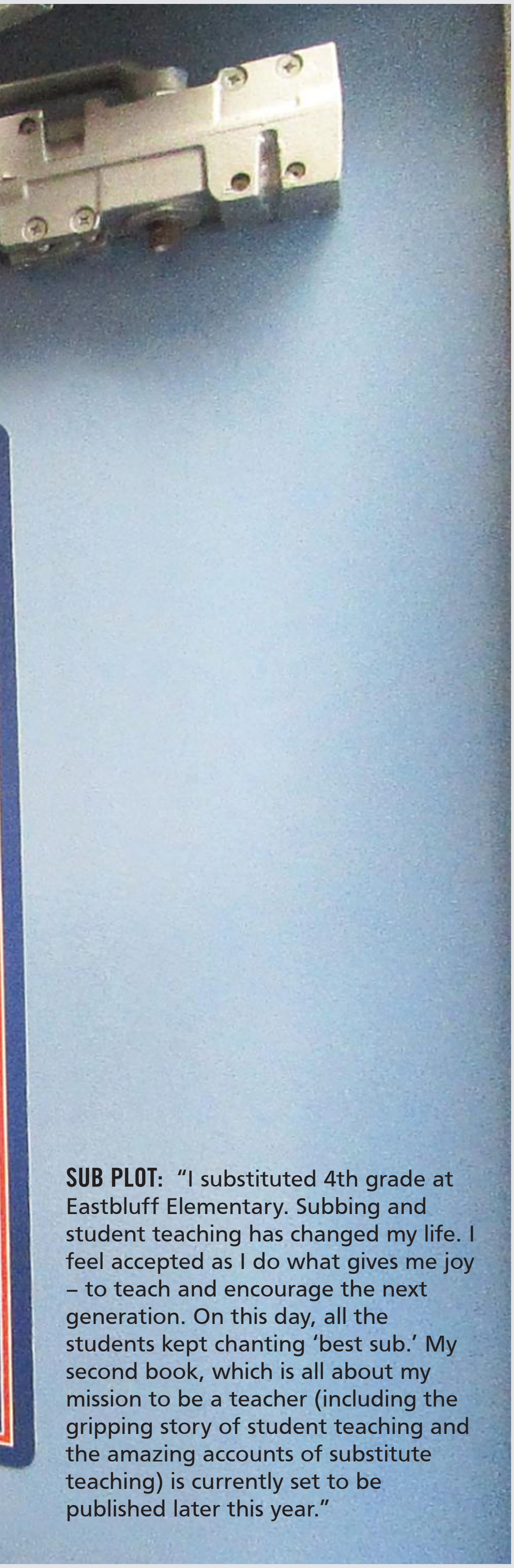
VIEWING THE WORLD– DIAGNOSED with AUTiSM

BY MATTHEW KENSLOW

I have Autism. I view Autism as having an enhancer plugged into my brain, enhancing my perception in life, making things either very easy or very hard. I believe that Autism has given me a different lens with which to view the world.

PHOTO BY SANDRA KENSLOW



SUB PLOT: "I substituted 4th grade at Eastbluff Elementary. Subbing and student teaching has changed my life. I feel accepted as I do what gives me joy – to teach and encourage the next generation. On this day, all the students kept chanting 'best sub.' My second book, which is all about my mission to be a teacher (including the gripping story of student teaching and the amazing accounts of substitute teaching) is currently set to be published later this year."

When I was three, I was diagnosed with a speech delay. At age four, it was recommended for me to be enrolled in the Preschool Intervention Program. However, at age six, upon further testing, I was formally diagnosed with "Asperger's Syndrome" under DSM IV.

From preschool to second grade, I was pretty much learning how the world works. I made some friends, but I could not understand why other classmates did not seem to like me. I remember walking by the swing set one day in kindergarten and hearing two classmates yelling at me, "Go away, Matthew!" and "You're *not* our friend!" In class, I endeavored to fit in. I jumped into a game that seemed to be getting popular, since a lot of my classmates were joining it. At first, the leader was happy that I joined. Inside me, I did not understand the fun of the game, but I pretended to have fun anyway. Suddenly, that leader completely changed. Inside class or outside, whenever I jumped in, she yelled loudly at me, "You're not playing with us!" These early recollections lived with me as I grew older. I could not understand for the life of me what it was about me to get those reactions. I never did anything wrong to *them*.

> **"AT SOME POINT IN MY EARLY LIFE, I BEGAN REALIZING THAT I COULD NOT SPEAK PROPERLY, WHICH IS WHY I HAD SPEECH THERAPY. MY MIND WAS SLOW TO UNDERSTAND THE SOCIAL CUES OF FELLOW STUDENTS."**

At that particular school, I was in special classes. However, for three years, I would spend parts of my day in a regular classroom. They were testing whether or not I could be mainstreamed. I was mainstreamed in third grade, when I switched schools. From third grade to sixth grade, I had pull-outs for speech therapy and R.S.P. (Resource Specialist Program). My mother was a number-one advocate for me to my teachers, and my teachers were very supportive of me, helping me fit in. For instance, on the first day of third grade, my teacher introduced me to everybody, including his previous year's class.

I began making many more friends, but still, the ominous cloud of teasing and discrimination continued to follow me. It was hard to fit in since I had different interests and different ideas of fun. I was not the type of child who likes screaming and jumping around. I did not have any interest in things like Pokémon cards, for instance. I remember sitting alone and being emotional, in a dugout one day, which caught the attention of fellow third graders who came over to console me. Some friends spent time with me, but others were more *hi-and-goodbye.* Other students simply wanted me to go away. One of them even chucked a handball at my face. There was one student who repeatedly call me the same name (a discriminatory word that haunts the Autistic community).

Despite the friends I had, I was very twisted inside. This lasted until high school graduation. I could not seem to put my foot forward and ask my friends if it would be possible to spend time with them. I was tired of having what was later described as "superficial friendships," where we talked a bit at school, but rarely hung out, outside of school.

At some point in my early life, I began realizing that I could not speak properly, which is why I had speech therapy. Ashamed, I assumed that was a deterrent. My mind was slow at processing information and understanding the social cues of fellow students. I took many things personally. I literally did not know what others meant. It hurt me when they began joking about it.

I put out a few videos on YouTube recently, dedicated to Autism and social interactions. In the middle of 2022, I was interviewed for a SiriusXM radio program. One of the hosts proposed the question, whether autistic individuals are antisocial or truly want to socialize. I gave my answer, but later came up with four reasons to back up my answer. Everybody with Autism is unique, so I cannot say that this would speak for every single individual. I propose that we are *not* antisocial, and I made an extensive YouTube video to dispel such a myth.

One, I was simply nervous to ask my friends.

Two, I was rarely asked by my friends to hang out with them. The rare times I was, I senselessly made up an excuse, because of reasons three and four.

Three, Could I completely trust them?

Four, what the heck would we do? I am somewhat traditional, enjoying conversations, neighborhood walks, puzzles, board games, and such. Growing up, all my friends were heavy into video games or computer games, which seemed to rob the time I had with them, thereby making me feel excluded.

I had heard of Autism when I was nine; one of my favorite movies was *Miracle Run* by Lifetime Movie Network. I must have watched it a hundred times. However, although I really liked drawing and running, I never associated myself with Autism. I did not have all the other things that the characters were exhibiting, such as echolalia and meltdowns. The only thing I knew, was that I never liked how I sounded, and some students did not treat me fairly. I did question why I had those two aforementioned pull-outs within the school day.

LEARNING TO LEAD: *(Above left)* Matthew at the College Park Elementary, circa 2000, in his Preschool Intervention Program; *(Above right)* Matthew holding the American flag at his Royal Rangers' outpost. Matthew credits the Royal Rangers as being the program that made him the leader he is today, teaching him survival, leadership, responsibility, and other skills.

Speaking about the pull-outs, there was one day in my R.S.P. class during upper elementary, when I raised my hand, looked at my R.S.P. teacher in the eye, and asked, "Do I have Autism?"

He somewhat shrugged it off and said something to the effect, "No, you don't." The other R.S.P. teacher immediately said something like, "You don't need to be asking that."

From that moment until my high school days, I, for whatever reason, did not believe I had Autism.

Then one day as a freshman, I asked my mother the serious question out of the blue, "What do I have?"

That was when I was formally told that I have "Asperger's Syndrome – a mild form of Autism."

That was the defining moment when my entire life began to make sense and I began putting stuff together.

I decided to develop skills with which to entertain people and ultimately make a difference in their lives. Back when I was in early elementary school, I got into art and writing. In third grade, I picked up piano playing. In fifth grade, I began juggling. All of these became my catharses. I entered talent shows and writing contests. I began juggling at my local elementary school in sophomore year and even did a couple of small assemblies. I wanted to make a difference in people's lives.

"I ASK PEOPLE WITHOUT A 'DISABILITY' TO HELP THOSE WHO DO HAVE A 'DISABILITY' FEEL INCLUDED. I TELL EVERYBODY, A 'DISABILITY' SHOULD BE VIEWED AS A 'DIFFERENT ABILITY' TO LIVE LIFE."

I got the idea that juggling can represent not giving up on one's passions. In 2018, I developed my juggling analogy. If you make a small mistake or a big mistake in life, and something drops (at this point I drop one on purpose), do not give up. Bend down, pick it up, and keep going and you will do amazing things.

Around the same time of my life, I developed a science demo analogy. I make a cloud in a bottle. In it, I explain that if a person bottles things up inside, he or she may begin to feel twisted and knotted up and pretty soon, might explode. This is the part where I release the tension of the transparent water bottle, making a translucent cloud. Ultimately, as I continue to get my point across, I take off the cap and release the cloud in the air before my audience's eyes. *My point is to learn to release emotions by finding somebody whom you can trust.*

As a person with Autism, I, for one, can testify how easy it is to be so frightened and angry inside, and we can actually accumulate many things, such as stories of discrimination, being teased, wishing something happened better, and such. People with Autism, like me, might run into a room and stay there for a while. What we are doing is processing things by ourselves. These are times when we need to be alone,

PHOTOS BY SANDRA KENSLOW

and it is a trait found in Autism. When the time is right, we will release the things that are troubling us. However, we might neglect to do so, leading to a "cloud", that lingers inside of us.

I ask people without a "disability" to help those who do have a "disability" feel included. This comes by talking with them and finding out what they like to do.

UP IN THE AIR: Matthew has juggled and played piano at the Annual HALO Benefit every year since 2012.

(I placed "disability" in quotes, because, as I tell everybody, a "disability" should be viewed as a "different ability" to live life.)

I view parents of "disabled" children as modern-day superheroes. The fact that they would be researching how to best raise their child, is a sign that they care. I encourage them to advocate for their child; continue to show them love and support. As they get older, I suggest teaching them life skills and how to advocate for themselves. My mother taught me cooking, balancing a checkbook, driving, and such. My high school R.S.P. was big on having us advocate for ourselves.

It always took longer for me to take tests. In my head, I usually knew the material, but my mind often distracted me. I was usually the last person to finish exams. I always had test-taking accommodations, such as extra time and a quieter space. Still, it was hard for various reasons. One, I wanted to get every single problem correct. Oftentimes, the answer choices seemed very tricky. Two, my mind cannot stop blasting music or replaying shows that I watched. Other times, my mind is distracted over stressful situations in my life, even if they are long forgotten by then. (These are also some of the reasons why I cannot get to sleep for hours after going to bed nearly every night.) Three, taking an exam requires *reading* the questions and answers. Oftentimes, they are super long. Reading is hard for the reasons I described above.

In stark contrast to reading, writing has always been a catharsis. I always wrote books and scripts, since elementary school, but never published them. I continued writing all the way up to my senior year.

In my first semester of college, in 2013, I began a new writing project. However, I told myself that if I start this, I am going to finish it this time. After a few years of writing, revisions, rereading, editing, and more writing, I hired a literary agent. My book was about a person growing up with Autism in the rural 1950s and 60s. The agent advised me to write a nonfictional piece about myself first, before publishing a fictional piece.

The next year, I completed my manuscript, *Juggling the Issues: Living with Asperger's Syndrome*. At age 23, I became a royalty-published author.

"I WAS INSIDE A GROCERY MARKET AND TWO TEENS WERE MAKING FUN OF ME. I LATER INVITED THEM TO GO AHEAD OF ME IN LINE, TO WHICH THEIR COUNTENANCE EXPRESSED REMORSE FOR JUDGING A BOOK BY ITS COVER."

Later getting a few Public Relations campaigns, I was able to encourage the entire world. I appeared on the news, radio, websites, magazines, blogs (et cetera), including Newsweek Magazine, Spectrum News, ABC7, Scripps News, Bloomberg, Insider, and dozens more. At the same time, my social media accounts began to grow, with 80,000 subscribers on YouTube and a million followers on Instagram.

I counted all of this as a tremendous victory for Autism Awareness and Acceptance. The reason why this is important to me is because my life has been quite a roller coaster. It was filled with love from family and friends, but it was also imbued with trials and tribulations. From 2014 to 2023, I had still experienced discrimination. I have been yelled at many times by people in vehicles. I have been cussed at, stared at, laughed at, ran away from, followed by a vehicle, and was nearly beaten by a name-calling individual with a skateboard in 2022.

In 2020, I overheard a parent telling his child not to communicate with me, even though I was a distance away.

In 2015, I overheard a father tell his son that I am a "weirdo" or something, just for nonchalantly walking past them. I turned around. He was looking at me, before veering off in a different direction with his family.

In 2017, a father expressed his annoyance with me just for walking in a public park. His young daughter got nervous because of what he did. Two days after that, I was inside a grocery market and two teenagers were snickering at me and making fun of me. However, I later invited them to go ahead of me in line, to which their countenance expressed remorse for judging a book by its cover.

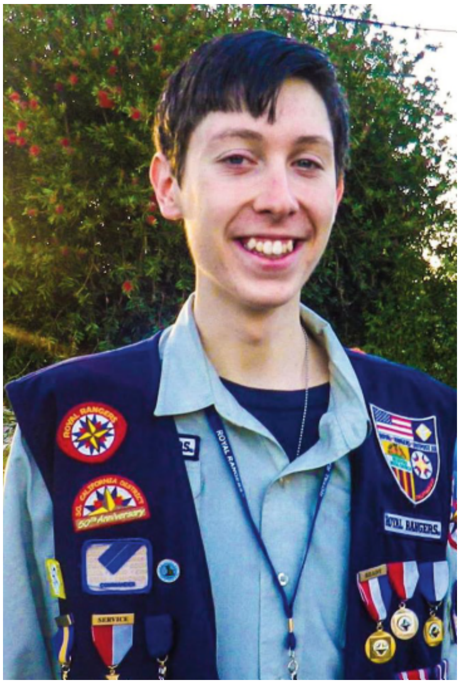
Nevertheless, I never allowed these adversities to win!

I never allowed Autism to have the prerogative to tear me down!

I came to terms with my limitations, but never allowed the label of "Autism" to limit me, regarding continuing my education. I am currently working toward a Master's in Education and ultimately starting a career as a middle-school math teacher.

I tell everybody that if I could do all the things that I do – get a book published, earn a medal equivalent to the rank of Eagle Scout, get degrees in chemistry and biochemistry, earn a full-math credential, become a substitute teacher who often hears "best sub," become a social-media influencer, play the piano, juggle, memorize things that *no human on earth has got to memorize without an eidetic or photographic memory, et cetera* – then You Can Too, Plus More!

PHOTO BY TERRY SHAW



HIGHLY DECORATED: Matthew has been a commander for Royal Rangers since 2013, and was awarded the Gold Medal of Achievement which took 10 years of perseverance to earn. He is now leading and training boys at the age he once was, including some boys who also have Autism.

I do not say that everybody has to do exactly what I do. I am simply saying that everybody has a unique skill set and different levels of proficiency per skill. *In my Be Number One analogy, I tell several people to be number one.* Being number one should be viewed as a *rank* of which anybody can achieve. My definition of being number one is that you persevere in your goals, and never give up in obtaining those goals. Be the best that you can. Do not set standards based on other people, but base them on yourself. I tell people that if I was driven by jealousy, then I would not be here today.

In conclusion, I am hoping that my life will encourage nearly everyone on earth and the next generations. I am a proponent of not just Autism Awareness, but Autism *Acceptance* and *Appreciation*. I contend that once everybody puts aside their differences and competitions, comes together, holds civilized conversations, and makes others feel included, then this world will be a better place.

Disability or not, anybody can do whatever they set their heart and mind to do. Do not judge a book by its cover. I am quoted as saying, "behind the disability, we have a heart." •

ABOUT THE AUTHOR:

Matthew Kenslow has grown up with a form of autism that was once referred to as Asperger's syndrome. Life has been an adventure as he pieced together all of his surroundings amid both praises and taunts. His mission is to teach others from a firsthand perspective about how people with autism interpret things differently from the rest of the world. He feels he has been blessed with the gifts to juggle, play piano and recall facts about the American presidents, geography, science and mathematics. He juggles at elementary schools and encourages the students to never give up on their passions. He has earned the Gold Medal of Achievement (which is equivalent to the rank of Eagle Scout) through Royal Rangers, a program he has been in since he was 5. Now, he is giving back to children and teenagers, teaching and mentoring them in a wide set of skills and knowledge. He graduated from Orange Coast College with an Associate of Science degree in Chemistry and with a Bachelor of Science degree in Biochemistry from Vanguard University of Southern California. He aspires to be a middle school math teacher. Recently, he earned a full math credential after student teaching Enhanced Mathematics at his former middle school, Ensign Intermediate School. Currently, he is going for a Master of Arts degree in Education at Vanguard University and is an employed substitute teacher for NMUSD, often being called by students as "the best sub" and begged by them to come back the next day or to sub for their class soon.

PHOTO BY SANDRA KENSLOW

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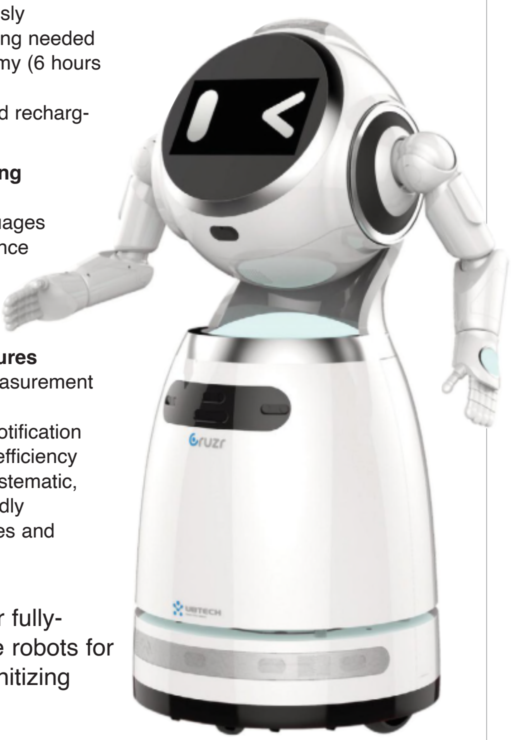

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THERE'S NO PLACE LIKE HOME

BY STACEY LEDBETTER

The rise of person-centered communities hold promise for young adults with autism and I/DD by providing sustainable housing and services along with new technology and tools that support independent living.

"What will happen when I'm not here?" is a recurring thought that weighs heavily on the minds of most parents of adult children with autism and intellectual and developmental disabilities (I/DD). I admit that I grapple with my own mortality when considering how my autistic teenage daughter will manage life on her own without me.

The reality is that once young adults with autism and I/DD leave high school and reach the age of 22, they hit the so-called "services cliff" that denotes the end of their free, school-based services, like psychotherapy and life skills training. There's an "autism avalanche" coming, too, as over 500,000 kids with autism will leave high school over the next decade.[1]

VERY FEW EMPTY NESTERS

The biggest challenge facing these young adults, by far, is where they will live. The lack of affordable and available housing presents a significant crisis for families. Most options center around group homes and immediate care facilities that provide food, shelter and a full gamut of services under one roof. Wait times are long, and not every adult with a disability needs the intensity and 24/7 programming of a group home.

Many adults with I/DD are caught in the middle—wanting to live independently, still needing supported independence, but not qualifying for the whole nine yards of a group home.

No surprise then, that three-fourths of young adults continue to live at home with family,[2] even if they don't want to. As adults with disabilities age, so do their parents. Over half of caregivers to I/DD adults are older than 50, and 10% are 75 or older.[3] Many are also responsible for caring for their own aging parents. Autism Speaks estimates it costs families $1.1 million to care for an autistic person over their lifetime, a cost that more than doubles to $2.4 million if there's an accompanying intellectual disability.

MODERN HOUSING THAT FILLS THE GAP

This is a crisis in need of innovation, and through the passion, resources and grit of special needs parents, the tides are starting to turn. Over the last few years there has been a movement to build sustainable, affordable person-centered communities and technology tools that create supported independence ecosystems for I/DD adults who do not require a high level of services and support. Parents are finally seeing their hopes come to life in these homes.

Person-centered communities are unique in many ways. Importantly, these communities decouple services from housing and provide a far less restrictive environment for residents. They're analogous to senior living communities that serve the housing and social needs of a population that's staying alive longer, but who want to keep their own doctors, therapists and individualized programming.

Unlike group homes where everyone shares a floor, person-centered communities consist of separate apartments and townhouses that offer easy access to transportation, life skills training, and amenities like a swimming pool and on-site laundry facility.

Some of these residential models are progressive, bringing together a mix of neurodiverse and neurotypical residents, allowing for a diversity of interactions that are beneficial to society and bring awareness to the social and emotional capacity of people with disabilities. The majority of homes are constructed with universal design principles to accommodate a variety of physical and sensory needs. Even neurotypical adults can appreciate sensory soothing communal areas that incorporate natural light, areas for quiet refuge, and a variety of comfortable seating configurations.

THE RISE OF SUPPORTIVE AND SOCIAL COMMUNITIES

Taking this modern approach to disability and shedding the institutionalized model, encourages autonomy and social interaction,

SOCIAL SCENE: Some residential models are progressive, bringing together a mix of neurodiverse and neurotypical residents, allowing for a diversity of interactions that are beneficial to society and bring awareness to the social and emotional capacity of people with disabilities.

and better supports I/DD adults as they continue to develop practical life, social and vocational skills. This is the affordable and future-forward housing solution that parents have been waiting for.

Finding person-centered communities around the country is starting to get a little easier, thanks to government grants, funding programs and public-private partnerships that make a portion of newly built housing units financially accessible to I/DD residents.

Two states, South Carolina and Arizona, are at the forefront of the modern I/DD housing movement. Oak Tree Farm in Conway, S.C., employs on-site staff members to do daily check-ins, and organize group activities and social events. The rent is approximately $500 per month, and the community assists residents with filing for a housing voucher, which can cover up to 70% of the costs.

There's also First Place, a 63-apartment complex in Phoenix for I/DD adults who are transitioning to a more independent life. First Place has tons of activities for its residents, and even has a training kitchen with hands-on cooking lessons that impart valuable skills and bring the community together.

TECHNOLOGY OFFERS A NEW LIFELINE

To be sure, a modern housing ecosystem wouldn't be complete without technology to go along with it. Adults with I/DD are benefiting from a crop of affordable technology tools and apps that let them experience supported independence in the communities where they live. These apps can be tailored to their needs, supplement or eventually replace caregivers, and give lifelines to residents, like social outlets and job opportunities.

One example is NFlyte, an app for residents, case managers and parents that helps adults with autism and I/DD gain practical life skills, such as: task management, meal preparation, maintaining an organized living space, personal hygiene, grocery shopping and budgeting. NFlyte supplements support services for person-centered homes, reduces cost per care for residents and increases the viability of young adults being able to move out of their homes.

SimplyHome is another solution that partners with I/DD home communities to create greater independence and confidence. SimplyHome can outfit a home for a resident with limited mobility to make it easier to operate lights and locks. The company can equip homes with beds, stoves, and motion sensors in addition to panic pendants to alert a caretaker in case of an emergency.

Hiki is a friendship and dating mobile app for the autistic community. It provides a protected space where neurodiversity is embraced, and being atypical is celebrated, while keeping residents safe from exploitation. Every part of Hiki, from ideation to design to launch, has been built by autistic adults to ensure that it is representative of neurodivergent needs.

Mentra is a job placement platform that has innovated a neurodivergent-friendly application process, that puts candidates in front of inclusive recruiters, rather than forcing applicants to navigate through the challenging process of finding a job with a disability.

Person-centered communities that embrace the social aspect of housing and the associated wrap-around technologies, are the keys to unlocking supported independence for adults with autism and I/DD. When we as primary caregivers are no longer able to be there, it's comforting to know that our child has a chance to live a purposeful and independent life, where they can enjoy some of the rights of passage celebrated in our culture, from cooking their own meals, to getting a job, to being in a stable relationship. It is only then that we as parents can rest easy, and the answer to the ever-looming question then becomes: "They'll be at home."•

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ABOUT THE AUTHOR:

Stacey Ledbetter is the mother of an autistic young adult, and founder and CEO of NFlyte. Motivated to find tools to empower her daughter to live her most independent life, Stacey built NFlyte as an all-in-one practical life skills platform for autistic adults with support needs. She serves as a committee member at SOS Care/Village Vision in Charleston, S.C., whose mission is to create affordable housing for I/DD adults.

EMPLOYMENT AND TRANSITION

BELLA'S STORY

MADE OF MILESTONES

BY CHRIS AGUILAR

> The doctors were right so many years ago.
>
> Bella would not go on to live a normal life, and we wouldn't want her to.
>
> As it turns out, her life is extraordinary.

LIGHTING THE WAY: Bella Aguilar, 17, is in her senior year of high school. Now, Bella and her family are looking forward to the next step: college.

PHOTOS COURTESY CHRIS AGUILAR

LIFE IS OFTEN MEASURED BY MILESTONES.

Many of those milestones bring joy – like the moment your child takes her very first step, or when she graduates high school. Some milestones, though, can bring sadness and heartache. The loss of a pet, for example, or a frightening and life-altering diagnosis.

Like many children, my daughter, Bella, has had her fair share of milestones. Until a few years ago, her life was defined, not so much by first steps or middle-school graduations. Instead, her milestones were marked by doctor's appointments, emergency room visits, and countless medications that affected her quality of life. We tracked life by the number of seizures she experienced, recovery time, and school activities missed. Events that should have been celebrations – birthdays, first days of school, favorite holidays – were often marred by worry and anxiety. My wife, Shannon, and I were constantly in a holding pattern, waiting for Bella's next seizure and hoping against hope that it would be her last.

Our story is not unusual – especially when compared to the stories of other parents and caregivers, who also love and care for someone with a disability or chronic illness. We've had ups and downs – but I count myself lucky because we've had the chance to watch as our daughter, now 17, gets a second chance at a life that we never thought would be possible for her.

A MAJOR MILESTONE: BELLA'S FIRST SEIZURE AND DIAGNOSIS

At just 18 months old, Bella experienced what we now know was her first seizure. At the time, her seizures presented as blank stares, and we began to notice her "zoning out" during playtime, for example. We didn't think much of it, even chalking it up to one of her many cute quirks, just like her unforgettable sweet yawns, or those looks she give us when she had the hiccups.

Two months later though, she got sick and needed to be hospitalized. It wasn't until then that a doctor clued us in. Our sweet, playful, brilliant daughter, the very same one we'd imagined saving the world someday, was experiencing seizures. The doctor told us that we should get an appointment to see a neurologist right away. Looking back, this hospital visit would be the first of many unexpected milestones, and the very start of our journey, caring for and loving someone with drug-resistant epilepsy.

We soon received the official diagnosis of epilepsy, from a neurologist. After studying her EEG, our neurologist told us the very thing that haunts every parent's worst fears. Bella would not be able to live a normal life. She would not graduate high school, and she would not be like her peers. In fact, we were told to prepare for a life that would be difficult for not only her, but us, who would most likely need to provide her with long-term, 24-hour care for the rest of her life.

Suddenly, all of those milestones we'd dreamed of as new parents: hearing her first word, cheering her on at little league soccer tournaments, seeing her off to school dances, and dropping her off at college, were gone in a blink of an eye. In a matter of what felt like just a moment, we were whisked away into a world measured by weekly doctor's appointments, countless tests, hospital stays, and treatment after treatment. All of which would soon define Bella's childhood, and our first decade as parents.

GROWING UP WITH EPILEPSY

We measured the years that followed by more testing, hoping that it would bring us one step closer to a treatment for our little girl. We'd watched as Bella's seizures increased, seemingly untouched and uncontrolled by the always-changing cocktail of medications that her doctors prescribed. "Big seizures" caused her to lose days to recovery and often resulted in memory loss. For years, we watched helplessly as Bella's beautiful mind struggled to keep up in school, maintain friendships. We watched painfully as she dropped out of activities she'd once loved and forgot even the simplest of things, like how to tie her shoes or how to spell her own name.

MILES TO GO: When Bella was little, doctors told Chris and his wife, Shannon, that Bella wouldn't be able to live a normal, independent life. With the help of seizure control, Bella is getting ready to go to college.

TOWER OF STRENGTH: Chris Aguilar and his wife, Shannon, have gotten the chance to see their daughter flourish in ways they never thought possible with the help of seizure control.

Another milestone came in the form of bad news, when Bella was just ten years old. We'd been splitting our time in: Orlando, Miami and Boston, desperate to understand if Bella would be a candidate for brain surgery. In December 2016, we learned that seizures were sparking from both sides of her brain, making her ineligible for what we thought would be the life-changing surgery she needed. We were devasted.

It was then, though, that someone in our close circle mentioned VNS Therapy™, a unique, add-on treatment for individuals with drug-resistant epilepsy. We were hesitant at first, exhausted and terrified of more disappointment. But as parents, we knew the fight wouldn't ever be over. We'd never give up; not until we found help for our Bella.

A VERY MEANINGFUL MILESTONE

Sure enough, Bella was a candidate for VNS Therapy™, a small device implanted under the skin of the chest and connected to the left vagus nerve. We learned that it delivered mild pulses to the brain through the vagus nerve to help prevent seizures before they start, and stop them if they do.

For people with drug-resistant epilepsy, which accounts for about one in three people with seizures, medication alone isn't the answer. For Bella, who continued to experience uncontrolled seizures, despite trying dozens of medications over ten years, this was a new option that offered something we hadn't felt as a family in a long time – hope.

In the months that followed her procedure, we began to see a decrease in the number of seizures she experienced. She was retaining information and her recovery time was much faster. Within just a few months, she started to build strong, lasting friendships, wanted to try every sport possible, and even attended her very first sleepover. We couldn't believe it. Our little girl was coming back to us.

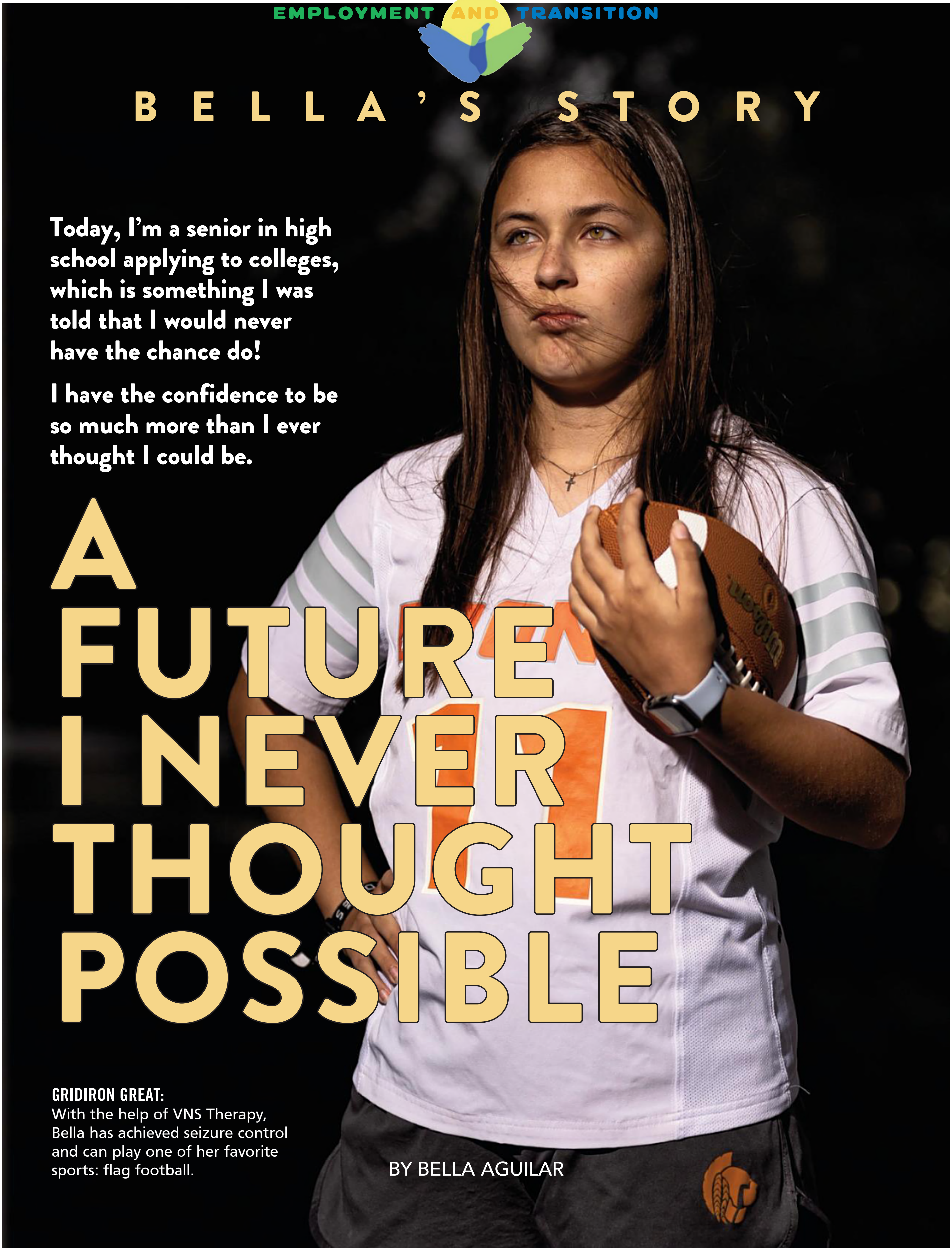
BETTER MILESTONES AHEAD

We came to realize this wasn't just a fluke or stroke of luck. After almost failing fourth grade, Bella made As and Bs in middle school, and we learned that she was in the top 10% of our entire county. Shannon and I watched in awe as the years passed, and Bella continued to improve each day, living a life we never even got the chance to imagine for her.

That brings us to our latest series of life's milestones: Bella, heading into her senior year of high school, braver, stronger, and more brilliant than ever. Bella, taking college courses and applying for out-of-state universities, more than ready for independence. Bella, vice president of her junior class, playing flag football, and volunteering during her time off.

Shannon and I have since realized that the doctors were right, so many years ago. Bella would not go on to live a normal life, and we wouldn't want her to. As it turns out, her life is extraordinary. Her past struggles power her to do good and be good. She'll change the world, and we know she will.

Life is often measured by milestones. Some bringing beauty, while others bringing darkness. We've learned to cherish every milestone, no matter how small, because without the darkness, we wouldn't know just how bright the light is. •



BELLA'S STORY

Today, I'm a senior in high school applying to colleges, which is something I was told that I would never have the chance do!

I have the confidence to be so much more than I ever thought I could be.

A FUTURE I NEVER THOUGHT POSSIBLE

GRIDIRON GREAT:
With the help of VNS Therapy, Bella has achieved seizure control and can play one of her favorite sports: flag football.

BY BELLA AGUILAR

MY NAME IS BELLA AGUILAR AND I HAVE LIVED WITH EPILEPSY SINCE I WAS 18 MONTHS OLD.

For a long time, my seizures limited what I could do. I couldn't play sports or attend sleepovers at friends' houses. I was also falling behind in school and had to do occupational therapy to re-learn how to write and even to grab and use eating utensils.

AUTHORING HER OWN STORY: From an early age, Bella has always been big on community service, and she often spends her downtime giving back to the communities, Now her dad, Chris, and her mom, Shannon, are getting ready to send her off to college next year.

My seizures would keep me home from school for days and sometimes even weeks. It was very hard to socialize and make friends. It was even harder to keep up with my schoolwork. I struggled to memorize facts for school and to remember things.

I spent countless days in rooms at children's hospitals in: Florida, Massachusetts, and Minnesota. I learned to socialize better with doctors and nurses in hospitals, than kids my own age. To help with my seizures I had a to drink a LOT of medicines. Sometimes the medicines worked for a little bit and helped. Other times, they did not work at all. It was frustrating being a small kid drinking so many medicines. Some of them didn't taste good at all!

When my parents told me about VNS Therapy™, I was cautiously optimistic as I learned about what it might offer. When I first got my VNS Therapy™ device, I wasn't used to it, and I remember feeling common side effects like hoarseness and cough. My voice quivered sometimes when I spoke, which I also learned could be a temporary side effect of VNS Therapy™.

A few months after my procedure, though, my quality of life was better than ever! I started doing better in school and remembering things in class. I used the fact that my voice quivered as an opportunity to tell people about VNS Therapy™ and how it worked in my life.

I went from falling behind in school to taking advanced classes. I was also invited to take the SAT in seventh grade, as a rising student for my county. I started doing sports. I joined the soccer, volleyball, basketball, and track and field teams in middle school. I was the only student in my school – both male or female – to make all four sports teams for the three years of school. They even gave me an award at my eighth-grade graduation. I felt so proud of myself for this accomplishment.

In high school, I felt more confident thanks to VNS Therapy™. I joined Student Government and started working on my school's Dance Marathon to raise funds for charity. I am also a varsity athlete and have been playing flag football for three years. Now I'm a senior in high school applying to colleges, which is something I was told that I would never have the chance do! Today, I have the confidence to be so much more than I ever thought I could be.

> *"I think back to the day you were diagnosed at 18 months old. I can remember that day so clearly. I sat there, tears sliding down my face as I was told you would get worse—your quality of life would decline; you would never graduate high school; your future would be one of struggles and defeat. I listened to those words, and they literally broke my heart and stole my dreams for you and your future. Today was a day we never thought would happen."*
>
> – Shannon Aguilar, Bella's mom, after Bella received her college acceptance letter to University of North Florida on July 12, 2023, the first of what they now expect to be many. •

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CGES offers opportunities for all Montclair students to benefit from interdependence, to engage with diverse perspectives and lived experiences, and develop a meaningful understanding of disability justice.

WHAT IS INCLUSIVE POSTSECONDARY EDUCATION FOR STUDENTS WITH INTELLECTUAL DISABILITIES?

BY JESSICA BACON AND KATHRYN LEONARD

PHOTOS BY MIKE PETERS / MONTCLAIR STATE UNIVERSITY

ACCESS POINT: Professors Jessica Bacon and Susan Baglieri (Co-founders of the IAC) and IAC fellows posing in front of University Hall; "A college education strives to prepare students with experiences, skills, and knowledge, for employment upon graduation. Through a liberal arts-based curriculum and person-centered planning, CGES will seek to support students in identifying an academic focus aligned to career interests."

Historically, access to post-secondary education has been denied to many individuals with significant disabilities. Those who have a wide range of support needs, including adults with intellectual disabilities (ID), are especially underrepresented and underserved in colleges and universities. Many institutions of higher education across the United States have responded to this disparity by creating supportive opportunities and pathways for people with ID to attend college.

Although inclusive postsecondary education (IPSE) programs vary widely across the United States, most create opportunities for students with ID to participate in various aspects of college life. Often, IPSE students enroll in a college or university, either as part of a transition program or after graduating from school. Once enrolled, students typically participate in all aspects of university life, including: auditing or taking for credit academic courses, pursuing employment internship or externship opportunities, and engaging in recreational and social activities on campuses. Some programs extend the opportunity for students to live on campus in college dormitories amongst traditionally-enrolled peers. A typical hallmark of IPSE programs is to promote belonging and integration through peer-supported models, which create opportunities for students with intellectual disabilities and their same-aged, traditionally enrolled peers, to engage in college life together within a mutually supported framework.

GROWTH OF INCLUSIVE POSTSECONDARY EDUCATION OPPORTUNITIES IN THE UNITED STATES

IPSE models have been around for decades, but concerted policy efforts have occurred over the past 15 years, with a goal to establish a national model for the growth of IPSE opportunity.

The passage of the Higher Education Opportunity Act (HEOA) of 2008 concretized a federal commitment to IPSE, when it incorporated a financial aid pathway for students with intellectual disabilities enrolled in an approved college program (**ed.gov**). In 2010, the Transition and Postsecondary Programs for Students with Intellectual Disabilities (TPSID) federal grant program was initiated. Over three, five-year grant cycles, the US Department of Education has awarded funding to 126 institutions of higher learning in 34 states (Think College, 2023). The TIPSID initiative also led to the establishment of Think College (thinkcollege.net). It is a national coordinating center that provides support, coordination, and training for postsecondary education institutions that have created formal opportunities for people with developmental and intellectual disabilities to partake in higher education. As of 2023, Think College identifies 324 programs in 49 states (**https://thinkcollege.net/college-search**). Providing opportunities for young adults with disabilities to participate in college programs and learn on college campuses is a clear initiative of the US Department of Education and the higher education landscape.

WHY IS IPSE AN IMPORTANT MOVEMENT?

Despite overwhelming research indicating the benefits of inclusive education for all students with disabilities (e.g. Cosier, et al., 2013) only 17.9 percent of students with ID labels are included for 80% or more of their day (OSEP, 2022). IPSE programming creates opportunities for students with ID labels to learn about advanced subjects that they may not have had exposure to during their K-12 education, and to do so in a natural environment alongside same-aged peers. College is a time for many early adults to learn new

FREE TO BE: Two IAC fellows playing frisbee in the quad; "College is a time for many early adults to learn new information, gain independent living skills, find their personal strengths, develop employment skills, and to grow a sense of identity and self. "

information, gain independent living skills, find their personal strengths, develop employment skills, and to grow a sense of identity and self. Students with ID benefit from being included in all that one is afforded on a college campus.

Outcomes data has begun to evidence that students who have attended an IPSE program increase their likelihood to continue their education, find competitive employment, and have satisfying social lives after graduation (Grigal, et. al. 2021). Not only does IPSE programming increase future opportunities for the students who attend, but it also creates a more inclusive society because students on college campuses are able to learn alongside their peers with significant disabilities. Undoubtedly, furthering the expansion of IPSE programs is one way to create a more inclusive society. Montclair State University is excited to announce that it is expanding its offerings, in order to become a part of the IPSE movement.

MONTCLAIR STATE UNIVERSITY'S CERTIFICATE IN GENERAL EDUCATION STUDIES (CGES)

Montclair State University has established the new Certificate in General Education Studies (CGES), a two-year, credential-granting, commuter program, for students with intellectual disabilities who are motivated to learn in a college environment. CGES aims to provide an inclusive educational experience, where students take a selection of undergraduate courses determined by their interests. Through a peer supported and intentional course of study, CGES enables students to further develop their skills for self-advocacy, intellectual pursuit, and employment.

A college education often strives to prepare students with experiences, skills, and knowledge, for employment upon graduation. The same is true for CGES. Through a liberal arts-based curriculum and person-centered planning, CGES will seek to support students in identifying an academic focus aligned to career interests. During the 2nd year of the student's program, they will be expected to complete a supported work experience related to their career interests, preparing them for life after graduation. College campuses are often hubs for developing professional networks and friendships. Beyond the classroom, students in CGES have opportunities to engage in campus life activities, including: exercising at the Student Recreation Center, joining student-led organizations, and participating in the daily social activities offered to all students. Ultimately, CGES offers opportunities for all Montclair students to benefit from interdependence, to engage with diverse perspectives and lived experiences, and develop a meaningful understanding of disability justice.

CGES is currently recruiting students for the inaugural class, which will start next Fall Semester in 2024. For more information please visit, **www.montclair.edu/teaching-and-learning/academic-programs/certificate-in-general-education-studies-cges.** ●

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ABOUT THE AUTHORS:

Dr. Jessica Bacon is an Associate Professor in the Department of Teaching and Learning at Montclair State University. Dr. Bacon coordinates programs in inclusive education and is a co-founder of the Increasing Access to College project and Certificate of General Education Studies, both of which offer inclusive higher education opportunities to people with intellectual disability labels at Montclair. Dr. Bacon's research is informed by disability studies and she investigates various topics related to inclusive education through a critical and intersectional lens. Dr. Bacon has recently published in journals such as Teaching Disability Studies, Critical Education, and Young Exceptional Children.

Kathryn Leonard is the Director of the Certificate in General Education Studies program at Montclair State University. Kathryn is a licensed social worker in the state of New York and earned a Masters of Science in Social Work from Columbia University School of Social Work with a concentration in Health, Mental Health, and Disabilities. She also has a Bachelor of Arts degree in Psychology with Minors in Disability Studies and Cognitive Science from the University of Delaware.

NEXT STAGES: Jessica Jankus was born with multiple developmental delays. As her parents approached their seventies, they found an accessible group residence for her and she seems happy there.

LIFE >>> TRANSITIONS

BY JORDAN JANKUS

We all experience transitions from one stage of life to another – graduating high school, moving on to college and work, getting our own place, marriage, etc.

For people with disabilities and their families, transitions may require more planning and preparation and in fact, become a way of life. For "exceptional parents," we transition from a more traditional growth track for our children as soon as the child is diagnosed with a disability, whether at birth or further along in their developmental stages.

Once we realize that our child will need additional services, we experience another life transition as we advocate to get them enrolled in early intervention services. Later, when they enter the local school system, we transition with them to a system that can be challenging in its complexities. As involved parents, we advocate that they be included in the social life of the school, that they

PHOTOS COURTESY JORDAN JANKUS

receive the necessary services to help them along their life journey: academic assistance, therapeutic services (speech, physical, occupational, behavioral, adaptive sports, etc.) and access to assistive technology. Most importantly, our parent advocacy must be directed at helping prepare our children for a full life as an adult.

If you go back to the 1960s, the future for many people with disabilities involved moving into large institutional settings of group care. Inspired by the civil rights movement, many people with disabilities and their allies advocated for their right to a self-determined life in a community setting. Not everyone is the same and this uniqueness must be recognized. In the past, the individua had to adapt to the institutional system's structure. Now self-advocates have insisted on a person-centered approach. While this is a noble goal, it's not one that's easily achieved without intensive advocacy from the individual and their family.

> You and your child must become your own lifetime advocates! There's a great phrase in the world of self-advocacy – "Nothing About Us, Without Us!"

Planning for the adult world should begin as early as possible, even though your child's date for moving on from high school may seem to be in the distant future. The worst time to ask for help in improving reading or social skills is six months before the person starts school. Start earlier! It's your and your child's rights!

Educate yourself and your child. Know your rights in the educational and adult care system. You and your child must become your own lifetime advocates! Self-advocates and their families must be involved in every decision! There's a great phrase in the world of self-advocacy – "Nothing About Us, Without Us!"

Your child with disabilities should be part of all planning meetings, whenever possible, even if it is difficult for them to actively participate. It is important that members of Special Needs Committees (also known in many schools as the Committee on Special Education ("CSE")) see your child as an individual, as a person, and not just some impersonal name and diagnosis on an IEP form. It is much more difficult for a committee to limit services if they must explain themselves to the person needing the services, along with their family.

MAKING THE DREAM WORK: See yourself and your child as partners in the system of supports. It's a lot of work, but you already know that, being "Exceptional Parents."

See yourself and your child as partners in the system of supports, whether in the K-12 educational system, or the adult system of supports. Be actively involved with teachers, therapists, school committees, case managers, etc. It's a lot of work, but you already know that, being "Exceptional Parents."

The adult system of supports – housing, employment counseling, transportation, academics, social networks – is not as robust as the K-12 educational system, so it is important for the family to advocate for their child, but also to teach their children strong self-advocacy skills. For example, in the K-12 settings, some students have a paraprofessional aide. That is a rare occurrence in adult systems, so planning must begin early to explore alternatives.

All of us continue our learning adventure. No one stops learning just because their educational experience ends at twenty-one or some other arbitrary date. Make sure that everyone understands that it is impossible to measure a person's life potential. No one is static!

People with cognitive disabilities need concrete experiences to help them make choices and learn new skills. Important life skills are best learned by doing, and not just by viewing a video or simplified text. Your child needs to learn how to use the bus system? Have someone take your child on a bus ride. Help your child understand how to get off at the right stop and learn to ask the driver for assistance, if needed.

If the student uses some type of assistive technology, make sure the tech is available to your child after they leave high school, and that adult support staff are familiar with its use, and are trained to help the person successfully use the technology. On several occasions, I have seen a communication device locked in a cabinet, unavailable to the person, because the adult care staff received no training in the use of the device.

Think back to when you were young and starting in the work world. What was you first job? Is that the job that you have today? Probably not. Why should we expect people with disabilities to decide on a vocation, when they have no practical life or work experience? Much of success in a job is due to good social skills. No matter what the job, if you are late or frequently absent, or can't follow directions, success is improbable. Vocational supports for people with disabilities are available and you should enroll your child, as early as possible, and demand help with job-related skills, but also sophisticated social skill training.

If your adult child isn't ready for a job after high school, there are many providers of adult day programs that can help a person develop their life and vocational skills. Just make sure that you and your child visit the programs and ask for a trial experience. You want a program that is stimulating and helps your child discover and develop new skills and not just act as adult babysitters.

Most of the adult care system is funded through Social Security and Medicaid. Your child will need to be enrolled in these funding streams, if they are going to access most adult support services. Your special needs department can provide help on starting the application process.

> If you plan to leave funds for your adult child, you need to consult with a special needs attorney.

While it is a subject that we'd rather not think about, we will not be around forever to care for an adult son or daughter with disabilities. Years ago, people with disabilities didn't have long lives, but now with improvements in medical treatments and other innovative care practices, they are likely to have more typical lifetimes. It helps to start thinking about future planning early, since many state support systems have long waits for residential supports, whether that be shared living, independent apartments, or group residences. My wife and I had to go through this tough decision process six years ago, when it was clear that as we approached our seventies, caring for Jessica's physical needs would be more difficult. We found an accessible group residence for her, and she seems happy there. Through the miracle of FaceTime and regular monthly visits home with us, everything has worked out better than we expected.

If you feel your adult child has the capability to manage their personal affairs, then there are person-centered services such as shared decision making, that can help them manage their finances and major life decisions. If the individual has challenges in managing their affairs, you may consider having a guardian appointed to help them. Just because you are their parent, that doesn't make you their legal guardian after they turn eighteen. Explore this with your high school's special needs department. Due to the asset limitations established by Social Security and Medicare, the person with a disability is limited to the amount of assets that they can hold. If you plan to leave funds for your adult child, you need to consult with a special needs attorney to ensure that their benefits will be protected by a Special Needs Trust or other legal protections, so those funds won't be included in the person's asset base.

When you raise a child with disabilities, you have a lifetime of commitment and advocacy ahead of you. Appreciate what you do for them by being kind and generous to yourself. Tap into your support network of family and friends. It's a journey that others have traveled before you. Learn from them and pass your knowledge on to the next generation of "Exceptional Parents." •

ABOUT THE AUTHOR:

Jordan Jankus is the proud father of Jessica, his adult daughter who was born with multiple developmental delays. In addition to his role as a parent, Jordan has worked in human support services for twenty-three years as a case manager, employment specialist, self-advocacy trainer and assistive technology specialist. From his life experience, Jordan provides his thoughts on the critical subject of Transition. You can read more of Jordan Jankus' writings on the world of disabilities, parenting, lifelong learning, and technology at his Substack blog, "Plastic Learning" **https://plastlearn.substack.com**

GUIDING SECONDARY STUDENTS WITH DISABILITIES TOWARD SUCCESSFUL EMPLOYMENT: A COLLABORATIVE APPROACH

BY JENN ADAMS

Transitioning from high school to the workforce is a significant milestone for any student, but for secondary students with disabilities, this journey can be particularly transformative.

It demands a coordinated effort among parents, related service providers, and educators, to ensure that these students are equipped with the necessary skills and support, to not only enter, but thrive in the world of employment. In this article, we will explore a comprehensive roadmap to help prepare secondary students with disabilities for successful employment following their high school years. It truly needs to be a collaborative approach among all individuals working with the student.

EARLY TRANSITION PLANNING

Early planning is the cornerstone of a successful transition. Ideally commencing at age 14 or even earlier. This process should involve active collaboration between students, parents, educators, and other stakeholders. Together, they set clear, measurable post-secondary goals, encompassing not just employment, but also education and independent living aspirations. This stage lays the groundwork for a well-rounded transition plan that aligns with the student's individual needs and aspirations. It ensures that the planning and training are occurring while the student is still in school, long before the student graduates.

IMAGE BY STORYSET

COMPREHENSIVE ASSESSMENT

The heart of effective transition planning lies in conducting comprehensive assessments that uncover each student's academic, functional, and vocational strengths, while identifying areas where they require additional support. These assessments should comprise: formal evaluations, self-assessment tools, and input from parents and professionals. Special Education teachers and related service providers should include these results in the Individualized Education Plan (IEP) for the team to use. The results serve as a foundation for shaping actionable goals and strategies tailored to each student's unique profile.

INDIVIDUALIZED EDUCATION PROGRAM (IEP)

With assessment data in hand, the development of an Individualized Education Program (IEP) becomes paramount. This program should align seamlessly with the student's post-secondary objectives. It should include specific accommodations, modifications, and related services that support both academic and vocational success. What's more, it should be a living document, subject to regular reviews and updates to reflect the student's evolving needs and goals. Incorporating the students interests and skills are imperative to these transition goals being met.

BUILDING SELF-ADVOCACY AND COMMUNICATION SKILLS

Empowering students to confidently express their strengths, needs, and preferences is a fundamental skill. Through a combination of instruction and guidance, self-awareness and self-determination are fostered, equipping students with the tools they need to communicate effectively with teachers, employers, and colleagues, in their future work environments. This needs to be practiced in the classroom and the home, and taught in a natural environment to help the student to generalize the skills for use later.

VOCATIONAL EXPLORATION

To help students make informed career decisions, it's essential to provide them with opportunities to explore various vocations. This can be achieved through internships, job shadowing, and vocational assessments. Encouraging students to identify their interests, skills, and passions, in relation to future employment while simultaneously addressing potential barriers, ensures they embark on the right path. Many high schools will have programs that allow students to try different career fields. Often going on field trips to local businesses can help students learn about different careers.

COLLABORATION WITH RELATED SERVICE PROVIDERS

The path to successful transition often involves specialized support from related service providers, such as: speech therapists, occupational therapists, and counselors. Collaboration with these professionals ensures a coordinated approach to addressing the unique needs of each student. It also promotes a holistic understanding of how various services can complement one another in the pursuit of a student's goals.

FAMILY INVOLVEMENT

Parents are key stakeholders in the transition process. Engaging parents in this journey not only empowers them to support their child effectively, but also strengthens the overall support network. Offering resources, workshops, and guidance enables parents to actively participate in their child's transition to employment. Open and consistent communication between parents and educators ensures that everyone is aligned in their efforts. It also needs to be determined by the team, how the student will independently function after graduation, and getting family input is essential to crafting a good plan.

FINANCIAL LITERACY AND INDEPENDENCE

Equipping students with the knowledge and skills to manage their finances is an essential component of transition planning. Financial literacy includes budgeting, saving, and understanding government benefits and services that they may be eligible for. Alongside financial literacy, promoting independence in daily living skills, such as cooking, transportation, and self-care, is equally vital for fostering autonomy.

PRE-EMPLOYMENT SKILLS TRAINING

Building practical skills that are directly applicable to the workforce is crucial. Training should encompass resume building, job searching, interview preparation, and workplace etiquette. Creating opportunities for mock interviews, role-play scenarios, and peer feedback helps students gain confidence in their ability to navigate the job market effectively.

JOB PLACEMENT AND NETWORKING

Collaborating with local businesses, vocational rehabilitation agencies, and community organizations is instrumental in facilitating job placements, internships, or apprenticeships. These opportunities should be tailored to match students' interests and abilities. Encouraging students to network and establish professional relationships within their chosen field, further enhances their prospects in the job market.

POST-SECONDARY EDUCATION CONSIDERATION

For some students, post-secondary education may be the desired path to employment. In this context, it's essential to explore various options, such as colleges, vocational schools, or online courses. Providing assistance with the college application process, offering guidance on financial aid, and ensuring necessary accommodations are in place for higher education, are all crucial aspects of this step.

CELEBRATING PROGRESS AND ADJUSTING PLANS

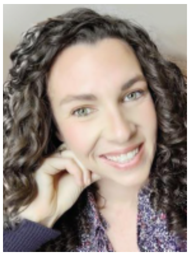
Transition planning is an evolving process. Many students will have plans that start at 14 years of age and can change many times before graduating. Recognizing and celebrating milestones and achievements is as important as regular reviews and adjustments to the transition plan. These reviews should take into account the student's changing goals, evolving strengths, and shifting needs. Input from the student, parents, and the support team should inform any necessary adjustments.

INCLUSION AND DIVERSITY:

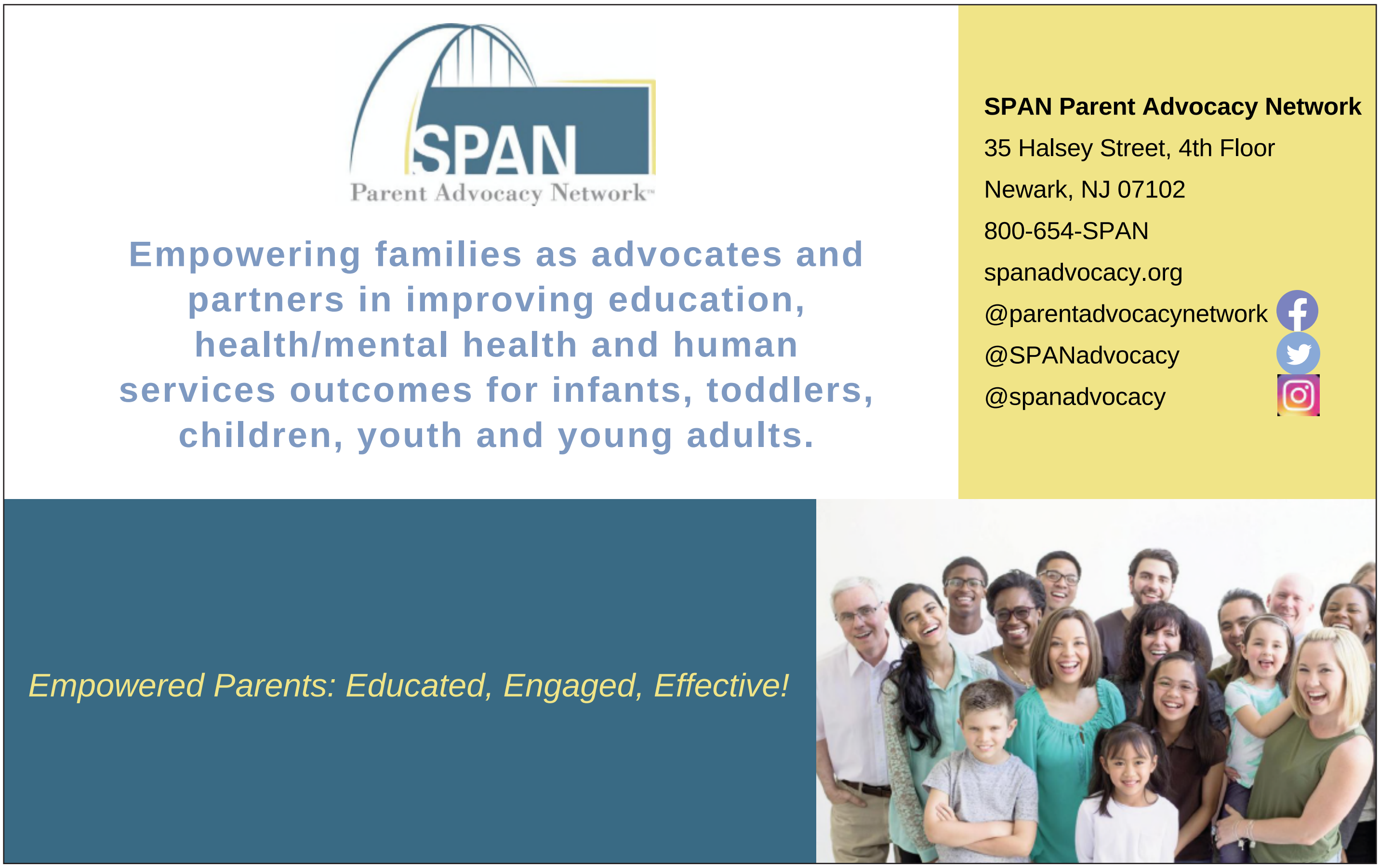
Preparing students for employment in today's diverse world is integral to their success. Emphasizing the significance of an inclusive and diverse work environment, fosters an appreciation for diversity and the value of different perspectives in the workplace. Offering training on disability awareness and inclusion for employers and coworkers ensures that the transition is smooth, not just for the student but also for their future colleagues.

In conclusion, guiding secondary students with disabilities toward successful employment is a meticulous, collaborative, and continuous process. By adhering to these detailed steps and sub-steps, we empower students to develop the skills, confidence, and connections necessary for a fulfilling career path beyond high school. Each step in this journey brings us closer to the overarching goal: ensuring that every student, regardless of their abilities, has the opportunity to reach their full potential in the workforce.

ABOUT THE AUTHOR:



Jenn Adams is a special education and elementary teacher living and work in Pennsylvania. She has taught in multiple classrooms, grade levels and settings including regular education, special education, and alternative education. She has taught grades Pre-K, 1st, and 5th-12.Currently, Jenn works for a public cyber charter school teaching students in grades 5th through 8th in an autistic support virtual classroom. Jenn obtained her Bachelor's degree in elementary and early childhood education in 2007 from Millersville University. She also obtained her Master's degree in 2014 in special education from Saint Joseph's University. Jenn also added the credentials of becoming a registered behavior technician (RBt) working closely with students with autism and intellectual disabilities working with principles of Applied Behavior Analysis. Lastly, Jenn is currently pursuing her principal's certificate from California University of PA. In her 14 years in education she truly has found that building relationships is what needs to come first and loves learning new ways to reach her students. During her time not spent in the classroom Jenn conducts parent training with colleagues in the special education field and provides information through her blog, website, and social media channels all called Teach Love Autism. Jenn also works hard every day to find a work and life balance and believes that is the key to happiness in doing what you love.



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BUILDING BLOCKS: Parent centers can play an important role in encouraging families to build self-determination skills in their loved ones with disabilities.

SUPPORTING FAMILIES TO FOCUS ON STUDENT SELF-DETERMINATION

BY LAUREN AGORATUS, M.A.

Family engagement and student empowerment need to be linked.

Families are used to supporting their children with disabilities, and it can be difficult for them to shift roles when adulthood approaches. Preparing for the transition to adult life can start early by giving choices to the child and giving the child responsibility. For example, you can let a toddler or preschooler pick which shirt to wear, given two choices. During transition, parents need to move from the family engagement model (parents are the main decision-makers) to the person-centered model of transition to adult life (youth are in the driver's seat).

HOW PARENT CENTERS CAN HELP FAMILIES

Self-determination is generally understood to be the ability for an individual to be the primary decision maker in regards to the path of his/her life. I'm Determined defines the essential elements as:

- **Choice making:** the skill of making choices
- **Decision-making:** careful consideration of solutions
- **Problem-solving:** finding answers to complex issues
- **Goal setting:** creating goals, planning, and attaining goals
- **Self-regulation:** monitoring one's own behavior
- **Self-advocacy:** speaking up for oneself or a cause
- **Internal locus of control:** belief in affecting outcomes
- **Self-efficacy:** belief in being able to accomplish tasks
- **Self-awareness:** understanding of one's own strengths, needs, and skills

Parent Centers, Family to Family Health Information Centers, and other family-run organizations, can help families understand the "dignity of risk" – having their child make their own choices. Families can start early, start small, build on choices, and add or take away supports as needed. Parent Centers, F2Fs, etc. can help families learn the benefits of self-determination, both for their child and the family as a whole. Charting the Lifecourse also has tools for individuals and families that help plan for achieving a "good life" *(see Resources).*

WHAT FAMILIES CAN DO

There are many ways families can build skills in their child that lead to decision-making and problem-solving. Self-determination includes:

- ✓ *Belief in oneself*
- ✓ *Setting goals for the future*
- ✓ *Awareness of supports needed to attain goals*

Families can use the same what is listed above. Below are some examples:

FUTURE DECISIONS : BUILDING SELF-DETERMINATION

CHOICE MAKING	• Would you like to go out to eat or cook something at home?
DECISION MAKING	• Your room needs to be clean by the time our guests arrive Sunday at 2. You decide how and when to get it dome by then.
PROBLEM SOLVING	• Develop a menu that fits your budget.
GOAL SETTING	• Set small goals for academic achievement or even for physical fitness.
SELF REGULATION	• Use a keyword when children act out and give them opportunites to self-regulate and demonstrate positive behaviors.
SELF ADVOCACY	• The student chooses a cause and gets involved in the community.
INTERNAL LOCUS OF CONTROL	• Give age appropriate choices, so the child has some control.
SELF EFFICACY	• Positively reinforce new skills and even unsuccessful attempts, as part of the process.
SELF AWARENESS	• Have the child articulate the impact of their disability using a strengths-based approach to explain support needs.

Families can also help their child use Charting the LifeCourse mentioned above. This focuses on 6 domains:

1. Daily life and employment
2. Community living
3. Safety and security
4. Social and spirituality
5. Healthy living
6. Advocacy and engagement

Students with disabilities benefit from the support of families to build and practice new skills, and Parent Centers can help families with self-determination for their child. •

Special thanks to Sean Roy of TransCen and Dr. John McNaught of I'm Determined.

SETTING GOALS : TRANSITIONING TO ADULT LIFE

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"Supporting Families to Focus on Student Self-Determination" Webinar recording (includes Spanish, ASL, captioning) and handouts
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Lauren Agoratus, M.A. is the NJ Coordinator for Family Voices, NJ Regional Coordinator for the Family-to-Family Health Information Center, and Product Development Coordinator for RAISE (Resources for Advocacy, Independence, Self-Determination, and Employment). She also serves as NJ representative for the Caregiver Community Action Network as a volunteer. Nationally, Lauren has served on the Center for Dignity in Healthcare for People with Disabilities transplant committee (antidiscrimination), Center for Health Care Strategies Medicaid Workgroup on Family Engagement, Family Advisor for Children & Youth with Special Health Care Needs National Research Network, National Quality Forum-Pediatric Measures Steering Committee, and Population Health for Children with Medical Complexity Project-UCLA. She has written blogs and articles nationally, including publications in two academic journals (**https://pubmed.ncbi.nlm.nih.gov/?term=agoratus+l**). Lauren was named a Hero Advocate by Exceptional Parent Magazine (**www.epmagazine.com**) Archives June 2022.

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What can YOU do?
THE CAMPAIGN FOR DISABILITY EMPLOYMENT

SELF-ESTEEM, ACCOMPLISHMENT AND PURPOSE:

MAKING COMPETITIVE INTEGRATED EMPLOYMENT WORK

BY ARTURO CAZARES

It can be difficult for today's parents to hear, but it wasn't all that long ago that schools and communities generally had low expectations for what those with special needs could achieve, both in school and in the workplace.

This perspective is exemplified by the fact that it was only in 2022 that California – where my agency operates – began offering an alternative pathway to a high school diploma, exclusively for students with significant cognitive disabilities.

ALTERNATIVE PATHWAY TO A HIGH SCHOOL DIPLOMA

Previously, parents of a California student with an Individualized Education Program (IEP) had just two options to explore how their child would complete secondary education: earning the traditional high school diploma pursued by most typical students, or a certificate of completion. This had the unintended effect of greatly limiting many students' employment options after they transitioned out of the public school system. That's because most jobs in the community require a high school diploma. Since a certificate of completion is not a substitute for a diploma, far too many young people would face another unnecessary hurdle when searching for employment.

Now, however, California school districts are required to exempt eligible students from coursework and additional requirements beyond what is required by

JOB WITH BENEFITS: A paying job in the community can instill self-esteem and a sense of accomplishment and purpose for a person with developmental disabilities.

California's Education Code to receive a high school diploma. Before the student with an IEP begins grade 10, the IEP team must determine if the student is eligible for this exemption, which requires the student to take the California Alternative Assessments for various subjects in grade 11 and complete coursework aligned with state standards.

This will go a long way toward facilitating more students' transition from public school to the world of competitive integrated employment.

WHAT IS COMPETITIVE INTEGRATED EMPLOYMENT?

"Competitive integrated employment" is exactly what it sounds like and it's what most people engage in throughout their working lives. It's competitive in that the person with disabilities holds a position that requires them to interview and demonstrate their qualifications, and could just as easily be held by a person without disabilities. It also requires the employer to pay the person with disabilities whatever is customary for anyone completing the same work. It's integrated in that the person with disabilities works alongside peers without disabilities, sometimes with the assistance of a job coach, who may provide more or less support depending on the individual's needs. It's employment in that the person with disabilities is paid to perform the job.

It's long been recognized that just as is the case for typical adults, a paying job in the community can instill self-esteem and a sense of accomplishment and purpose for a person with developmental disabilities. This is one of the reasons the State of California and Regional Center of Orange County have both adopted Employment First policies, which mandate that we explore competitive integrated employment as the first option for the working-age adults we serve.

Though we, like many others, are challenged to secure competitive integrated employment for all of the adults with developmental disabilities who want jobs, Regional Center of Orange County and our community's employment service providers have been recognized for our efforts to help the adults we serve, achieve their career goals.

This includes creating partnerships with prospective employers to identify jobs that match the skills of the those we serve, and partnering with employers on internship programs that enable people to gain important job skills and experience that can set them up for longer-term success in the workplace.

INTERNSHIPS CAN MAKE A BIG DIFFERENCE

Among the great internship success stories is that of Project SEARCH. Created in 1996 with a program at Cincinnati Children's Hospital Medical Center, Project SEARCH now includes sites across the U.S. and globally. In our community, we and our service providers have successfully established Project SEARCH internships at several area hospitals. These almost year-long internships provide real-life work experience that give persons with developmental disabilities exposure to different potential career avenues, and provide new skills and experience that can build a resume for future employment. In fact, a number of our Project SEARCH graduates have been offered employment in both traditional and non-traditional roles, often with full benefits.

For example, one young man we serve who has autism, works in a hospital's patient financial services department, while a young woman we serve who also has autism, found rewarding work in a hospital's food service department.

In California, we also have a state-funded option called the Paid Internship Program that has seen some great successes. We at RCOC have been especially pleased at the efforts of businesses like Edwards Lifesciences. A global leader in patient-focused medical innovations for structural heart disease, as well as critical care and surgical monitoring, Edwards Lifesciences has demonstrated outstanding leadership in providing life-enhancing opportunities for adults with disabilities, as a host site for various paid internships, some of which have resulted in full-time employment with the company.

However, smaller enterprises can also benefit from paid internships, to enhance the diversity of their workforces and provide opportunities for those with disabilities.

PARENTS AS JOB DEVELOPERS

Another internship success story I like to share is that of Jeffrey Baek, a young man with autism. Previously successfully employed for six years at a Ralph's grocery store, Jeffrey wanted to pursue other career interests in film and video. He also wanted to get into a line of work where he could make more money, that would allow him to travel more with his family.

Jeffrey's mother, Jinsook Baek located the ideal opportunity for him with a local Korean-owned filmmaking company, and persuaded them to bring Jeffrey on as a paid intern through the Paid Internship Program. What began as a three-month trial, worked out so well that Jeffrey continued the internship for a year, giving him excellent work experience. He learned how to use CGI, transitions, effects, and cinematic experiences, and also greatly benefitted from learning how to better engage with coworkers.

Jinsook's efforts are representative of what we see as an exciting new approach, in which parents increasingly take the initiative to tap their own professional networks, and sometimes even their own employers to uncover work opportunities, not just for their loved ones, but for all individuals with disabilities. It's leading to greatly enhanced career options for those we serve, and more inclusive and diverse workplaces, which is good for all of us. •

ABOUT THE AUTHOR:

Arturo Cazares is Director of Community Services for Regional Center of Orange County, the private, nonprofit organization contracted by the State of California to coordinate lifelong services and supports for more than 25,000 Orange County, California residents with developmental disabilities and their families. The Regional Center is the first stop for those seeking to obtain local services and supports to help them live safely and with dignity in the community. Developmental disabilities include intellectual disabilities, autism, epilepsy and cerebral palsy. Learn more at **www.rcocdd.com**.

TIPS TO HELP YOUR CHILD THRIVE THIS YEAR IN SCHOOL

BY DR. REBECCA JACKSON

Navigating a school year with any child can be overwhelming and exhausting. Add any developmental or learning challenges to the school year, and the ups and downs can feel even more stressful and extreme.

As parents, we want to do everything we can to support our kids, to ensure their school experience is a positive one, but it can be hard to know where to start, or what to do to make this year better than the last.

Looking to the brain and neuroscience for insights can provide some great strategies to be applied at nearly every age.

EP SPECIAL SECTION • THRIVE AT SCHOOL •

STRATEGIES FOR SUCCESS: Parents who want to help support their child in school this year can benefit from consistency, patience and a few suggestions based on neuroscience and experience.

SETTING UP FOR SUCCESS : GREAT STRATEGIES TO HELP YOUR CHILD THRIVE THIS SCHOOL YEAR

Beyond consistency and patience (which is key), here are a few additional suggestions based on neuroscience and experience, to help support your child this year in school!

ENSURE GOOD REST AND FUEL TO PROVIDE OPTIMAL SUPPORT!

A tired or stressed brain is a negative brain. A good bedtime/wake-up routine ensures plenty of sleep.

CREATE A HEALTHY MORNING ROUTINE

To minimize stress and prepare for optimal attention and focus, prep everything the night before - lunches, backpacks, and outfits. Allow your child time to wake up. Avoid access to phones or tablets to minimize distractions. Eat a healthy breakfast, and get your child moving! Even just 1-3 minutes of engaging large muscles and spiking the heart rate can help wake the brain up to activate memory and attention.

HEALTHY SNACKS CAN MAKE A BIG DIFFERENCE!

Check their schedule for snack and lunch times. Focus on providing protein and healthy fats, and minimize sugars and food dyes that can spike and crash energy and disrupt attention.

TO HEAR ALL ABOUT YOUR CHILD'S DAY, WAIT UNTIL AFTER THEY'VE HAD A SNACK!

Don't ask right away, unless they want to share!

ATTENTION: UTILIZE YOUR CHILD'S ATTENTIONAL WINDOW TO HELP SUPPORT HOMEWORK

It's crucial to set homework expectations based on your child's current attention span, and not based on the amount of homework assigned that day, or based on their age or grade level. Don't assume that because they are 10 years old, they have a 20-minute attentional window of focus. Each child varies in their development, which directly impacts their ability to sustain focus. Encouraging your child to work as independently as they can, within their window of attention, then providing extra support once the time has surpassed that window, will help set you both up for tremendous success!

To determine your child's attentional window, subtly observe and time them while they are working. Pick a day they are well-rested and fed. Don't start the timer the first time you say, "Time to sit down for homework," but when they actually begin to work. Then, note how long they can stay on task without redirection or support. There is no wrong answer here. This is simply providing you with realistic information about your child's current abilities! Whether it is one minute or 20, you can use this as a guide to know when, and how much additional support they will need from you, as they work.

If your child can focus for 10 minutes at a time, but homework requires half an hour, plan for it! This will require you to either join your child in supporting their attention and work beyond the first 10 minutes, or break the homework up into multiple 10-minute chunks.

REDUCE STRESS: HELP YOUR CHILD IDENTIFY AND REDUCE STRESS BEFORE HOMEWORK OR STUDYING

For many kids knowing they have an upcoming test to study for, or a long list of homework assignments, can trigger feelings of stress, which can make it even harder to do the needed work. Simply put, stress hijacks the brain. Stress can make it harder to utilize the higher-level functions needed for homework such as, sustained attention, and memory, and depletes the brain's energy resources.

While we can't always influence all sources of stress, when it comes to stress related to schoolwork, letting our kids know we are there to help, can go a long way.

Start by acknowledging how your child is feeling, and share with them what action, words, or body language you noticed, that led you to believe they were stressed. (This can help to bring awareness to feelings and actions.) Don't downplay or minimize their feelings. Instead, validate those feelings by letting them know you feel that way sometimes too. Offer your help and support, so they know they're not alone. You can ask how you can help, or tell them your plan to help get the work done. For example: "I can tell by your facial expression and tone of voice right now, that you are feeling stressed. I feel that way sometimes too. How can I help right now? Let's start by making a list of what needs to get done, so we don't forget anything. Then we'll review your study guide together!"

Over time you can pull back on how much you are helping, allowing your kids to be more independent in their work, but when stress is high, knowing they're not alone can help!

BUILD CONFIDENCE: CELEBRATE THE EFFORT NOT THE OUTCOME

Whether your child is a straight A student, or works hard at their individual level, celebrating the effort, not the outcome can be helpful. With a focus on effort, and mastering something new, you can help support what is considered a growth mindset.

Carol Dweck, a Stanford psychology professor, spent 40 years studying growth mindset and motivation.[1] Her work helped teach us that telling kids they were intelligent could result in kids who were less comfortable taking

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[1] https://www.edweek.org/leadership/opinion-carol-dweck-revisits-the-growth-mindset/2015/09

risks, and may shut down more quickly when something became challenging. Dweck describes this as having more of a fixed mindset. When we combine that mindset with our own parenting expectations of what a child “should” be able to accomplish, we’re setting our kids up to shut down when faced with a challenge and fall short of expectations. Kids who were praised for effort were found to try harder, and persist longer at tasks. These kids tended to be more resilient and considered to have a growth mindset. Be careful in praising the effort, it needs to be genuine, and there is more to simply saying “good job working hard” to tap into a growth mindset. It’s also giving kids the message that the brain can be changed and improved. It’s helping kids understand that if something is hard, it just means they haven’t mastered it - yet.

Next time your child is struggling with school work, acknowledge how hard you see them working, and talk about what you can do next to continue to support this area of learning. Then, point out something else that had been hard for them, that through hard work they did eventually master. “I appreciate how hard you are working on math tonight, and can see that you’re starting to catch on. Let’s review these flash cards again tomorrow morning during breakfast, so you feel ready for the day. Remember when memorizing your math facts was hard? Now you’ve got it down! Keep working hard and we’ll get there. You’re brain is getting stronger through this practice.”

SET GOALS: ASK YOUR CHILD WHAT THEIR GOALS ARE FOR THE YEAR

The brain loves goals. When you set a goal that excites you, the brain releases dopamine, a feel-good neurotransmitter, which can boost your mood and energy. But dopamine doesn’t stay present in the brain for long, making it harder to remain consistent in doing the work required to achieve the goal. To help, break a big goal down into smaller steps. This creates mini-goals. Checking off the mini-goals while working towards bigger goals can re-engage motivation and excitement, increasing the odds of achieving the goal. It is also an outstanding executive function practice for planning and follow-through.

Have a conversation with your child about something (or things) they’d like to accomplish this year. Help them think about how they would feel when they accomplish that goal. Maybe it’s making new friends, trying a new sport, or getting a good grade in a hard class. Help your kids identify a goal that is personal and exciting to them, and remember, this needs to be their goal, not yours!

Next, map out a plan of the mini goals, or steps and timeline needed along the way. Write out the goal and steps and keep it out and visible, as a constant reminder. A note taped on the bathroom mirror, or at their desk with a big smiley face, as a reminder of how good they’ll feel when they achieve their goal!

SCHOOL PORTALS: CREATE A ROUTINE OF STRUCTURE AND SUPPORT

Parents have more visibility and information than ever at their fingertips, thanks to school portals. While the portals can be a helpful way to keep track of work, grades, and even behaviors, they can be overwhelming, and confusing at times. Not all teachers update the portals with the same consistency or information, which can create more questions than answers.

Start the year by finding out how each teacher uses the portal, and how frequently they recommend checking it for their class. If they only update grades bi-weekly, then checking weekly to review completed work, won’t be helpful, and may make it look as though your child hasn’t completed an assignment.

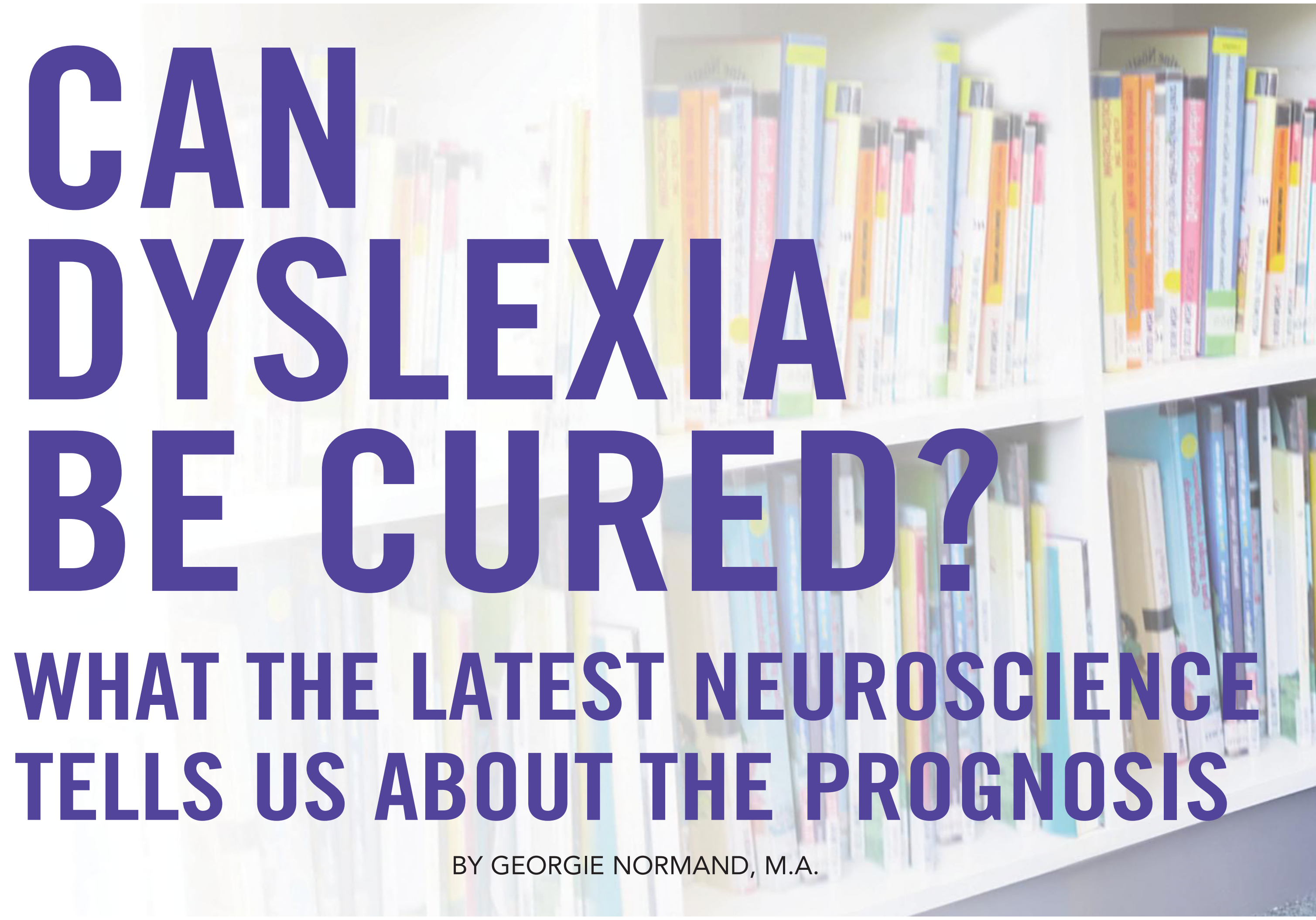
Choose a night to sit down and review the school portal together with your child. Review what has been completed, as well as what is coming up. Focus on keeping the interaction positive and supportive (replace “why didn’t you turn that in?” with “let’s find out more about this assignment”). Work together to create a plan for the upcoming week. Ask questions to understand what work has been completed and graded, and what is coming up. This will benefit you, as well as ensure your child has a good grasp on the status of their assignments and tests. Anytime the information is unclear, encourage your child to email their teacher, and CC you on the communication. This will help to provide a direct answer, as well as teach your kids that it’s okay to speak up and ask questions.

Next help support the plan with gentle reminders and guidance, where needed, to help keep your child’s work on track.

Learning isn’t just for kids! As parents, we are continuing to learn and grow as well. If you learned something new and helpful in this article, share that information with your kids. Talk about what you learned, and how you are going to work to incorporate it into this school year to help set them up for success in school. •

ABOUT THE AUTHOR:

Dr. Rebecca Jackson is an industry leader in brain health and optimizing the brain to enhance how you feel and function. She brings 15 years of Brain Balance experience as Chief Programs Officer. In this role, she leads research on improving cognition, development, and well-being, drives programmatic enhancements, and creates new programs to meet the growing demands of people wanting to achieve more -for themselves and their children. Dr. Jackson is the author of the book *Back on Track* (**https://mcpress.mayoclinic.org/product/back-on-track**), and is a frequent media guest as an expert on improving brain health, development, and cognition. Dr. Jackson's work has been featured in Mayo Clinic Press, Forbes, Psych Central, Business Insider, and more. She has appeared on local and national news and shows such as The Doctor’s Show, and NBC’s Nightly News. Visit **http://brainbalancecenters.com**



CAN DYSLEXIA BE CURED?

WHAT THE LATEST NEUROSCIENCE TELLS US ABOUT THE PROGNOSIS

BY GEORGIE NORMAND, M.A.

Although neuroscientists do not use the word "cured" when referring to dyslexia intervention outcomes, the science looking into this question is very encouraging.

EP SPECIAL SECTION
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In this age of neuroimaging, we can actually track brain changes that occur as a result of reading intervention. This is an emerging science in dyslexia, but recent imaging studies demonstrate that the brain can and does respond to intervention. When a group of researchers reviewed 39 before-and-after neuroimaging studies, they found evidence of positive changes in activation, connectivity, and even brain structure after reading intervention. Some of these studies reported a *normalization* of the reading network in the brain after intervention.

THE LANGUAGE OF NEUROSCIENCE

Neuroscientists that study dyslexia use the word *recovery* rather than *cure*. They define recovery as the normalization of any weak processes of reading and reading-related brain networks. *Compensation* is another related process that can be seen in imaging studies of individuals with dyslexia when they are reading. It refers to the finding that areas of the brain not typically associated with reading, show hyperactivation in individuals with dyslexia. Some believe that this hyperactivation is evidence that individuals with dyslexia use a variety of compensatory strategies when reading.

Even non-dyslexic readers use compensatory strategies, but we now know that dyslexic readers use them to a greater extent, and for a longer period of time. Reading intervention sometimes increases the activation of pathways not normally involved in reading, but not always. More research is needed in this area of dyslexia.

Connectomics is another term important to how dyslexia recovery can be viewed and measured. It refers to how efficiently cognitive processes required for reading are being coordinated throughout the brain. Think of it as the *"it takes a village"* idiom. Reading success involves not just one brain region, but the entire brain network architecture. This is why explicit and systematic phonics instruction, by itself, will not remediate dyslexia.

In dyslexia, there is a lack of coordination between brain regions. This explains why dyslexic children and teens often fail to reach grade level fluency, even after years of phonics instruction. New studies have found that by targeting these inefficiencies in the intervention, they can make progress much faster.

GAME THEORY: When dyslexic children are "pushed" to read at a faster and faster pace, they improve in every area of reading and in much less time, compared to traditional phonics-based approaches. Turning this process into a game keeps students motivated, especially when they find they are reading more effortlessly each day.

Important processes in the brain such as visual attention, error monitoring, speed of processing, working memory, and other processes important to fluent reading, are components of what is called *executive function*. Since fluent reading relies heavily on all of these components, neuroscientists are finding ways to target executive function as part of reading intervention.

Reading fluency training is one such successful strategy to improve executive function in dyslexia. When dyslexic children are "pushed" to read at a faster and faster pace, taking them beyond their typical reading rate and comfort zone, they improve in every area of reading, and in much less time compared to traditional phonics-based approaches. This process, when it is added to systematic reading instruction, helps to synchronize the brain regions involved with reading, leading to long term improvements in all aspects of reading. Turning this process into a game keeps students motivated, especially when they find they are reading more effortlessly each day.

INCREASING OPTIMISM

Neuroimaging, new electroencephalogram (EEG) technologies, and other advances in neuroscience are providing a window into how different types of intervention change the brain. Recovery is possible by incorporating new research-based strategies into intervention.•

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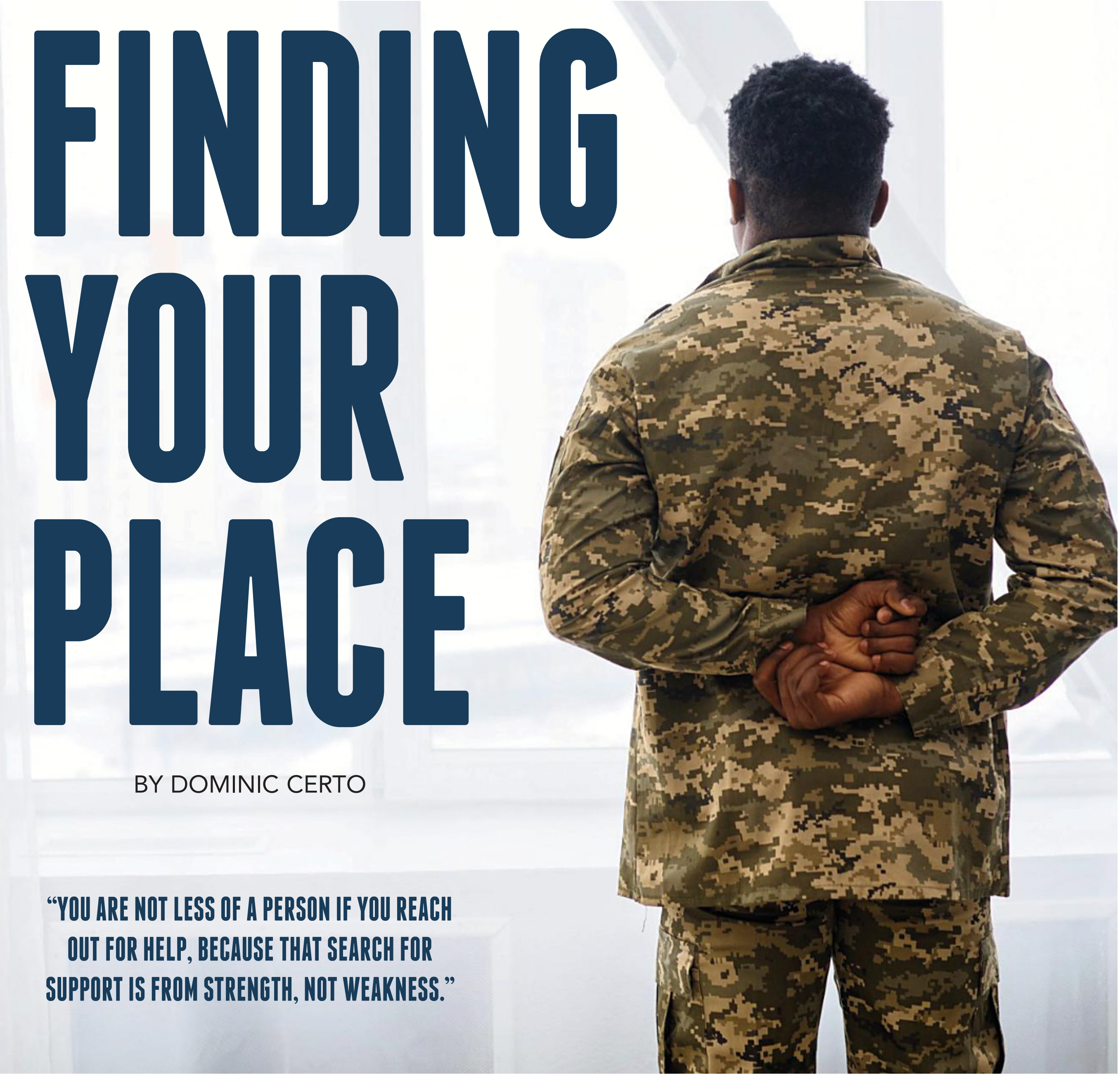
MILITARY SECTION

ARMY
NAVY
AIR FORCE
MARINES

MILITARY LIFE

FINDING YOUR PLACE

BY DOMINIC CERTO



> “YOU ARE NOT LESS OF A PERSON IF YOU REACH OUT FOR HELP, BECAUSE THAT SEARCH FOR SUPPORT IS FROM STRENGTH, NOT WEAKNESS.”

The demonstrable problem facing most military with combat experience is managing post service emotional, mental, and physical readjustments. Countless veterans suffer from one, if not all three of these problems. It’s difficult to come back to a sane, satisfying, comfortable lifestyle, after a life of shock, violence, and at times, inhumane acts, when all around you is a culture focused on the exact opposite.

I realized this, not only from my own experience as ac combat corpsman with the Marines in Vietnam, but as Chairman of The Advisory Board at Operation Homefront, where we worked to settle and readjust disabled veterans and their families into a better life. These challenges came at a price and a commitment, but the commitment and price begin with the individual and their desire to refocus on something new.

In 1970 I returned from the Vietnam War struggling to deal with experiences that I had while involved with operations in a heavy combat area. The death, destruction and insanity of war made an impression on me as a young 19-year-old man. I came back somewhat bitter, disillusioned, and insecure, as I

INNER STRENGTH: Finding your place begins with the individual. Realizing that there are organizations and people that are willing to help you with your struggle is key to finding the road to recovery and success.

faced having a family and two young children. I knew my responsibility was needed, and I knew I had to accept a whole new culture of thinking. But, the fear and doubt remained, as well as the very vivid memories. In the beginning I was occupied with finding work, as much as possible, to pay the bills. On top of that I needed to control my dreams and moments of PTSD. There was a young wife, who didn't know what was lurking in my brain and emotional storehouse. I had two beautiful children needing a responsible father. These elements, along with prayer and my belief in God, pushed me to work and achieve, but never eradicated the past. Somehow, I managed, but the struggle was endless. So many nights, my dreams returned to haunt me. Eventually, finding my place came after pushing forward and not giving up. I learned to cope and compartmentalize all the abstractions in a place that needed to remain separate from a new life. Eventually, my efforts put me on track and made me stronger, to build my own companies, and write books that served as a catharsis for all those things inside of me. Eventually, I was able to help other veterans with the same problems, with my book, articles and by appearing on TV shows and podcasts, about how they could deal with the same problems. I brought attention to the increasing suicide rates of all combat veterans, and especially Vietnam combat vets. The numbers of homeless, drug addicted, and suicidal veterans were astonishing and growing. Something had to be done.

Things have improved over the years, there are more organizations, groups, and people who are willing to help and understand. Unlike the post-Vietnam war period, where everyone was reluctant and even fearful to deal with the returning combat veteran, today there are focus groups who not only aid in the financial aspects of readjustment, but in the emotional and psychological problems as well. Today there is acceptance and understanding for the military people who need that help. So many organizations like Operation Homefront, Tunnels to Towers, The National Center for PTSD, and many more, are ready to step up and lend a hand. Even the VA has improved, providing numerous agencies that will respond, if only the veteran applies.

SUPPORT FOR VETERANS

Remember there is no disgrace in your experience as a combat veteran. There is no humiliation in showing your pain. There are only roads of support to help you find your place. Here are just a few and a way to start.

National Center for PTSD
POSTTRAUMATIC STRESS DISORDER

NATIONAL CENTER FOR PTSD
www.ptsd.va.gov/gethelp/peer_support.asp

OPERATION HOMEFRONT

OPERATION HOMEFRONT
operationhomefront.org

VET CENTER

VET CENTERS
www.vetcenter.va.gov

Finding your place begins with the individual. It may be easier said than done, but the fact remains that it must be started, because without a start the fall to failure is too great. Realizing that there are organizations and people that are willing to help you with your struggle is key to finding the road to recovery and success. You are not less of a person if you reach out for help, because that search for support is from strength, not weakness. It is from a desire to be better and stronger. It is an integral part of all humans.•

ABOUT THE AUTHOR:

Dominic Certo, author and businessman, served with the 7th Marines in Vietnam and is an advisory board member of Operation Home Front. He has since served as an advisor and Chairman of the Advisory Board for Operation Homefront. Certo has served as President of Hillside Publications, and Chairman of The Certo Group. The Certo Group is a food services company founded by Certo in 1985 which went public in 2004. Certo was knighted by the Royal Family of The Reigning Order of St. John in Russia. He has also received two Presidential Volunteer Service Awards.

U.S. MILITARY ★ BOOK EXCERPT 11TH OF A SERIES

THE RESILIENT WARRIOR

DO YOUR THING

BY TRAVIS PARTINGTON

Book Editor's Note: Featuring self-help, mental health, and mind and body tactics from a variety of sources – veterans, former and active U.S. Marines, Navy, Army Rangers, Green Berets, family members and caretakers – ***The Resilient Warrior*** *is collaborative collection providing needed wisdom for complete well-being for all of us. The first step to thriving is surviving, and the first step to surviving is knowing how to get what you need, when you need it. The following excerpt of this essential self-help guide to living a healthy, resilient, fulfilled and better life is the eleventh in a series that EP Magazine has featured over the last several months.*

Do something that adds value to others authentically.

For active military service members, veterans, and non-veterans, I had an idea to create a place to meet and share ideas on how to be there for each other. I looked at different ways to do this and decided the best way to get the message out was to use a podcast/internet radio format. And, Oscar Mike Radio was born.

To take a step back: 2014 had to be the lowest point in my life. I felt disconnected from friends, family and wanted to shut myself off from life. About that time, I joined the Marine Corps League and started going to funerals of veterans who had committed suicide. I knew I was in a valley in my life, but could not figure out why my fellow veterans had abandoned hope and chosen a permanent solution to a temporary problem. I knew I wanted to do something, but was not sure what to do. Write a blog? I can write, but wasn't sure if that would work. I could do a video show, but even though I do video now, I passionately believe I have a face for radio.

Right around this time, I started doing guest hosting at WVBF AM 1530 in Taunton, MA. I was on the show "South Shore News and Views", and I had a really great time working on the radio. An idea started to form that I could do a radio show. However, there were several barriers to launching on an AM/FM station. I did not have the money for airtime, nor did I have sponsors who could help me pay for the airtime. I also was not able to dedicate time to go to a physical location, due to work and other obligations.

Some time went by, and in April 2016, I went to the first Dale Dorman Media Day at Massasoit Community College. My voice teacher suggested I go and meet with some media profession-

ON MISSION: *(Above left)* The author working in the HAWK Missile Launcher in the Arizona desert; *(Above right)* The author was promoted to Lance Corporal at 35K feet while the pilot made the announcement to the entire plane. His entire battery stood while he was pinned.

als, and believe me, that day really changed everything.

More than the voiceover breakout sessions, I wanted to check out the Whoobazoo workshop on podcasting. Whoobazoo is a podcast network run by Keith Hayes and Anthony Arnold. Keith was talking about getting into podcasting, and what a podcaster could do if they were willing to apply themselves. I took notes and talked with Keith after the workshop. He asked me what I was going to be podcasting about, and asked if I had any audio editing experience. I told him I wanted to do a military/veteran's podcast, and I was going to call it Oscar Mike Radio. When Keith asked why, I told him "Oscar Mike" can mean "On the Move" or "On Mission." I felt that would capture what I was trying to do with the show. Keith told me to download Audacity and a digital audio workstation program, and to record something.

With some help, I got a laptop and microphone, and started recording. On July 22nd, 2016, my first show dropped. Five people listened to it, and honestly? It was pretty bad. Podcasting is not like being on the radio; because it is recorded, and you are often by yourself – including when you edit your work. My tone, pacing and energy was just not there. But I did it. Keith gave me some advice and candidly told me what to do to improve. I kept working, reading, trying, but failing to improve.

Slowly, but surely, I eventually started to get in a groove. Preparing for a podcast became easier, I started to relax. I wanted Oscar Mike Radio to be like when I was driving with other Marines in my 5-Ton truck pulling inert missiles to the range. Those conversations were relaxed, great and when guys would open up. Once that started happening, the podcast started getting fun and before I knew it, I was at number 100.

Episode 100 was significant because I had (at the time) WAAF DJ Mistress Carrie on my podcast. Having her on helped me in so many ways. A guest like Mistress Carrie demonstrated that I could talk to people in a way that was engaging and authentic. I started working to improve my craft, when it came to interviews.

It was about this time that I noticed a change in myself and my approach to life. I was not so closed off to people. Even though Oscar Mike Radio does not pay me anything, knowing that I had to outline, produce, and promote content weekly, forced me to engage with others in a way that I hadn't done before. I enjoyed the challenge of trying to bring life to a story, or a person's struggle to victory, on a weekly basis. Having something to do and execute, to the best of my ability, got me believing in myself.

I have talked with veterans, Gold Star family members, CEOs, film makers, artists, trauma victims, business owners, coaches, volunteers, heads of nonprofits, and people everywhere who support veterans. One of the highlights of 2020 was talking with Kev Breen of Immersive Labs who served in the United Kingdom's Royal Corps of Signals. Getting to share what Kev is doing with Immersive Labs is proof that what I am doing has value. Understanding this has led me to embrace the unknown, and say "yes" when saying "no'' may have been the safer, less risky option.

As I write this, #220 drops. I am excited for the future. Giving of myself to do this show has provided a purpose and way to learn about myself. I have learned that there is nothing I cannot do. I have learned that asking for help is a good thing. I would tell anyone, that you do not have to suffer alone. There are still people out there who are "Oscar Mike" to ensure no one gets left behind.

VALUE ADDED: *(Above)* the author's boys, Trevor, Tanner and Tucker, hate taking pictures, but did it for their dad; *(Lower left)* Recording at the Abington, MA War Memorial; *(Lower right)* Getting ready for a 3D archery competition in Fall River, MA.

It may not be a podcast, or a video show, but whatever you are thinking about as "your" thing, I would say do it. Do it with one hundred percent effort and determination, with no expectation of a reward nor compensation. I will not promise you fame or fortune, but I will promise that you will change your life and the lives of those around you. This is my Life Hack. Do something that adds value to others authentically, and you will come away healed and restored in a way that a pill will never be able to do. You can do it. I believe in you; just take the first step. •

ABOUT THE AUTHORS:

Travis grew up in the Midwest before moving South with his family. He joined the Marine Corps and served as a radar operator for HAWK Missile System. After the Marine Corps, Travis moved to the Boston area, and worked for a financial services firm. Travis hosts the military and veterans podcast, Oscar Mike Radio. It has over 350 shows and is in the sixth year of production. In addition, Travis has done voice over work and writing. In 2022, Travis' contribution to the anthology, "Let Go or Be Dragged," made Travis an International Best Seller. Travis enjoys the outdoors, archery, and riding his motorcycle. Being a father is the most rewarding aspect of Travis' life.

Nick Benas grew up in Guilford, Connecticut. The author of *Mental Health Emergencies, Warrior Wisdom, Tactical Mobility,* and co-author of *The Warrior's Book of Virtues,* Benas is a former United States Marine Sergeant and Iraqi Combat Veteran with a background in Martial Arts (2nd Dan Black Belt in Tae Kwon-Do and Green Belt Instructor in Marine Corps Martial Arts Program). Nick attended Southern Connecticut State University for his undergraduate degree in Sociology and his M.S. in Public Policy. He has been featured for his business success and entrepreneurship by more than 50 major media outlets, including *Entrepreneur Magazine, Men's Health,* ABC, FOX, ESPN, and CNBC.

Richard "Buzz" Bryan is currently the Outreach Coordinator for the West Palm Beach VA medical center. The co-author of *The Warrior's Book of Virtues,* Buzz previously served as the OEF/OIF Transition Patient Advocate (TPA) for the Veterans Integrated Service Network (VISN4) based in Pittsburgh, PA for ten years, working specifically with Iraq and Afghanistan veterans. Buzz was a member of the Navy/Marine Corps team and retired from the United States Navy in July 2011 after 22 years of honorable service as a Fleet Marine Force Senior Chief Hospital Corpsman.

Veterans Crisis Line Fact Sheet

Veterans Crisis Line
DIAL 988 then PRESS 1

Confidential crisis help for Veterans and their families

The Veterans Crisis Line is a toll-free, confidential resource that connects Veterans in crisis and their families and friends with qualified, caring U.S. Department of Veterans Affairs (VA) responders.

Veterans and their loved ones can **Dial 988 then Press 1**, chat online at VeteransCrisisLine.net/Chat, or send a text message to **838255** to receive free, confidential support 24 hours a day, 7 days a week, 365 days a year, even if they are not registered with VA or enrolled in VA health care.

The responders at the Veterans Crisis Line are specially trained and experienced in helping Veterans of all ages and circumstances—from Veterans coping with mental health issues that were never addressed to recent Veterans struggling with relationships or the transition back to civilian life. Veterans Crisis Line responders provide support when these and other issues—such as chronic pain, anxiety, depression, sleeplessness, anger, and even homelessness—reach a crisis point. Some of the responders are Veterans themselves and understand what Veterans and their families and friends have been through.

Since its launch in 2007, the Veterans Crisis Line has answered more than 6.2 million calls and initiated the dispatch of emergency services to callers in crisis more than 233,000 times. The Veterans Crisis Line anonymous online chat service, added in 2009, has engaged in more than 739,000 chats. In November 2011, the Veterans Crisis Line introduced a text-messaging service to provide another way for Veterans to connect with confidential, round-the-clock support and since then has responded to more than 253,000 texts.

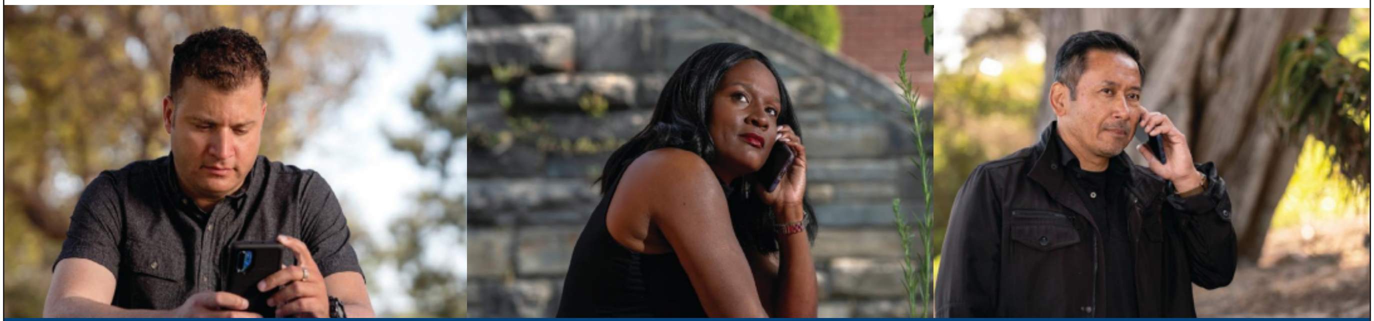
In 2011, the National Veterans Suicide Prevention Hotline was renamed the Veterans Crisis Line to encourage Veterans and their families and friends, who may be the first to realize a Veteran is in emotional distress, to reach out for support when issues reach a crisis point, even if it is not a suicidal crisis.

As of July 16, 2022, Veterans and their loved ones in the U.S. can Dial 988 then Press 1 to reach the Veterans Crisis Line.

VA is working to make sure that all Veterans and their loved ones are aware of the Veterans Crisis Line. To reach as many Veterans as possible, VA is coordinating with communities and partner groups nationwide, including community-based organizations, Veterans Service Organizations, and local health care providers, to let Veterans and their loved ones know that support is available whenever, if ever, they need it.

Whether you're a Veteran or a friend or family member concerned about one, confidential assistance is only a call, click, or text away.

For more information about the Veterans Crisis Line, visit **VeteransCrisisLine.net**.
For more information about VA's mental health resources, visit **www.mentalhealth.va.gov**.



Confidential crisis chat at **VeteransCrisisLine.net/Chat** or text **838255**

U.S. Department
of Veterans Affairs

07/2022

OUR JOURNEY IN CAMO SHELLY HUHTANEN

Not Broken

Was I going to ignore my student's view and continue to think the same way? The answer was simple. Someone from my son's community had the ability to speak, and I needed to listen.

With my office reorganized at home, my bookbag dusted off and resupplied with dry erase markers and a gradebook, I began a new semester of teaching at the local university. This is the first time I have taught five courses and I'll admit, I'm a little nervous about the workload. I keep telling myself it's all about balance. I need to be there for Hayden when he needs to talk. He's back in school and seven hours away. I try my best to be present during his calls, because every minute counts with him. With him away from home, I don't have the opportunity to pop into his room and check on him, like I did this past summer. I need to be there for Broden and be available for parent meetings with his BCBA (Behavioral Therapist). We have monthly meetings to discuss his progress, and I also need to update the programs we are working on at home. Each morning, I'm helping Broden through a 40 to 50-step process on how to shower. It takes time, but it will be worth it in the end. Broden's journey to living a more independent life is crucial. There are only 24 hours in a day and I need to squeeze in some time to eat and sleep. In a nutshell, it has been a challenge, but a challenge worth taking.

INFINITY AND BEYOND: My student with autism reached her arm out and showed me the infinity symbol patch on her jacket, "This is the patch I was talking about. It shows that we are unique, but we are whole."

At the beginning of each class, I have the students introduce themselves. They usually state: where they're from, how many siblings they have, what degree program they are interested in pursuing, and which dorm they live in for the year. Occasionally, I'll have a student who chooses to share a little bit more than others. That is greatly appreciated, because it can start to build connections with other students in the class. I'll introduce myself and talk about my family, and my interests. Usually, when I discuss Broden having autism, and the fact that I write for a magazine, I'm either greeted with uncomfortable stares because they are not familiar with autism, or they will later come up to me after class and say they know someone with a sibling with autism. This semester was different.

This semester I had a student who introduced herself as someone who had autism. After I introduced myself, she raised her hand, "Your column is entitled, "Puzzles and Camo? That is offensive to the autism community. We are not broken. Therefore, we do not think a puzzle piece represents our community. We identify with another symbol." The class fell silent, and I squirmed a bit in my chair. I had never been challenged before in class about the topic, and certainly not by someone who had autism, "Interesting. I haven't heard that before and thank you for sharing how you feel. I would love the see the infinity symbol in which you identify." The student nodded. I could see some students in class look at each other. They weren't used to this type of interaction in class, and especially not in the first week of school. After class was dismissed, the student approached me again, "We do not like the puzzle piece. Just because we are unique or different, doesn't mean we are broken. It does not represent us." I listened and nodded to show that I was listening to her, and acknowledged what she was saying. I told her again that I would love to see the colorful infinity symbol that she described. My student told me she had a jacket that had the symbol patch on it, and she would wear it to class the next time we meet.

I sat in an empty classroom waiting for my next class that day. How did I feel about what had just happened? Part of me was frustrated. Since Broden was diagnosed, I knew of the puzzle piece. I talk about inclusion. I'm passionate about representing marginalized

PHOTO PROVIDED BY SHELLY HUHTANEN

groups, like those with disabilities. Did I have it wrong? My column is entitled, “Puzzles and Camo” for Pete’s sake! With a slightly bruised ego, I started to research the controversy around the puzzle piece. My student was correct. There was a controversy around the puzzle piece representing autism. I found myself reading articles concerning both sides of the argument, and then I started thinking about Broden. Do I see Broden as broken?

Two days later the student came to class. She slowly came up to me and asked, “Can I sit next to you in the circle?” I smiled and nodded. She reached her arm out and showed me the infinity symbol patch on her jacket, “This is the patch I was talking about. It shows that we are unique, but we are whole.” She allowed me to take a picture of it. I smiled and confirmed that it was a special patch. As more students slowly filed into class, the student started to ask me questions about Broden, “Does he know how to swim? I teach people with autism how to swim. It’s important they know how to do that.” I talked more about Broden and told her that it was very difficult to find people who understand autism and teach swimming. She would be a great asset in town, if she chose to teach swimming again.

> “How can we do better as a community to support people with autism? First, we need to listen. Second, we need to shift the way we think and realize that their opinions matter.”

After class, I couldn’t get the last two days of interaction with my student out of my head. I realized that everything had changed, and I had a choice. Was I going to listen to my student with autism and change the way I had thought for over 15 years, or was I going to ignore my student’s view and continue to think the same way? As a mom with a son with autism and as a teacher, the answer was simple. I was given a gift. Someone from my son’s community had the ability to speak, and I needed to listen. My student is not broken and Broden is not broken. How can we do better as a community to support people with autism? First, we need to listen. Second, we need to shift the way we think and realize that their opinions matter. If we do not do those two things, then how can we do better for this community, Broden’s community? •

OUR JOURNEY IN CAMO

Shelly Huhtanen is an Army wife stationed at Fort Jackson, SC. She enjoys sharing her experiences of her day-to-day life caring for her son with autism. Shelly authored *Giving a Voice to the Silent Many* that encompasses many stories of raising a child with autism in the military. She also teaches Public Communication at the University of South Carolina and has contributed to *EP Magazine* for over 10 years.

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EP provides informative articles, resources and inspirational stories for children and adults with disabilities and special healthcare needs. The information covers all ages from infancy to elderly. *EP Magazine* also includes a military section dedicated to the unique challenges of military families caring for loved ones with disabilities, including returning veterans.

EP Magazine has a varied and constantly growing readership of individuals, families, caregivers, education and medical professionals. Our partnership with various organizations and universities greatly increases our exposure nationwide.

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IT CAN BE HARD TO GET HIS ATTENTION.

While you're dropping off your child, discuss a plan to help him avoid alcohol and other drugs.

Talk with your children about what to do if they are faced with a decision about alcohol and other drugs, such as texting a code word to a family member. Practice the exit plan in a safe environment. For tips on how—and when—to begin the conversation, visit:

www.underagedrinking.samhsa.gov

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SMA-18-5086FLY