PLUS: **UNITED STATES MILITARY SECTION**

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EXCEPTIONAL PARENT
MAGAZINE

JUNE 2022
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THE GREAT OUTDOORS:

WARM WEATHER TIPS *and* PRECAUTIONS

PLUS:

5 IDEAS TO KEEP KIDS BUSY *this* SUMMER

ADAPTIVE SPORTS & SUMMER FUN:

MEET GIANNA

THE ONE-HANDED LADY GOLFER GIANNA ROJAS *and* ADAPTIVE GOLFERS

AND:

DISRUPTING ABLEISM THROUGH EDUCATION

EP MAGAZINE
1971 2022
51
YEARS
CELEBRATES

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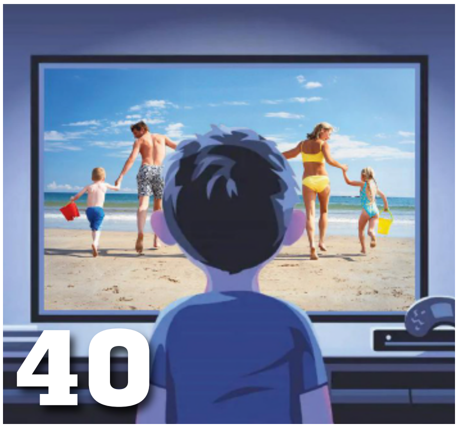

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ON OUR COVER

EP's interview with the One-Handed Lady Golfer, Gianna Rojas, anchors the Adaptive Sports portion of our Annual Summer Fun Issue. Her positive energy shines through in the conversation as she discusses her outlook on adaptive sports and recreation. Insightful articles on finding fun and safe summer activities and staying fit are featured, as well as a special section on avoiding summer learning loss. *Coverage begins on page 22.*

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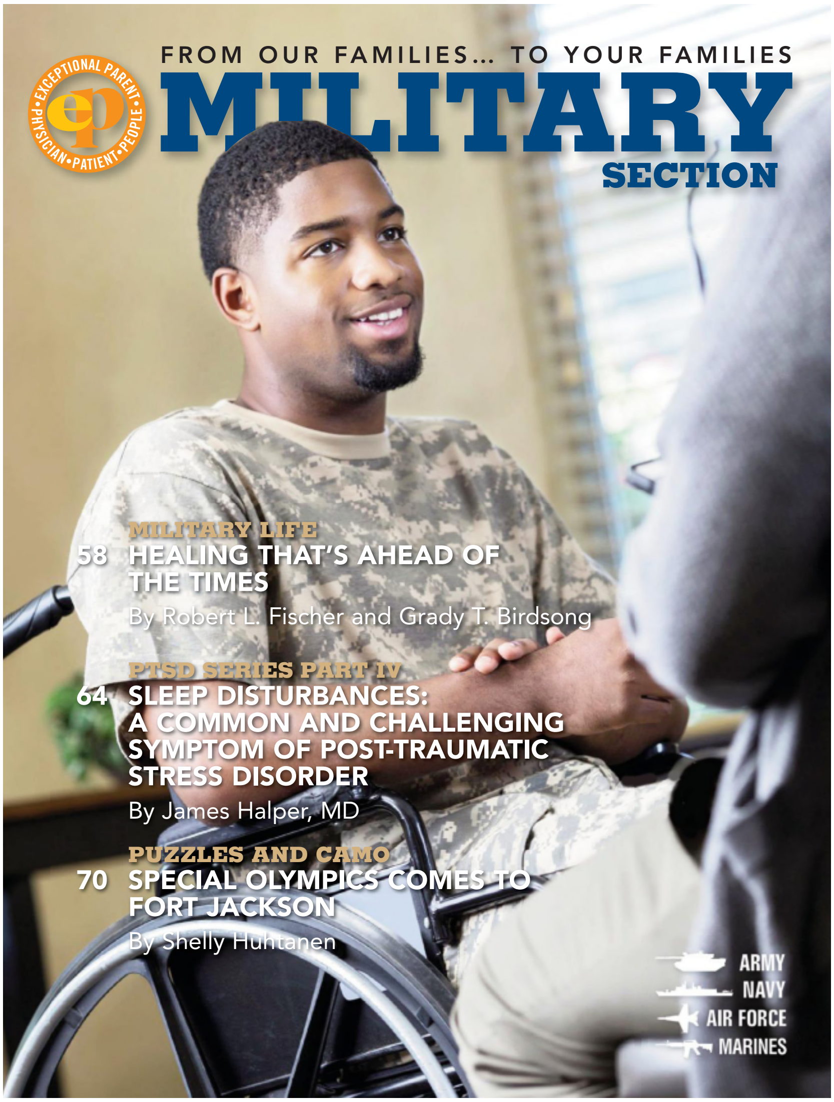
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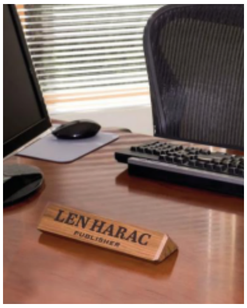
Sunscreen vs. Screens

EP Magazine offers a wide selection of ideas and guidance in our Summer Fun issue. Our articles on adaptive fitness training and empowering lives through sports are helpful and instructive.



Summer is here and another challenging school year is coming to a close. The summer months are often an even more daunting challenge to parents of school-age children, particularly of those with special needs. Determining ways to keep kids busy and safe during their long vacation can be a formidable task for every type of family.

The British Medical Journal recently reported that, in an environment exacerbated by the pandemic, an estimated 22% of US children and teens were obese last August, up from 19% a year earlier (www.bmj.com/content/374/bmj.n2332).

> "Gianna's story is a testament to the spirit of all disabled athletes who want to share their love of the game with others."

EP Magazine offers a wide selection of helpful ideas and guidance in our Annual Summer Fun issue. Our contributors examine the effect of too much summer screen time and how inactivity can be detrimental to childrens' physical – and mental – health. Our coverage also includes a wealth of information and resources for healthy, productive and safe summer activities – including some suggestions from the American Kennel Club!

We are also excited to present a robust section exploring the world of adaptive sports. These articles on adaptive fitness training and empowering lives through sports are helpful and instructive. In our exclusive cover story, our Editor In Chief, Faye Simon, interviews Gianna Rojas, the One-Handed Lady Golfer. Her story is a testament to the spirit of all disabled athletes who want to participate and share their love of the game with others, especially those who want to come back to the game, as well as those that have not yet had had the opportunity to compete. Gainna had dedicated her career to helping people realize their dreams on the field of play. "My purpose isn't for my handicap or my score, or for me to have bragging rights and trophies," she says. "My purpose is that 13-year-old girl who needs to see somebody like her out there doing something that she would like to do and think, 'Wow, if she can, maybe I can, too.'"

EP rounds out this month's coverage with a special section on avoiding summer learning loss. As always we are interested in your comments, input and feedback; get in touch at epmagazinevp@gmail.com.

EP Magazine has been busy diligently developing new ways to introduce advertisers and corporate clients to our motivated and growing audience. Demand is on the rise for space in our print and digital magazines, newsletters, and email marketing campaigns. To learn about these great new opportunities, contact EP's Editor In Chief, Faye Simon, at epmagazinevp@gmail.com •

Leonard J. Harac, PhD

Publisher

FROM THE PUBLISHER'S DESK

Leonard J. Harac, PhD, is the publisher of *EP Magazine* and President of Harac Consulting. He has a wide range of experience architecting business strategy over an array of industries. Dr. Harac is an experienced publisher, the author of numerous articles, the co-author of a published novel, a high school and university lecturer, and a student mentor. Dr. Harac brings 40+ years of business experience to the running of *EP Magazine.*

Information and Support for the Special Needs Community

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WHAT'S HAPPENING

STUDENT WITH NONSPEAKING AUTISM URGES FELLOW GRADUATES TO 'USE YOUR VOICE' IN POWERFUL SPEECH

A non-verbal autistic student delivered an inspiring speech at the Rollins College commencement ceremony recently using a text-to-speech computer program.

COMMUNICATION FOR ALL: “My life will be dedicated to relieving the 31 million non-speakers from suffering in silence and to giving them voices to choose their own way.”

Elizabeth Bonker is affected by non-speaking autism, so she communicates by typing. She used a computer program to deliver her address at Rollins' graduation ceremony in Florida on May 8, urging her fellow graduates to remember that “Life is for service.”

Bonker, who received a degree in social innovation, told her graduating class of 529 students “No, the irony of a nonspeaking autistic encouraging you to use your voice is not lost on me. Because if you can see the worth in me, then you can see the worth in everyone you meet.”

In her speech, Bonker thanked her four fellow valedictorians, who unanimously elected Bonker to deliver the commencement speech and those at Rollins, including the “faculty, administrators, and staff who fed our brains and nurtured our souls.”

She also acknowledged the approximately 31 million non-speaking autistic people worldwide. According to Autism Speaks, an estimated 40% of autistic people are nonspeaking,

“I have typed this speech with one finger with a communication partner holding a keyboard,” Bonker said in her speech. “I am one of the lucky few nonspeaking autistics who have been taught to type. That one critical intervention unlocked my mind from its silent cage, enabling me to communicate and to be educated like my hero Helen Keller.”

Bonker, who has been advocating for the rights of autistic individuals since the age of 13, is also the founder and executive director of Communication 4 ALL, a nonprofit that aims to ensure that communication is available to all people with autism who are nonspeaking, particularly in educational settings.

LIFE IS FOR SERVICE : A POWERFUL ADDRESS

BE THE LIGHT: Watch Elizabeth Bonker's 2022 Rollins College commencement address: www.youtube.com/watch?v=8g5aJExZQwg&t=5s

“My life mission is dedicated to gaining communication for all 31 million non-speakers with autism worldwide. And it will start with students in school,” Bonker said. “We can change the way the world sees nonspeaking autism. It is a neuromotor disorder, not a cognitive one.”

Bonker also urged her fellow graduates to remember that, like the late Rollins alum Fred Rogers of *Mister Rogers*' *Neighborhood* fame did, “Life is for service. “During my freshman year, I remember hearing a story about our favorite alumnus, Mister Rogers. When he died, a handwritten note was found in his wallet. It said, “Life is for service.” You have probably seen it on the plaque by Strong Hall. Life is for service. So simple, yet so profound.”

Bonker is also a poet and lyricist. She published the book *I Am In Here* in 2011 and in April, Bonker released the first two songs of her *I Am In Her*e album, “I Am in Here” and “Silent Cage” – for which Bonker wrote the lyrics and The Bleeding Hearts, a Boston-based band, performed and wrote the music.

After graduation, Bonker plans to continue her career in music, work at Communication 4 ALL and advocate for nonspeaking people with autism everywhere.

“I hope that we are creating a movement of autistics and allies to give everyone a voice,” Bonker noted.

PHOTO COURTESY WWW.ROLLINS.EDU

WHAT'S HAPPENING

THE PRIVATE SECTOR STEPS IN TO PROTECT ONLINE HEALTH PRIVACY, BUT CRITICS SAY IT CAN'T BE TRUSTED

BY DARIUS TAHIR

Most people have at least a vague sense that someone somewhere is doing mischief with the data footprints created by their online activities: Maybe their use of an app is allowing that company to build a profile of their habits, or maybe they keep getting followed by creepy ads.

It's more than a feeling. Many companies in the health tech sector — which provides services that range from mental health counseling to shipping attention-deficit/hyperactivity disorder pills through the mail – have shockingly leaky privacy practices.

MIXED SIGNALS: There is considerable doubt that the private sector proposal will create a viable regulatory system to guard patients' data. Many participants, such as Apple, Google, and 23andMe, dropped out during the gestation process.

A guide released this month by the Mozilla Foundation found that 26 of 32 mental health apps had lax safeguards. Analysts from the foundation documented numerous weaknesses in their privacy practices.

Jen Caltrider, the leader of Mozilla's project, said the privacy policies of apps she used to practice drumming were scarcely different from the policies of the mental health apps the foundation reviewed – despite the far greater sensitivity of what the latter records.

“I don't care if someone knows I practice drums twice a week, but I do care if someone knows I visit the therapist twice a week,” she said. “This personal data is just another pot of gold to them, to their investors.”

The stakes have become increasingly urgent in the public mind. Apps used by women, such as period trackers and other types of fertility-management technology, are now a focus of concern with the potential overturning of *Roe v. Wade.* Fueled by social media, users are exhorting one another to delete data stored by those apps – a right not always granted to users of health apps – for fear that the information could be used against them.

“I think these big data outfits are looking at a day of reckoning,” said U.S. Sen. Ron Wyden (D-Ore.). “They gotta decide – are they going to protect the privacy of women who do business with them? Or are they basically going to sell out to the highest bidder?”

Countering those fears is a movement to better control information use through legislation and regulation. While nurses, hospitals, and other health care providers abide by privacy protections put in place by the Health Insurance Portability and Accountability Act, or HIPAA, the burgeoning sector of health care apps has skimpier shields for users.

Although some privacy advocates hope the federal government might step in after years of work, time is running out for a congressional solution as the midterm elections in November approach.

Enter the private sector. This year, a group of nonprofits and corporations released a report calling for a self-regulatory project to guard patients' data when it's outside the health care system, an approach that critics compare with the proverbial fox guarding the henhouse.

The project's backers tell a different story. The initiative was developed over two years with two groups: the Center for Democracy and Technology and Executives for Health Innovation. Ultimately, such an effort would be administered by BBB National Programs, a nonprofit once associated with the Better Business Bureau.

Participating companies might hold a range of data, from genomic to other information, and work with apps, wearables, or other products. Those companies would agree to audits, spot checks, and other compliance activities in exchange for a sort of certification or seal of approval. That activity, the drafters maintained, would help patch up the privacy leaks in the current system.

“It's a real mixed bag – for ordinary folks, for health privacy,” acknowledged Andy Crawford, senior counsel for privacy and data at the Center for Democracy and Technology. “HIPAA has decent privacy protections,” he said. The rest of the ecosystem, however, has gaps.

Still, there is considerable doubt that the private sector proposal will create a viable regulatory system for health data. Many participants – including some of the initiative's most powerful companies and constituents, such as Apple, Google, and 23andMe – dropped out during the gestation process. (A 23andMe spokesperson cited “bandwidth issues” and noted the company's participa-

IMAGE: MARIA PONOMARIOVA / GETTY IMAGES

tion in the publication of genetic privacy principles. The other two companies didn't respond to requests for comment.)

Other participants felt the project's ambitions were slanted toward corporate interests. But that opinion wasn't necessarily universal – one participant, Laura Hoffman, formerly of the American Medical Association, said the for-profit companies were frustrated by "constraints it would put on profitable business practices that exploit both individuals and communities."

Broadly, self-regulatory plans work as a combination of carrot and stick. Membership in the self-regulatory framework "could be a marketing advantage, a competitive advantage," said Mary Engle, executive vice president for BBB National Programs. Consumers might prefer to use apps or products that promise to protect patient privacy.

> ***A group of nonprofits and corporations released a report calling for a self-regulatory project to guard patients' data when it's outside the health care system, an approach that critics compare with the proverbial fox guarding the henhouse.***

But if those corporations go astray – touting their privacy practices while not truly protecting users – they can get rapped by the Federal Trade Commission. The agency can go after companies that don't live up to their promises under its authority to police unfair or deceptive trade practices.

But there are a few key problems, said Lucia Savage, a privacy expert with Omada Health, a startup offering digital care for prediabetes and other chronic conditions. Savage previously was chief privacy officer for the U.S. Department of Health and Human Services' Office of the National Coordinator for Health Information Technology. "It is not required that one self-regulate," she said. Companies might opt not to join. And consumers might not know to look for a certification of good practices.

"Companies aren't going to self-regulate. They're just not. It's up to policymakers," said Mozilla's Caltrider. She cited her own experience – emailing the privacy contacts listed by companies in their policies, only to be met by silence, even after three or four emails. One company later claimed the person responsible for monitoring the email address had left and had yet to be replaced. "I think that's telling," she said.

Then there's enforcement: The FTC covers businesses, not nonprofits, Savage said. And nonprofits can behave just as poorly as any rapacious robber baron. This year, a suicide hotline was embroiled in scandal after Politico reported that it had shared with an artificial intelligence company online text conversations between users considering self-harm and an AI-driven chat service. FTC action can be ponderous, and Savage wonders whether consumers are truly better off afterward.

Difficulties can be seen within the proposed self-regulatory framework itself. Some key terms – like "health information" – aren't fully defined.

It's easy to say some data – like genomic data – is health data. It's thornier for other types of information. Researchers are repurposing seemingly ordinary data – like the tone of one's voice – as an indicator of one's health. So setting the right definition is likely to be a tricky task for any regulator.

For now, discussions – whether in the private sector or in government – are just that. Some companies are signaling their optimism that Congress might enact comprehensive privacy legislation. "Americans want a national privacy law," Kent Walker, chief legal officer for Google, said at a recent event held by the R Street Institute, a pro-free-market think tank. "We've got Congress very close to passing something."

That could be just the tonic for critics of a self-regulatory approach – depending on the details. But several specifics, such as who should enforce the potential law's provisions, remain unresolved.

The self-regulatory initiative is seeking startup funding, potentially from philanthropies, beyond whatever dues or fees would sustain it. Still, Engle of BBB National Programs said action is urgent: "No one knows when legislation will pass. We can't wait for that. There's so much of this data that's being collected and not being protected."

KHN reporter Victoria Knight contributed to this article.

ABOUT THE AUTHOR:

Darius Tahir, Correspondent, is based in Washington, D.C., and reports on health technology with an eye toward how it helps (or doesn't) underserved populations; how it can be used (or not) to help government's public health efforts; and whether or not it's as innovative as it's cracked up to be. He joins KHN after stints with Politico, Modern Healthcare, and The Gray Sheet. He's a graduate of Stanford University and grew up in Rochester, New York.


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WHAT'S HAPPENING

PULITZER PRIZE-WINNING PLAY TO SHINE LIGHT ON DISABILITY EXPERIENCE, CAREGIVING ON BROADWAY

Martyna Majok's acclaimed play that focuses on the experience of two different people with disabilities and their caregivers is heading to Broadway. The show ***Cost of Living*** will make its debut at the Samuel J. Friedman Theater this fall, the Manhattan Theater Club said.

COST EFFECTIVE: Katy Sullivan and Gregg Mozgala will reprise their starring roles in *Cost of Living* when it debuts on Broadway this fall.

Cost of Living, Martyna Majok's play that won the 2018 Pulitzer Prize for Drama, will be getting its Broadway premiere this fall, The announcement follows an acclaimed Off Broadway run of the play by MTC. The director Joe Bonney and stars Katy Sullivan and Gregg Mozgala will resume their roles for the Broadway staging at the Samuel J. Friedman Theatre.

This insightful, intriguing work is about the forces that bring people together, the complexity of caring and being cared for, and the ways we all need each other in this world.

> ***The Pulitzer committee described Cost of Living as an "honest, original work that invites audiences to examine diverse perceptions of privilege and human connection through two pairs of mismatched individuals: a former trucker and his recently paralyzed ex-wife, and an arrogant young man with cerebral palsy and his new caregiver."***

Cost of Living is an in-depth exploration of disability, caregiving, and privilege. Its synopsis reads: "What is the road that brought us here? Unemployed truck driver Eddie sits at a bar alone, recalling his final moments with wife, Ani, when a car accident turned the focus of their relationship from divorcing to caregiving. Overworked, under-qualified, and nearly homeless, Jess takes on another job to make ends meet – this time, as a personal caregiver for a wealthy and beautiful graduate student named John, who has cerebral palsy. The histories, influences, and challenges of four lives converge in the meeting of two strangers in a small, empty apartment in Bayonne, NJ."

Cost of Living premiered at the Williamstown Theatre Festival in 2016 and appeared Off Broadway the following year. The Pulitzer committee described Cost of Living as an "honest, original work that invites audiences to examine diverse perceptions of privilege and human connection through two pairs of mismatched individuals: a former trucker and his recently paralyzed ex-wife, and an arrogant young man with cerebral palsy and his new caregiver."

"I was once employed as a personal caregiver for two men with disabilities," said playwright Majok, "and I suppose when I started writing, I had been wondering about care. About the nature of helping others and being helped. And I was thinking about need and survival – and not just in an abstract sense but in the real and the tangible. I tried to build a home for four people in Cost of Living where they could feel held by each other - and where I could be held. And hopefully, someone in an audience."

Majok, who has won several prestigious awards for her work, is known for giving the voiceless a voice in her plays, which include stories of people who are immigrants, women and disabled. "I grew up in a multicultural neighborhood where almost everyone was from somewhere else," she says. "And we rarely see conversations between immigrants from different places onstage."

"Cost of Living provides a piercing look at the obstacles faced by disabled people and, more importantly, the human condition in general" said Frank Scheck for the *Hollywood Reporter*. "The characters, dialogue and situations resonate with emotional truth about loneliness, financial desperation and the vulnerability of disabled people forced to rely on others to assist them with basic human needs."

For more information on the play and the Samuel J. Friedman Theatre, visit **www.manhattantheatreclub.com/shows/2022-23-season/cost-of-living**

PHOTO COURTESY DANIEL RADER

WHAT'S HAPPENING

ALL NYC PUBLIC SCHOOL STUDENTS TO BE SCREENED FOR DYSLEXIA AS PART OF PILOT PROGRAM

New York City announced the largest, most comprehensive approach to supporting public school students with dyslexia in the United States.

WORDS TO LIVE BY: The intervention program will extend its pilot launch in the fall at 80 elementary and 80 middle schools. By the fall of 2023, the city said, its goal is to have at least one school in every borough offering a specialized program for dyslexic students.

For the first time, all New York City public school students will be assessed for being at risk of dyslexia, be supported in their neighborhood school, and receive specialized instruction through the development of special programs and academies. announced the initiative at a school in Harlem where the pilot program will debut.

“As a student, I struggled with identifying my dyslexia until long after leaving the public school system. Today, we are announcing the most comprehensive approach to supporting dyslexic students in New York City to prevent students from experiencing that disadvantage,” said Mayor Adams. “By changing the way we approach dyslexia, we can unlock the untapped potential in students who may feel insecure about their dyslexia or any other language-based learning disabilities they may have.”

> *Dyslexia affects the ability to read, write and process letters, words and numbers in a way and speed that others take for granted. Children who are diagnosed with dyslexia are usually given the broader tag of “learning disabled” on their Individualized Educational Plans (IEPs).*

“Early screening ensures that every child who needs support will get the help and resources they need,” Chancellor Banks said. “These screeners are emblematic of this administration’s commitment to uplifting all of our students and making sure they are well equipped to succeed.”

“Every student deserves the resources and support needed to thrive in our schools,” added Sheena Wright, Deputy Mayor for Strategic Initiatives. “Today’s announcement on Dyslexia Awareness Day brings us one step closer to living up to that promise. From universal screenings to first-of-its-kind pilots, New York City is leading the way in building a more equitable school system and committing to a comprehensive investment in dyslexic students.”

Beginning in fall 2022, the DOE will pilot two first-of-their-kind programs within New York City public schools, where 80 elementary schools and 80 middle schools across the city will receive targeted support and training to screen and identify students at risk for dyslexia and provide targeted interventions. Every student will participate in short, adaptive literacy screeners as part of the pilot at these schools.

All schools will be supported by district-based Academic Intervention Support coordinators on how to adjust core instruction and provide intervention when screeners, and other evidence of student work, indicate that students are not making adequate progress.

By offering accessible screening across the city, Mayor Adams and Chancellor Banks are breaking down a major barrier that has faced working families for many years. For the first time, every child from every zip code will have this important opportunity afforded to them, free of charge. Identifying student needs at an early age while breaking down cost barriers is a win for students, working families, and school communities across the city.

In addition, Literacy Academy Collective in P.S. 161 in the Bronx and Lab School for Family Literacy in P.S. 125 in Manhattan will both offer specialized programs for students with dyslexia and other language-based learning disabilities. The DOE will immediately move to build programs at additional schools with the goal of having at least one school offering specialized instruction in each borough by fall 2023.

WHAT'S HAPPENING

THE NEURODIVERSITY CAREER CONNECTOR: A JOB SEARCH PORTAL FOR NEURODIVERGENT CANDIDATES

To address the lack of neurodiverse talent hiring, member companies of the Neurodiversity @ Work Employer Roundtable are launching the Neurodiversity Career Connector (NDCC), a career portal dedicated to neurodivergent jobseekers.

This new job marketplace connects neurodivergent people with companies already committed to neurodiversity hiring programs. Currently, the Neurodiversity Career Connector features job listings by U.S. employers seeking applicants who are neurodivergent. This commonly includes but is not limited to autism, ADHD, dyspraxia, dyslexia, dyscalculia, and/or Tourette Syndrome.

"It's a phenomenal resource," says Jason Ross, who recently landed a cybersecurity job through NDCC. "It's made for us, by us. That level of understanding, baked in from the jump, is a meaningful distinction for this platform versus going on any general job platform and throwing your resume into the world."

The Neurodiversity @ Work Employer Roundtable includes a group of nearly 50 companies with neurodiversity hiring programs and support systems in place for new employees. The goal of the group is to decrease job barriers and increase neurodiversity hiring in the workplace.

According to the Neurodiversity @ Work Employer Roundtable there are ways to increase support for neurodivergent candidates such as:

- *Assign job coaches/mentors.*
- *Allot time weekly for employees to connect with other employees to share feedback on their lived experience. This is especially important for those who are in a remote work environment.*
- *Take advantage of the trainings offered through the Neurodiversity @ Work Employer Roundtable for managers of employees hired through the Neurodiversity Career Connector.*

The Employer Roundtable is powered by Disability:IN to help close the disability employment gap. The Neurodiversity @ Work Employer Roundtable started in 2017 with six founding members: DXC Technology, EY, Ford, JP Morgan Chase, Microsoft, and SAP. Since 2017, over 40 additional employers have joined the Roundtable – all with a commitment to and experience in hiring and supporting neurodivergent talent. You can find the complete list of employers at https://ndcc.simplifyhire.com

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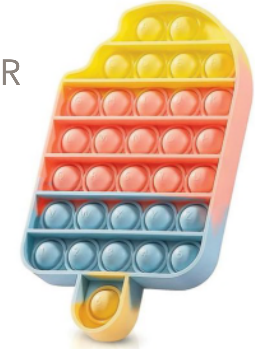
Four sturdy chalk sticks and four durable chalk holders come in this multicolor first chalk set. Adjustable plastic holders have a ridged ball end that is easy for beginners to grip, as well as a textured band around the sides that encourages development of the tripod grasp in preparation for writing. The easy-to-adjust holders keep chalk dust off hands. Refillable and reusable. Just right for growing hands! When chalk wears down, it's easy to adjust the holder, making it possible to get every last artwork out of the green, red, blue, and yellow chalk sticks. Promotes pre-writing skills, hand-eye coordination and creative expression. Ages 3+.

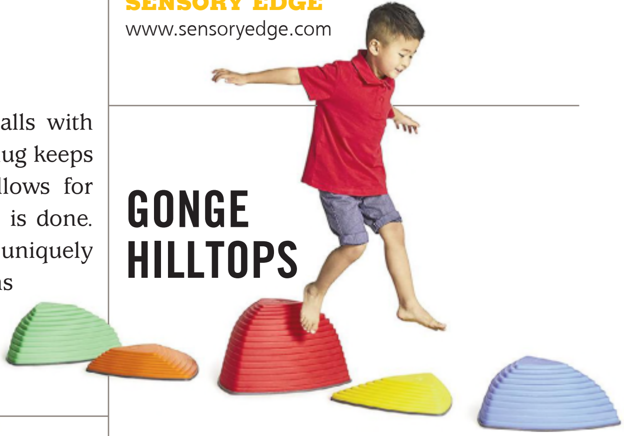
KAPLAN
www.kaplanco.com



POPSICLE BUBBLE POP FIDGET TOY

The Popsicle Bubble Pop Fidget Toy is a sure-fire hit with kids. Fun pastel colors and the shape is perfect for summer parties. Press the bubbles down, then flip it over and start again! Fine motor skills can improve as kids push and pop the bubbles to increase finger strength and dexterity. 100% silicone, reusable, washable, non-toxic and eco-friendly. Helps improve pre-writing and everyday life skills. Auditory Discrimination and Stimulation engage as kids pop and push it to make fun sounds. Use to teach colors, counting, and learning letters. Ages 3+.

SENSORY EDGE
www.sensoryedge.com



GONGE HILLTOPS

Five Gonge Hilltops in different heights will inspire children with autism to jump from top to top. Gonge Hilltops develop children's ability to estimate distances and make them familiar with heights. Each top is provided with rubber "feet," which prevent them from slipping and protect the floor. Hilltops are made so that they cannot over turn. Set of 5 tops in three heights: Approximately:1' 2" wide by 3" high, 1' 4" wide by 7" high, and 1' 5" wide by 10" high. Ages 3+.

AUTISM PRODUCTS
www.autism-products.com

REVERSING SUMMER LEARNING LOSS AT HOME

READING STRATEGIES FOR STUDENTS WITH DISABILITIES AND THOSE LEARNING ENGLISH AS A SECOND LANGUAGE

BY CLAUDIA RINALDI, PH.D

EP LOOKS AT • SUMMER LEARNING LOSS •

Summer fun is on its way! As school ends, summer can also be a stressful time for parents and their children with and without disabilities. Students with disabilities, in the schools, tend to have structured schedules, predictable routines with various teachers, and repetition of activities and assignments, all which make the day easier to follow.

When summer comes, some families and their children with disabilities may struggle to find a routine to ensure that they don't lose the academic skills they learned over the year. For children who are also learning English, parents may worry that they may lose some of their skills in the English language. This article provides some ideas on how you can make the best of the summer with your child. As you continue to read this article, remember that as parents our role is to support our children in their development and to ensure that they have a good balance of fun and learning throughout the day.

WHAT IS SUMMER LEARNING LOSS?

Many school leaders and teachers worry about the summer academic or learning loss for students with disabilities. This means that when summer comes, the students may not practice literacy and math skills, and they may lose skills they learned the previous year. For students also learning English, this is also a time when they may practice English less. One way schools help is by offering summer school, but even then, it is usually just a few weeks. Another way is to educate parents on how they can help their children practice reading while building vocabulary at home.

Teaching reading is probably one of the hardest challenges for students with disabilities and those learning English. Many students can be one, two or even more years behind their classmates, so it is important to think about how you can help your child continue doing activities that foster reading and math while having fun during the summer.

Students with disabilities benefit from routines, schedules, and predictability. When summer comes, it is important for parents to think about how to keep some aspect of the time in routines. For example, does your child do better when he or she wakes up consistently around the same time? Does your child have favorites books that he or she can read alone and some more challenging books that you can read together? Does your child enjoy talking about words he or she sees and hears in the home and community? Can your child help you with cooking or other activities that use reading and math as a way to practice?

For students who are learning English, it is also important to maintain the native language. Their native language is rich in vocabulary that parents and extended family bring to conversation. It is critical to continue to engage your child in learning new vocabulary in their native language, which the family speaks. What we know from research is that all the skills in the native language transfer to English. This transfer is key to learning to read, so if you can teach your child to read in your native language, it will help your child learn English faster. One way you can do this is by having children's books in your native language and practice the same activities presented below in your native tongue. Remember that all these can help you get started in a very engaging and fun way, while helping maintain academic activities at home. Another fun way to practice reading in English and the native language is to have some easy books in English for your child to read and translate to you in your native language.

READ ALL ABOUT IT : ESTABLISHING A GOOD BALANCE OF FUN AND LEARNING THROUGHOUT THE DAY

DEVELOP A ROUTINE

(Daily)

If your child does better with predictable schedules and routines, I recommend that you sit with them and talk about what that can look like at home. Once you identify two or three activities each day, take a picture of the child doing them and post them in a place where they can use it daily. The goal with creating a predictable schedule is that you and your child can know what you will do together and when. Ask your child to place the picture of each activity they choose to do, in the morning, midday, and afternoon. Choosing together can also help you plan the day and set expectations.

PRACTICE READING AT AN INDEPENDENT LEVEL

(10-12 minutes)

Independent reading level refers to books that your child can read by themselves or know about 95% of the words. This practice is important in building fluency and comprehension. Set these kinds of books in a basket, so that your child can pick one each day. You can also find some of them online and even in a variety of languages. Remember these books are read without any help from adults. For this activity, the goal is for your child to read the book to you, a friend, a stuffed animal, a favorite doll, or a pet. They will be asked to read it twice and try to come up with questions. Once they are done, they can put the book back in the basket and prepare for the second activity reading with help from a parent/adult.

READING AT INSTRUCTIONAL LEVEL

(10-12 Minutes)

Instructional reading level refers to books where the child needs assistance with many words. They may recognize many common words, which we call "sight words," but they are encountering new vocabulary, sentence structures, and decoding patterns. The Repeated Reading Strategy involves having the parent/adult and child read the book or text three times.

1. The first time the adult reads it using their finger as they are reading each word.
2. The second time you ask the child to try and read the words he knows together while you read.
3. The third time you ask your child to try and read it alone and you help while showing each word as they read.

VOCABULARY DETECTIVE

(10 minutes)

Vocabulary refers to the learning of new words for a child. Vocabulary is a large predictor of comprehension. Helping your child to add new words to their vocabulary will help them continue to connect concepts and practice new sentences that increase communication and interaction about the word. Each day tell your child to look around the home and community to find one or two words or things they don't know nor are familiar with them. For example, it can be finding new words at the grocery store, or on a TV show, in a book, or even a word someone said. Focus on talking about what the word means, write the word down on a 3 x 5 index card, talk about how they can use the word, and then model using it, and challenge your child to come up with ways of using it, throughout the day. Once you have five words, you can have the child review all the words during the week, to practice reading and vocabulary.

HITTING THE BOOKS : READING RESOURCES

READING ROCKETS
Family Guide to Reading At Home
www.readingrockets.org/guides

COLORINCOLORADO
Reading Tips Sheets for Parents
www.colorincolorado.org/reading-tip-sheets-parents

Books by Topic List that you can find at the library or bookstore. The list includes books from diverse backgrounds
www.colorincolorado.org/books-authors/books-kids

EPIC!
Free online books for children
(parent can read 1 free book per day)
www.getepic.com

FREE KIDS BOOKS
Free online books for children in multiple languages; available languages include Spanish, German, Farsi, French, Hindi.
http://freekidsbooks.org

IN SUMMARY

Engaging your child to interact with you reading books and interacting with the environment, creates a print rich experience during the summer. Sharing the experience of reading together increases the love for: reading, spending time together talking, and learning about new stories. Rereading stories they are familiar with lets them feel like successful readers, while they practice commonly used words or sight words. Remember that all these activities should not take more than ten to fifteen minutes, and if the child is frustrated stop and revisit the selection of books or words to make sure they are at the level you seek for each activity. For students who are learning English as a second language, all the activities can be done in the native language. The process of learning to read occurs only once and then transfers much faster to learning in other languages. Although children's books that children can grab and take with them is the preferred way, there are many websites that have books available in multiple languages that you can use in the repeated reading strategy. Finally, remember that learning should be fun, so keep it short and enjoy a summer of reading and learning together. •

ABOUT THE AUTHOR:

Claudia Rinaldi, Ph.D., is Chair and Professor of Education at Lasell University in Newton, MA. Her areas of research are the implementation of the Multi-Tier System of Supports (MTSS) framework with English learners, teacher education in bilingual special education, and diversifying the teacher pipeline. Claudia has authored many publications and a book called Practical Ways to Engage All Struggling Readers. She leads a graduate program in Teaching Bilingual Students with Disabilities and leads a college mentoring program called Pathways to Teacher Diversity. Claudia believes that teachers must respond to the belief that all students can learn and succeed beyond barriers like culture, language, disability and poverty.

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SUMMER SCREENS: HOW MUCH SCREEN TIME IS TOO MUCH?

BY LAURA LINN KNIGHT

- *In Europe,* The Independent *recently reported that obesity is at 'epidemic proportions," as one in three children are now obese or overweight*[1]
- *In the United States, obesity in US children increased at an unprecedented rate during the pandemic*[2]
- *Teen sadness rates and depression are at all time high*[3]
- *Screen time decreases the level of physical activity in autistic children*[4]
- *Screen time usage in children is considered to be one of the top 3 harmful effects from the aftermath of the COVID-19 Pandemic*[5]
- *Screens can negatively affect cognitive development, language and attention development, psychosocial behavior and brain structure*[6]
- *Screen use releases dopamine in the brain, which can negatively affect impulse control*[7]

EP LOOKS AT SUMMER LEARNING LOSS

Examining these negative impacts of screens, it is time to make a plea for parents to reconsider screen time usage this summer. This is not because I am anti-screens. Nor do I believe that children should never be allowed to watch movies or play video games. As a parenting educator, former elementary school teacher, and mama of two, I see the benefits of screens and I don't believe children need to be raised without screens entirely. However, screens too often take the role of babysitter, friend, and physical social interaction.

As parents try to balance screens with daily life for their child, this can be a tricky road to navigate for parents of children with disabilities. Having taught children with disabilities for many years, I understand the helpfulness of screens in a child's life.

I fondly remember an autistic boy in my classroom that I had the pleasure of teaching for two years. Working with his one-on-one aide, we found that this student benefited greatly when I used a projector in the classroom to display classwork. The interaction with the screen kept this boy more engaged with the work we were doing. This is an example of the positive educational role screens can play in the life of a child.

Additionally, research shows that screens can bring calming effects for some children with disabilities and act as a buffer when environmental noises and social interactions are too intense.

And yet, screens can go beyond their intended benefits when they are overly used to suppress a child's boredom, as the chief entertainer, and as a place for children and teens to escape to when they are feeling sad, rather than getting the parental connection they so desperately need.

An overuse of screens can get in the way of healthy sleep patterns and hinder a child who is learning how to better understand facial expressions, social cues and build connections with others.

Additionally, the bright lights of screens and addictiveness of video games release dopamine in a child's brain. Dopamine is a neurotransmitter and hormone. One of its important roles in the brain is attached to pleasure and reward. In short, it makes us feel happy. There are good ways to get dopamine and not so good ways. Some good ways to get more dopamine into your body is through exercise, healthy foods, and in-person social interactions. Harmful ways to get dopamine is through drugs, alcohol abuse, and screens.

Kathryn Lorenz, MD says that "Prolonged use of watching TV, video games, scrolling through social media – all of that use acts like a digital drug for our brain."

Lorenz goes on to add that "studies have shown screen time affects the frontal cortex of the brain, similar to the effect of cocaine."

As summer approaches, many parents are overwhelmed with the high costs of summer camps, the fears of COVID in group settings, and the difficult balance between caring for children over the summer and work.

When parents feel stressed and overwhelmed, screens provide an immediate solution that temporarily seems to "fix" the problem. How can we go beyond the temporary "fix" though and stop the overuse of screens?

Let's find a balance that is supportive for both parents and children!

Here's how…

The first step in decreasing screen time in your home is to reflect on your values as a family. Understanding what your values are as a family will help guide your decisions around when and where to use screens.

This reflection can also include goals that you are working on with your child. For example, if your child is working on learning social cues, you may decide that dinner should be screen-free so that your child can tune into the conversation.

In our home, a big family goal that we have is spending quality time together.

When we became aware that quality time together was high on our family value chart, then that value began to inform our daily actions.

SUNSCREEN TIME: Parents are encouraged to make space in their schedule for play and connection, instead of having kids sit in front of screens for prolonged periods of time.

Will we have our kids sit in front of screens for prolonged periods of time or make space in our schedule for play and connection?

The second choice makes more sense when we know what we are trying to accomplish as a family, right?

You can download a free Family Value Chart on my website, **www.LauraLinnKnight.com/blog**

Next, I encourage families to create a plan. This is a crucial step because nothing can change if there isn't a plan for creating that change! It is like going to the gym. If you want to begin working out more, you will first make sure you have the proper clothing, sign up at your local gym, and then schedule your workouts on your calendar. Without a plan, action is hard to take.

Find a time when you can sit down alone if you are a single parent, or with your partner, and create a list of activities that your child can do rather than using screens. You can download a free printable list on my website as well.

Decide about how much screen time you will allow each day and in what context.

Once you decide, use a timer to track your child's screen usage so that you can adhere to the plan the best you can (you don't need to be ridgid, but rather aware of the overall goal).

During the times that a child feels bored and has used up all of their screen time, you can use your list of alternative activities. This is you and your child's guide, and it will help your family keep moving towards your goals.

Lastly, make sure that you are carving out time for drawing, picnics at the park, making healthy treats in the kitchen, and anything else that will continue your bond as a family (and increase healthy dopamine levels).

Reducing screen time can feel challenging at first, but remember why you are making this choice. Think of the long-term benefits you are giving your child by saying yes to an engaged life where screens are used mindfully. •

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5. https://gritdaily.com/too-much-screen-time-can-harm-your-kids/
6. https://www.lovethatmax.com/2018/01/screen-time-kids-teens-with-disabilities.html
7. https://www.premierhealth.com/your-health/articles/health-topics/screen-addiction-affects-physical-and-mental-health

ABOUT THE AUTHOR:

Laura Linn Knight is a former elementary school teacher, a certified mindfulness and meditation teacher, author, and parenting educator who helps parents and families improve their home environment by offering practical tools for the entire family to implement and practice. Knight's work is devoted to empowering parents, caregivers, and children with the tools they need to live a joyful, balanced life. As a mother of two, Knight will help you build confidence in your parenting and foster a calmer environment in your home. To learn more about Laura Linn Knight, visit her website at **LauraLinnKnight.com** today.

It's just like RIDING A BIKE…

By Dan Judson, Physiotherapist

"Hey, wanna go for a bike ride?" This is a question heard in households and neighborhoods routinely. Learning to ride a tricycle is a rite of passage that is celebrated in our culture and across the world. It is a moment that causes cameras to be pulled out and photos to be shared with family and friends. It represents a milestone of independence and a skill that will remain useful and fun for many years to come. "It's just like riding a bike, once you learn you never forget".

What is adaptive biking?

Learning to ride a bike may never have been considered as an option for many children with physical needs or challenges. Adaptive tricycles make riding a possible reality. An adaptive tricycle is one that can be configured to accommodate physical challenges allowing the rider to be supported and to pedal if possible. If the rider cannot pedal independently there is an option of having the rider's legs moved passively, or the pedals can be disengaged to allow the rider to be pushed. Any supports that an individual may require in their wheelchair can be incorporated into an adaptive tricycle. In a nutshell, if you want to go from point A to point B on a tricycle it is possible. Dedicated engineers and companies that listen to feedback from families and therapists have made it possible for anyone who wants to ride to be able to do so.

Therapy made fun

Children with physical issues arising from genetic or neurological conditions like cerebral palsy most often have functional limitations and low levels of cardiorespiratory fitness that negatively impact independent mobility. These issues can make it difficult for caregivers and therapists to find ways to facilitate change that is meaningful and enjoyable. Clinical research supports the fact that adaptive tricycles offer a means of 'working' on these areas and affecting true change. It is also something that a family can do together, that a child can do with friends, and it is fun!

What are the benefits of adaptive biking?

A variety of studies have measured the effects of riding an adaptive tricycle on children with physical disabilities. The following list outlines some of the potential benefits discovered. Individual physical improvements and results varied according to a variety of factors, and the social and emotional benefits from participating were consistently noted.

1. Improvement in cardiorespiratory fitness
2. True change in gross motor function
3. Development of balance
4. Improvements in cycling ability, speed, and distance – leading to further physical improvements
5. Tone moderation
6. Self-satisfaction and accomplishment

As a physiotherapist I am happy to have an effective therapy tool that brings a smile to a child's face. And as a parent it's truly a moment of pride to see the look on the faces of children riding for the first time, and an equal amount of joy from seeing the expression on the faces of neighbours or friends cheering them on. It is a moment of unity around a shared experience.

Freedom Concepts' fully customizable adaptive bikes can be tailored to the individual abilities of the rider - All ages, all riders, all abilities.

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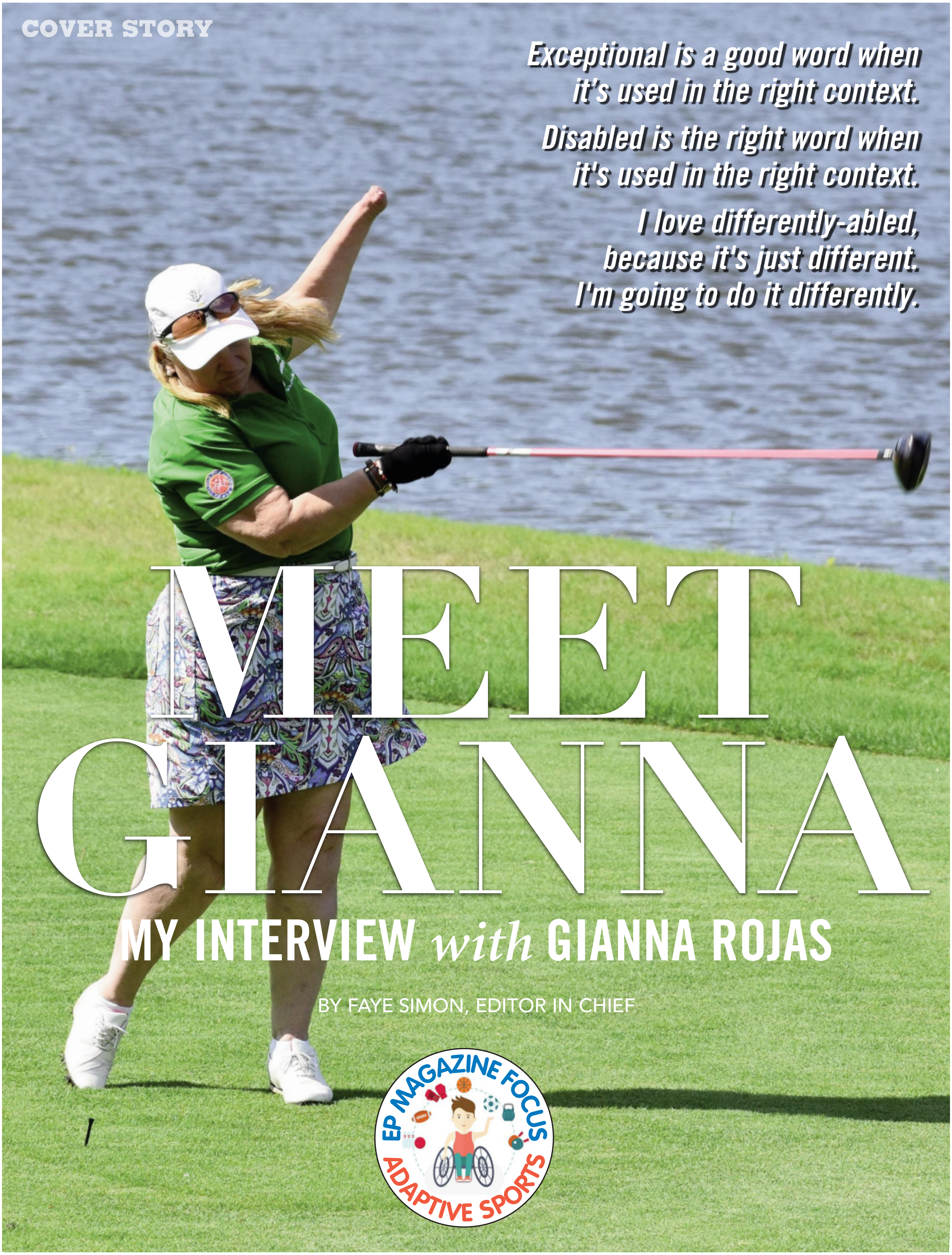
ANYONE CAN RIDE

COVER STORY



> *Exceptional is a good word when it's used in the right context.*
>
> *Disabled is the right word when it's used in the right context.*
>
> *I love differently-abled, because it's just different. I'm going to do it differently.*

MEET GIANNA

MY INTERVIEW *with* GIANNA ROJAS

BY FAYE SIMON, EDITOR IN CHIEF

EP MAGAZINE FOCUS
ADAPTIVE SPORTS

PHOTOS PROVIDED BY GIANNA ROJAS

I HAVE HAD THE PLEASURE OF MEETING AND TALKING TO GIANNA ROJAS MANY TIMES. GIANNA, THE SELF-PROCLAIMED “ONE-HANDED LADY GOLFER,” HAS INSPIRED AND MOTIVATED MANY PEOPLE, WITH AND WITHOUT DISABILITIES.

Faye Simon: Gianna, thank you for sharing your story.

Gianna Rojas: I want to share everything. I don’t want to keep it. I can’t take it with me. It’s not going to do anybody any justice.

FS: Please tell us about yourself.

GR: My mother took a pill called Thalidomide, which was given to pregnant women for morning sickness in the late fifties, early sixties. I was born a year before President Kennedy told all women to get rid of it. If you took the pill, it did its job wonderfully, but it didn’t do so well with the fetuses. A lot of the fetuses did not even have a chance. Although there were many babies that were lucky enough to be born, many had internal challenges that they have to deal with, and some were limb deficient. I have both.

People ask me if my siblings have anything. No, they don’t. I am the oldest in the family. It was the pill, not something that gets passed down or is genetic. When I found out I was pregnant, I got chromosomal and genetic testing done, to see if I could pass it on, just to know what to expect. Everything was fine. It’s not something that can be passed down. There are other reasons for all kinds of things, sure. But that particular pill did wreak havoc.

BEST MEDICINE: Gianna with an Abilities Expo attendee; “Golf has proven to be an incredibly effective medium, and when some level of mastery is achieved, its powerful medicine.”

My dad was in the Navy. Growing up like many other military families, mine moved and changed schools every couple of years – which meant I was regularly the new kid. Like every new kid, I had to build rapport again. The only trouble with being the new kid for me was that I was visibly different. I was born with no fingers on my left hand.

As a child, I had to learn early on how to break the ice with people to make them comfortable with me. As soon as I did, we would move again, and I would have to start all over. I’ve faced more than my fair share of being picked on, left out and bullied. I was even locked in a locker in middle school for three hours until someone finally heard me. Even at the bus stop and at the playground, boys and girls would push me down, my glasses would fall off, and I couldn’t find them.

People still teach their children “Don’t look, don’t stare, don’t ask questions. It would be rude.” But that makes me invisible and the bias continues, because the questions aren’t answered.

When I was growing up, there was no term for it. Now we call it “bullying.” There was no “anti bullying” in school when I was a child. Some of the schools I went to were Catholic schools. So, you know, nice in the classroom, not so nice out of the classroom. I remember even up until the 12th grade, the girls were still pulling my hair and kicking my chair. The same girls would ask me to hang out with them when nobody else was around.

I was consistently thrown around in the cycle: building rapport, moving, getting bullied. We moved up and down the East Coast. We came to NJ when I was in the 9th grade. I stayed in NJ when I was old enough to “jump ship.” It is not easy when you’re a child and you’re that kid that’s not getting invited, and is getting picked on, or feels the vibrations of people around you that are uncomfortable. I had a rough childhood, I’ll put it that way.

FS: When you were beat up and bullied did anyone help?

GR: Only when it got too far out of hand. I didn’t complain a lot or it would get me beat up more.

FS: Did you have friends who stuck up for you when you were bullied?

GR: I had “friends” who would only be my friend when we were not around other people. I had no real girlfriends. I had a first boyfriend who only would be my boyfriend during spring break and not when we went back to school. But I did have a boyfriend in high school that did not mind what everyone else said.

FS: Do you have any advice for kids being bullied and/or parents whose kid is being bullied?

GR: That’s where using a tool, like an activity is helpful. My hope is that I get to talk to that 13-year-old girl, that was me, and find her some way to be able to get out and find something she’s confident in, whether it’s golf, or any other sport. I think sports are the perfect thing, to be able to say, “Not today, bully. I’m going to go play golf. You go pick on somebody else” and not have that be something that leaves a mark on you.

I think that it’s so much better for kids now than it was when I was growing up, because it’s not cool to pick on the kid that has challenges anymore. We’re not scapegoats anymore. What I believe is the biggest barrier, and sets up what I consider “conditional bias,” is that we were always taught and people still teach their children “Don’t look, don’t stare, don’t ask questions. It would be rude.” But that makes me invisible and the bias continues, because the questions aren’t answered. I believe the stigma is not out of ill intention. I just think disabilities are misunderstood.

FS: What is your experience with people, now that you are not a child?

GR: As I mentioned, "Don't look, don't stare, don't ask questions – that would be rude" is taught with the best of intentions. With someone like me with a visible difference, even as an adult, it makes me feel invisible.

An example, is the story of a boy in a clothing store, who popped out from behind a clothing rack and saw my hand. I remember him going to his mommy "Mommy she has a funny hand." Mom said "That is not nice" and walked away, not even acknowledging me. Like many people with disabilities, when you don't interact, don't engage or acknowledge them… it is like we are invisible. So, I was invisible and he didn't get his questions answered. He probably had no idea what this was all about *(Gianna pointed to her hand).*

UP TOP: Gianna meets an adaptive athlete; "When you're standing, hugging and crying, the impact is heartwarming. I am confident in saying that we change so many people's lives.

If I had had the opportunity with him, had his mother looked up and acknowledged me, I would have said, "He hasn't met my little buddy." I would say to the little boy, while showing my hand, "This is my buddy. Doesn't a buddy help you do everything? Well, he helps me get dressed. He helps me tie my shoes. He's real soft like a pillow. When I watch TV, sometimes I'll lay on him. His name is Charlie, but he's afraid you won't like him. He's really shy." I would cover my hand and tell him to say, "Come out, Charlie." I would have him say it a few times, until I could see he was comfortable. Then I would say, "Oh, there he is." I made it a he because I'm a she, and they are not afraid of me. They can be afraid of Charlie. That's fine. But that separates me from what they are afraid of – my hand. It doesn't define me. So, they're not afraid to come near me. They just don't understand.

I find the opportunity to engage, to start the conversation. Because, and I've been telling this to my own people that all have disabilities, it's our job to break the ice now. And it's okay to break the ice now. If it is an adult that I notice staring or uncomfortable, I might say "I see you are curious. Would you like me to tell you about it?" So, I have engaged. I've started the conversation. If I start the conversation, it opens up the discussion, and helps those wondering, "What do I do? Should I ask? Should I not ask"? People don't know how to talk to you. They don't know what you're thinking. They don't know what to do. They haven't experienced it. It doesn't even have to be spoken, they are just uncomfortable and they don't know how to deal with something different. "What do I call you? Do I call you disabled? Are you going to get offended?" Labels are a big barrier. That's why I like the Exceptional Parent title, it struck me. I think exceptional is a good word when it's used in the right context. Disabled is the right word when it's used in the right context. I love differently-abled, because it's just different. I'm going to do it differently. Every person, even if they have a disability, has some ability. It took me a whole lifetime to be able to say this.

I believe that the next generation is going to be even better than the last about accepting people with differences, because of all that we're doing, the exposure, the talking about it, making it okay.

I believe that the next generation, hopefully, is going to be even better than the last generation about accepting people with differences, because of all that we're doing, the exposure, the talking about it, making it okay.

FS: Do you find that most people with challenges want people to ask what happened?

GR: It depends on where they are in their journey. If early on, if it is an illness or an injury, they often do not want to go back and relive the trauma.

FS: How do you advise people whether to ask or not?

GR: Take a step back and use your better judgement. Don't do it in a way that is offensive or degrading. Each situation is different. Remember they are people and talk to them like any other person. You can leave it up to the person to share. If you are not going to connect with the person, do not just stare. Staring is rude. Either connect or move on, we do not want gawking. If you cannot just say hello like you would to someone without a disability, then just move on. There is no one right or wrong way. Everyone is different in their journeys. I would like society to know it is okay to politely sat "I noticed you only have one leg. Do you mind if I ask what happened?"

FS: How do you feel about people asking to help you, when they notice your hand?

GR: There's a raw nerve that has been poked my whole life. So, when something like that does happen, sometimes it's a little bit of a trigger. It's not a negative, I have to remind myself sometimes. People generally are compassionate and empathetic. We're taught that we should help when we can. But the misconception, and where sometimes people like myself may take it even more negatively than intended, is because we in our minds automatically think, "You think I can't do it? You want to take it away from me while I'm doing it and do it for me because you think I can't do it?" Then you're not giving me the opportunity. However, it is ok when somebody comes up and says, "Hey, can I give you a hand with that?" But I usually prefer to do it myself, because I have my own system. For me, it may be a little different than for others who became disabled, because I was born with it. It feels natural to do things myself. I don't know any different way. I have to remind myself that people want to help and it is a gift to them to let them help me. However, my husband will stand back and watch, because he knows, I don't need any help, nor want it. If I need it, I'll ask for it.

FS: What advice do you have for people wanting to help?

GR: When you really want to jump up and help somebody in a wheelchair open a door, take a breath. Just take a moment and see if they really need your help. We have worked very hard for our own independence. I do not like when someone says, "Here give me that, I'll do it." You can ask "May I help you?" It gives us the option of saying "No, thank you for your offer," just like anybody else would without a disability. But you have to ask politely and take no for an answer. Do not assume automatically that they need your help. I am teaching those with a challenge that they should try to take responsibility to ask for help, when needed.

EXCELLENT APPROACH: An adaptive golfer on the fairway; "Today, Adaptive Golfers hosts accessible golf clinics across the country, as well as training for golf instructors and course operators interested in better equipping their facilities to support golfers of all different abilities."

FS: Tell us about your adult life and how you got into golf.

GR: I was living on my own when I met my husband while I was bartending. He came in with his friends after work. I said something stupid about football. He is a Dolphins fan, I'm a Jets fan and they're usually archrivals. I said something backwards, and he thought it was cute. He invited me to a football game. From then on, we dated seriously and then got married. We have been married 36 years, have two children and three grandchildren. I can honestly say that I am absolutely adorably in love with him and nothing turns my head or my heart, no matter what I do, even though, I'm around men all the time.

As an adult, I began to get that feeling of being left out again. I was feeling like that 13-year-old girl again. My husband, his friends and their wives would meet most weekends to play golf. Also, all these years, the couples were playing golf with my husband, but he doesn't have his wife with him. They were nice enough to call me when they rounded the 15th hole to join them for lunch. Just like all golfers do, they would sit and talk about their morning round. I found myself not having much to add to the conversation. I was happy to be there, but I didn't have much to contribute. Sometimes, they would go back out, and I would go back home by myself. Finally, I had enough of that.

I asked my husband. "How can we figure this out?" I was born this way and I've always learned everything a different way. It was a lot of trial and error. I decided to start hanging out at the driving range, but we just couldn't figure anything out. We talked to different teaching professionals that were my husband's mentors golf coaches. But nobody had been trained to teach somebody with one hand. I was advised to come to the beginners' clinics, which I did. The first thing they teach you is "One hand goes here. The other hand goes here for gripping," and they've lost me. The teacher said "Let's come back after the clinic and we'll try to figure something out together, because it's not something that we're going to figure out with the group here." I agreed and also felt that it was not fair for the group to wait for me. So, we would go back after the clinic and talk. We tried a bunch of different things. I tried lefty, I tried righty, I tried a prosthetic. But because my arm developed differently, the lengths are different. We tried some prosthetic devices, and all kinds of crazy gadgets, but I was never able to keep two points of contact on the club. In golf, they always teach two points of contact on the club, which is why you'll see people with amputations wear prosthetic arms. But it wasn't working for me. So, since I couldn't use a prosthetic, we just started with the one hand. We tried lefty clubs, we tried righty clubs, and it took probably about three years of just chipping away at it, no pun intended.

When you really want to jump up and help somebody in a wheelchair open a door, just take a moment and see if they really need your help. We have worked very hard for our own independence.

FS: What advice do you have for parents that have children with disabilities?

GR: Parents often have limiting beliefs about their own children's abilities. Because of that, they often do not take a step back, because they want to make sure everything is easier for their children. In spite of their best intentions, the coddling robs the children of their independence.

As a child, I was held back and being limited. There was a lack of exposure, because my parents did not put me out there. I didn't get offered the opportunity to play sports. I didn't get pushed to go to dance class or gymnastics. I didn't get that because they thought I could not do it. Don't keep them in. Push them out. Step back. As a parent, you want to empower your children. Your job is to empower them, to bring out their individuality, and help them shape it, as different as it may be, for whatever the unique child is. And that's not just a disabled child, that's any child. It is important that parents do not limit and hold kids back. Don't balk at putting them in softball. If they don't like it, they don't like it. If they're not good at it, they're not good at it. But give them every opportunity. You should treat your child as any other child. Who would have thought I would be playing golf? Allow your child to explore. Don't just do everything for them.

Some parents, even though the child could communicate with me, communicated for them. An example, I was talking directly to the son and the mother answered for him. You can't do it all for them. You wouldn't think of people with mobility challenges going to CrossFit. The first thing they do at CrossFit, is the teacher will come and push the amputee out of his wheelchair. "The first thing you need to know is how to get yourself back up in that chair. If you can't, we're going to build your strength. That's going to be your first goal, getting yourself off the floor back into that chair." That's the first CrossFit exercise so they can be independent. So, the more we pick them up and put them in the wheelchair, the more they're not going to be able to do that themselves.

FS: How did you get the idea to create Adaptive Golfers?

GR: I've got to step back in my story. I was the state of Florida's poster child for the March of Dimes from 1972 to 1976. The national poster child came to Florida for a photo shoot with a known celebrity. They were still coming out of the polio stage and into more awareness about birth defects. The vaccine was out and it was helping get rid of the polio virus. A neighbor told my mom about the photo shoot, and my parents brought me down. During the photo shoot, a man walks in the room and my dad turned white. I had no idea who the man was. I knew my dad played golf, as he sometimes went on the weekends to play, but I didn't know what golf was. I was sitting on this man's lap in a photo shoot, with the national poster child. Turns out it was Arnold Palmer. Arnold Palmer's father had polio. Throughout his whole career, Arnold Palmer was a huge supporter of the March of Dimes.

TEE TIME: A golfer prepares for a round in his special cart; "There are experienced instructors, manufacturers, and organizations working to help adaptive golfers discover the wonders and therapeutic values of the game. "

Now going forward to me as an adult. A friend of my husband at the golf club where I had begun to play golf, introduced me to the chairperson for the March of Dimes walk, up in Sussex County. After I helped out as a volunteer, I said, "I wouldn't mind getting reconnected with the March of Dimes, if you need some help with calls or something." Then an internship became available and my friend talked me into accepting the internship. Then they offered me a position, as a Community Director, and I worked for the March of Dimes for six and a half years. I ran the walk at Liberty State Park and I built awareness for the March of Dimes.

So, after six and a half years of running the walk at Liberty State Park, a huge, high-profile walk, I got a phone call and was told that the March of Dimes was laying off 150 positions. They took the county walks and combined them into regional walks and got rid of all the county community directors. After this phone call, my friend and I were sitting in a diner, when she said to me, "You know, Jeanie, you've got something here with this golf." I was using my ability to play golf to draw attention to my birth defects, to be able to start the conversation. All the research I did was going to be a resource, because throughout my journey trying to find out how to play golf, there was no one out there that said, "Hey, one-handed lady, I can teach you to play golf and here's the kind of equipment you need." I started forging relationships and I got involved with organizations, just as an ambassador. I didn't fit into any of the categories. I'm saying that because there's PGA Hope and the Veterans Golf Association, which, even though I'm "guilty by association" as a military Navy brat (my brother, step brothers and nephews are Navy) and I've been brought up in military life, which I fit well in, I'm not actually a veteran. Then there is the One Arm Golfer's Association. I have two arms. I only have one hand.

> *Coddling robs the children of their independence. I was held back as a child and being limited. Don't keep them in. Push them out. As a parent, empower your children. Give them every opportunity.*

So, I continued to forge relationships and got to know amazing organizations. My friend said, "Why don't you look and see what URLs are available?" I typed in adaptive golf and that was taken. Since, I'm the golfer, we came up with Adaptive Golfers. Now I am a world ranked adaptive golf player and I'm on the US disabled golf team.

My sole purpose and mission, no matter how much I'm doing outside of all of this, is to get the stuff that I didn't know that was even out there, for the golfers who need it. But we don't have an industry ready for us, so I can hoot and holler and get all these people turned on to golf that have all these different abilities, but the golf industry has no idea what to do with us when we get there. I've become an advocate, ambassador and an educator in that arena. It's not just me, there have been pioneers preaching to the golf industry for decades. There's so much research and stuff that was never acknowledged. I have somehow been blessed with the opportunity and the voice, to be able to be the concierge between the industries, not just the golf industry, but the allied health and rehabilitative industries.

FS: Tell us about Adaptive Golfers

GR: I founded Adaptive Golfers after experiencing, personally, the difficulty in finding instructors and resources to allow me to play golf.

When I began to notice that I was missing out from joining my husband, his friends and friends' wives, on their rounds of golf, I realized it was time to start doing something rather than watching from the sidelines. During my quest to find an adaptive way to learn to play golf, I learned how limited options were for golfers with different needs. I soon began forging relationships with leading experts and product manufacturers and decided to create Adaptive Golfers, an in-person and online space, where those with different abilities can find programs and events, using modified clubs and equipment, that fit the space I struggled to find early on, in my own golf journey. I am the self-proclaimed "One-Handed Lady Golfer."

I want to make it possible for children and adults with disabilities to learn or return to golf. I want that little girl, that was me, to be able to say, "Not today, bully, I'm going to go play golf. Go pick on somebody else."

Despite the more than 61 million individuals living with physical, cognitive, sensory, health, and age-related handicaps in the United States, those with different needs have incredibly limited access to the resources they need in order to pursue golf.

While some technologies and programs do exist, most are inaccessible to those who need it the most, or they serve as one-size-fits-all solutions, attempting to address a community where no two individuals are alike.

Through Adaptive Golfers, the mission is to re-imagine golf to allow any and everyone to discover the incredible benefits the game has to offer. Today, Adaptive Golfers hosts accessible golf clinics across the country, as well as training for golf instructors and course operators interested in better equipping their facilities to support golfers of all different abilities. People with disabilities have an even greater chance of reaping the rewards golf brings. The reason: People with disabilities spend far less time outside the home socializing. They tend to feel more isolated and participate in fewer communal activities. Besides the apparent physical benefit of Adaptive Golf, the impact on their self-identity is profound. Golf has proven to be an incredibly effective medium, and when some level of mastery is achieved, its powerful medicine. Adaptive Golfers helps to create a sense of camaraderie and inclusiveness, providing encouragement and support to help re-build an individual's sense of dignity and self-esteem. Wellbeing is critical for humans. For those with adaptive needs, we feel "well" when we gain a sense of control over the consequences of our disability.

SWEET SPOT: Gianna speaking with a prospective golfer; "Every experience like this gives me back a little piece of my heart that was taken from me growing up."

Through the benevolence and the generosity of others and funding from the Make Golf Your Thing Grassroots Grant Program, Adaptive Golfers can offer programs and clinics to children with physical or cognitive challenges, young girls and women with disabilities, wounded veterans, first responders, and individuals who have suffered strokes, heart attacks, TBI, loss of limbs, etc. "Neither the ball nor the hole care if you roll it with your nose." Therefore, instead of disabilities, I prefer to say "different abilities."

Through the educational programs, Adaptive Golfers provides education to golf courses and facilities, instructors, parks and recreation, schools, and allied health and rehabilitative industries to bridge the knowledge gap on golf as a therapeutic activity.

There are experienced instructors, manufacturers, and organizations working day in and day out to help adaptive golfers discover the wonders and therapeutic values of the game.

> ***Don't say "Can I?" Say "How can I?" "How" makes you want to keep trying until you get to that outcome of what you want, whatever it is, whether it's golf or anything else.***

I believe in the words attributed to John F. Kennedy: "One person can make a difference, and everyone should try," and I live my life accordingly. I recognized that what was lacking for individuals like myself was a voice. So, I decided to use my voice to advocate globally for adaptive golf. I am passionate about bringing attention to the success stories of Adaptive Golfers and share my own story in the hopes of inspiring others who may question their own abilities. This is all heart. My purpose isn't for my handicap or my score, or for me to have bragging rights and trophies. My purpose is that 13-year-old girl who needs to see somebody like her out there doing something that she would like to do and think, "Wow, if she can, maybe I can, too." I am trying to leave some sort of legacy when I'm not here any longer, that maybe I've changed somebody's life.

FS: Share an example of one of your many touching stories.

GR: I had a booth at an expo. A man who had a stroke three years ago could barely move. He used to play golf. He just happened to be passing by. When he saw the word "golf" at my table, he moved his head slightly and his wife asked if he wanted to go over and meet me. I started talking to him. I said that the best thing is for me to get connected with his rehabilitation team and have them use golf motions as a therapeutic activity. Just small motions: moving one arm, throwing a ball from the bed to the garbage can. This big strong (in persona) man was bawling saying, "Thank you thank you." I hugged him and he would not let go of me, saying in my ear, "Thank you, thank you." Giving him a little glimmer of hope that he can get back to golf, in some form or another, really helped.

And I can tell you, when you're standing, hugging and crying, the impact is heartwarming. I am confident in saying that we change so many people's lives. One little chance meeting and giving him a little glimmer of hope that he can get back to golf, in some form or another, is what this is all about. Every experience like this gives me back a little piece of my heart that was taken from me growing up.

FS: This is really wonderful and I'm so glad that we're doing this article. You're doing such wonderful things and making a big difference. You're truly an inspiration. I'm thrilled the magazine is able to give you more exposure, so even more people can be inspired by you.

GR: I love *EP Magazine*. It makes a big impact. You are giving the audience – parents, caretakers, individuals with disabilities – a tool.

FS: What advice would you give others with a disability?

GR: Don't say "Can I?" Say "How can I?" "How can I?" gives you that opportunity for trial and error. If you say, "Can I?" You might try it once, then say, "See, I told you I can't." "How" makes you want to keep trying until you get to that outcome of what you want, whatever it is, whether it's golf or anything else. •

For more information about Gianna Rojas and Adaptive Golfers, please visit **www.adaptivegolfers.org**

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NOT GONNA MISS HER SHOT: Samantha Fraser of the Gwinnett, GA County Public Schools' adapted basketball team practices her layup skills; Programs begin by teaching students the fundamentals of their sport and are designed to fit into a school's existing sports curriculum.

ADAPTIVE SPORTS AND RECREATION EMPOWERING LIVES THROUGH SPORTS

DISABILITY TO ABILITY

BY GARIMA JAIN, N.D., C.N.C., CHW

Adaptive sports are competitive or recreational sports for people with disabilities. Adaptive sports often run parallel to typical sport activities. However, they allow modifications necessary for people with disabilities to participate, and many sports use a classification system that puts athletes with physical and other challenges on an even playing field with each other. [1]

ADAPTIVE SPORTS AND RECREATION OPTIONS

There are many adaptive sports and recreational options to explore which include outdoor recreation activities (adaptive kayaking, fishing, or snow skiing), performing arts (adaptive dance group), individual sports (wheelchair racing or hand cycling) and team or competitive sports (wheelchair basketball, wheelchair tennis, quad rugby, or sled hockey). There are many assessments that can be performed to select an appropriate sport option based on an individual's strengths and unique challenges.

PHOTO COURTESY ADAPTEDSPORTS.ORG/CATEGORY/PRESS-RELEASES

RESOURCES/PROGRAMS IN THE COMMUNITY

Many community-based and nonprofit organizations offer programs at no or low cost. Every state has a parks and recreation association with a focus on adaptive outdoor recreation activities like fishing, hunting, water skiing, or canoeing/kayaking. Federally, state, and/or local government-funded programs have an obligation to provide disability access including making needed accommodations under Section 504 of the Rehabilitation Act and the Americans with Disabilities Act.

Public schools are mandated to provide physical education and school-based sports to every student and are a great resource for information or to start adaptive sports programs to provide equal opportunity to all students. There have been great advocacy efforts to get the National Collegiate Athletic Association (or NCAA) to sanction adaptive sports. As a result, many colleges and universities have adaptive sports programs, including wheelchair basketball or track and field and also offer Scholarships to top athletes.

LET'S PLAY : ORGANIZATIONS' COMMITMENT TO "EMPOWERING LIVES THROUGH SPORTS"

There are many organizations making a difference for individuals with disabilities but only a few organizations which are making phenomenal strides in the world of adapted sports.

American Association of adapted SPORTS PROGRAMS®

THE AMERICAN ASSOCIATION OF ADAPTED SPORTS PROGRAMS (AAASP)

Includes wheelchair basketball, wheelchair football, track and field and wheelchair handball. The AAASP implements programs at schools designed for students in grades one through 12. The program begins by teaching students the fundamentals of the sport and is designed to fit into a school's existing sports curriculum. They also recruit sponsors and partnerships to assist schools in raising funds for equipment and to run the program.

https://adaptedsports.org

DISABLED SPORTS USA

DISABLED SPORTS USA (DSUSA)

A chapter-based network which operates 100 community-based programs focused on 30 different sports in 37 states and has served more than 60,000 athletes with a disability. Among the most popular sports are alpine "sit" skiing, snowboarding, biathlons, kayaking, water skiing, sailing, rafting, hiking, fishing, canoeing, golf, cycling and rock climbing, among others. Sports are offered in the winter and in the summer, which gives children a chance to be involved in an activity in which they feel confident, year-round. DSUSA leads a variety of adaptive sports programs for people with different types of disabilities

www.moveunitedsport.org

PARALYMPIC SPORT CLUB

U.S. PARALYMPICS SPORTS CLUBS

Paralympics is a multi-national athletic event held every four years in tandem with the Olympic Games and likewise has summer and winter games. Paralympians compete in six main categories – amputee, Cerebral Palsy, intellectual disabilities, wheelchair, visually impaired and others who do not fit into those categories. Within those categories, athletes are again divided by a condition, which maintains the integrity of the competition. The goal of the Paralympics is to bring the spirit of athletic competition to all people – no matter what their physical condition is. You can visit the website and search for the local clubs near you by zip code at:

www.teamusa.org/Team-USA-Athlete-Services/Paralympic-Sport-Development/Getting-Started/Find-A-Club

Special Olympics

SPECIAL OLYMPICS

Provides year-round sports training competition in several sports. The organization is dedicated to providing athletic opportunity to children and adults with intellectual disabilities, giving them the opportunity to develop physically, demonstrate courage and sports acumen, and have fun. Participants can take part in 35 sports, everything from traditional Olympic sports like Alpine skiing and figure skating to non-traditional games like badminton and handball.

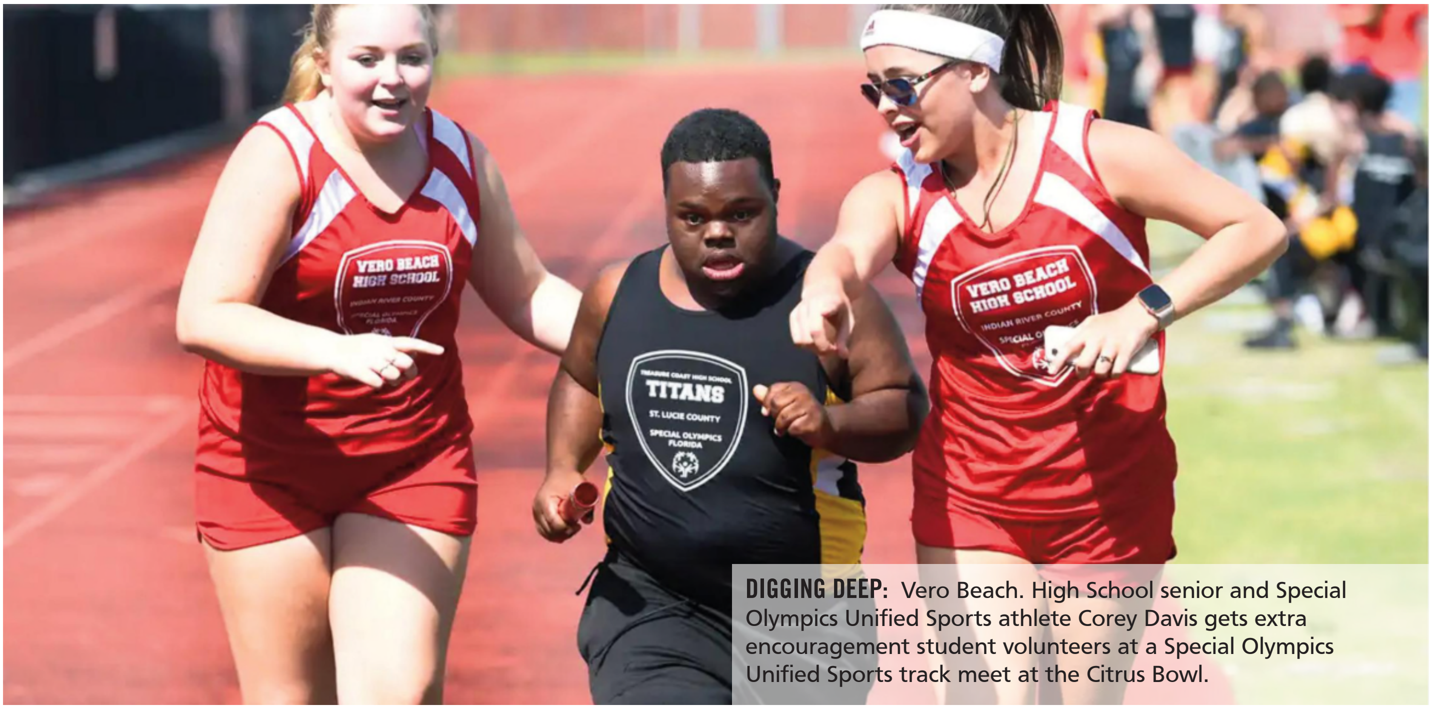
www.specialolympics.org

Special Olympics Unified Sports®

UNIFIED SPORTS

An integral part of Special Olympics Unified Champion Schools, which was founded in 2008 and funded through the Office of Special Education Programs at the U.S. Department of Education to use Special Olympics as a way to build inclusion and acceptance in schools. Unified Sports are now in more than 4500 elementary, middle and high schools in the United States. Seventy percent of Unified Champion Schools (Pre-K through Grade 12) are engaging in Unified Sports! Also 215 US colleges and universities have Special Olympics College Clubs on campus, providing ongoing Unified and inclusionary activities for students and Special Olympics athletes. 73 of the 215 US colleges and universities activating Special Olympics College conduct ongoing Unified Sports on their campus.[2]

www.playunified.org



DIGGING DEEP: Vero Beach. High School senior and Special Olympics Unified Sports athlete Corey Davis gets extra encouragement student volunteers at a Special Olympics Unified Sports track meet at the Citrus Bowl.

ADAPTIVE EQUIPMENT FACILITATES "ACCESS AND INCLUSION"

Adaptive recreation can only be accomplished with the use of adaptive equipment, which can be very expensive. The reality is most insurance companies do not cover the cost of adaptive sports equipment. This is an unfortunate barrier which results in individuals living with physical challenges not having access to the critical adaptive sports and programming needed to be active. Adaptive equipment offers many additional benefits for individuals with disabilities as they can be a replacement for the skills a person lacks, and can reduce daily frustrations, allow accessibility, and empower and encourage participation creating inclusive opportunities within the community for people to participate with their non-disabled peers. There are organizations that offer grants3 for individuals to apply for Adaptive Sports Equipment, Automotive, and Home Needs

BENEFITS OF ADAPTIVE SPORTS AND RECREATION

According to the Centers for Disease Control and Prevention (CDC), 61 million adults in the United States live with a disability which means 26 percent (one in 4) of adults in the United States have some type of disability. The CDC data further shows that one in two people with disabilities are physically inactive3 which makes them more likely to have comorbid conditions such as high blood pressure and depression, and can also lead to social isolation and decreased quality of life. Adaptive sports and recreation provide the opportunities for individuals living with disability to be physically active and also help:

- *Improve overall health, increase life satisfaction, decrease depressive symptoms, and develop a positive self and athletic identity in individuals.*
- *The universal popularity of sports serves as an ideal tool for fostering the inclusion and well-being of persons with disabilities.*
- *Sports help reduce stigma and discrimination associated with disability as it transforms community attitudes about persons with disabilities by highlighting their skills and reducing the tendency to see the disability instead of the person.*
- *Through sport, persons without disabilities interact with persons with disabilities in a positive context forcing them to reshape assumptions about what persons with disabilities can and cannot do.*
- *Sports help individuals with disabilities acquire vital social skills, develop independence, and become empowered to act as agents of change.*
- *Studies have shown that playing an additional year of adaptive sport is associated with an increase in likelihood of employment.*[4] •

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Garima Jain, N.D., C.N.C., CHW is Family Support Specialist, on NJ Integrated Care for Kids (InCK). Hackensack Meridian Health, in partnership with Visiting Nurse Association Health Group, the New Jersey Health Care Quality Institute, New Jersey Chapter of the American Academy of Pediatrics (NJAAP), Central Jersey Family Health Consortium and SPAN Parent Advocacy Network has entered into a collaborative agreement with Centers for Medicare and Medicaid Services (CMS) to establish the NJ Integrated Care for Kids (InCK) model which is a family-centered model aimed at providing coordinated care for children and youth on NJ Family Care families. Garima has been involved for over a decade with various education, advocacy and healthcare projects at SPAN Parent Advocacy Network (**www.spanadvocacy.org**)

PHOTO COURTESY SPECIALOLYMPICS.ORG/WHAT-WE-DO/SPORTS/UNIFIED-SPORTS

ADAPTIVE EXERCISES FOR PEOPLE WITH PHYSICAL DISABILITIES

BY DANIEL STEIN

It's still possible to get fit even when you have limited mobility. Disability or not, exercise and physical activity do a lot of good to ensure your good health. However, physical challenges can pose a big problem when it comes to getting fit. The fear of injuring yourself more than helping you become healthy is a valid fear.

But you don't have to worry anymore. While it's true that physical challenges might make exercising a bit harder than usual, it's still doable with proper care and the right equipment to give you a little fitness help. Before, the idea of exercise and being fit meant hitting the gym and sweating it out. But that's not actually the case right now.

As long as you move to get your heart beating fast, then you are on your way to better health. A little activity here and there is, even more, better than no activity at all.

That is, there are exercises that you can do even if you have limited mobility. You may not be able to do standard gym exercises because of that. The good news is that we have just the perfect exercise routines for you to do at home. Now, you can start getting healthier even without a gym pass. Ready? Here we go:

PHOTOS PROVIDED BY DANIEL STEIN

ON YOUR WAY TO BETTER HEALTH : ADAPTIVE EXERCISES 1 - 3

WHEELCHAIR PUSH-UPS

In one study, wheelchair push-ups were found to be effective at helping you gain muscle, promote arm and upper body strength, and also build physical endurance.

Chronic sitting can lead to the lack or overuse of certain muscle groups in the body. The best way to find balance? Perform the routine for wheelchair push-ups.

This type of exercise relieves pressure and prevents you from feeling sore. This is also why wheelchair push-ups are sometimes called “pressure lifts.” This exercise also moves your triceps and biceps brachii, two muscle groups that help you lift yourself up independently or with just a little help or support.

Here’s what you need to do to perform this adaptive exercise:

1. *For safety, lock your wheelchair and unhook the safety belt.*
2. *Put both your hands on the wheels of the wheelchair.*
3. *Take a deep breath and as you inhale, push yourself up from the wheelchair.*
4. *Hold your breath for 3 seconds then release it at the same time that you sit back down on your wheelchair. If you can and you are able to, you may increase the hold for 5 seconds or more.*
5. *Do this for at least 15 reps.*

Interested in more exercises like this? Read our list of the best Special Strong wheelchair exercises, including the Medicine Ball Criss-Cross and Sitting Bicycle Crunches at

www.specialstrong.com/exercises-for-people-in-wheelchairs

BAND ROWS

Using a band row is a form of strength training resistance exercise which helps target muscles in your upper back and chest wall. With this exercise, you not only tone your body but also strengthen it and burn stomach fat due to prolonged sitting.

What’s good with band rows is that it helps improve upper body strength which in turn lowers your chances of getting injured when moving. It also helps improve posture. Here’s how you can do this exercise:

1. *Using a door anchor, secure a resistance band to the top of a door, or three feet above your head.*
2. *Grab both ends of the band with each hand and move away from the door to create tension*
3. *Slowly pull the resistance band towards your torso, keeping your elbows close to your body*
4. *Exhale and pause for a second before you release the tension and inhale at the same time.*
5. *Do this for at least 15 reps.*

After the upper body exercises, your should also make sure that you pay attention to your lower body.

KETTLEBALL DEADLIFTS

The kettlebell deadlift is one of the best exercises for total lower-body strength since it moves every muscle in your lower body like your quadriceps, hamstrings, and glutes. It also works your upper body muscles and can be done at the comfort of your home!

Now before you do this exercise, make sure that you choose the right kettlebell for you. That is, kettlebells are colored differently to indicate different weights. Following the international standards, the following color codes has a corresponding weight:

- Pink - 8kg (18lbs)
- Blue - 12kg (26lbs)
- Yellow - 16kg (35lbs)
- Purple - 20kgs (44lbs)
- Green - 24kgs (53lbs)
- Orange - 28kg (62lbs)
- Red - 32kg (71lbs)

It’s best to start with the lightest kettlebell weight if it’s just your first time doing this exercise. Then you can add more weight as you progress. With that, here are the steps to help you do this adaptive exercise.

1. *Place a light kettlebell between your feet (5-8kg/11lbs-18lbs)*
2. *Grab the kettlebell with both hands while looking down at the ground*
3. *Keeping your back straight and your chest lifted, lift the kettlebell a few inches above knees for 3 seconds.*
4. *Note: Try to squeeze and keep your glutes tight when lifting.*
5. *Do this for 15 reps.*

ON YOUR WAY TO BETTER HEALTH : ADAPTIVE EXERCISES 4 & 5

BALL SLAMS

As an adaptive exercise for people with disabilities, ball slams are pretty much a versatile form of exercise that you can do to get multiple fitness benefits. Doing this exercise is really enjoyable even with a weighted rubber ball since everything looks like a fun game to play.

However, take note that ball slams have thicker surfaces so they're ideal for higher impact throwing exercises. There are also a few routines you can do for this type of exercise.

Here are the steps for an overhead ball slam:

1. *Place a medicine ball between your feet (5-8kg/11lbs-18lbs)*
2. *Pick up the medicine ball and lift it above your head*
3. *While bracing your core and using as much power as you can, throw the ball down to the ground*
4. *Repeat this for at least 10 reps.*

MEDICINE BALL CHEST PASS

Last, but not the least, is the medicine ball chest pass. It's another easy exercise you can do with both hands and all you need is a wall. You can also have a workout partner to do this exercise properly. It all depends on your preferences.

Here are the steps to do this exercise:

1. *While seated, face the wall or your partner. A distance of 2 to 3 feet from them would be good.*
2. *Placed both your hands on the ball at chest level.*
3. *Using a 2kb/4lb medicine ball, push the ball towards the wall or your partner then catch it.*
4. *Do this for at least 15-20 reps.*
5. *For added progression, you can add more repetitions, use a heavier medicine ball, or do a quicker pass of the ball from the wall or your partner then back to you.*

STRETCH OUT

Stretching may look too simple to be considered an exercise, but it improves your mobility and also helps with flexibility. You can stretch your arms, your legs, and even your neck. Move your arms back and forth. Shake your wrist or your fingers. Just remember to be gentle when you do stretches.

EQUIPMENT LIST

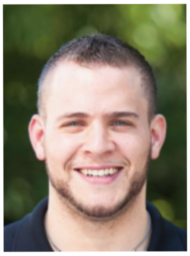
Even at home, you can benefit from having the following equipment at home to do these exercises properly:

- Resistance bands
- Slam balls
- Kettlebell
- Medicine balls

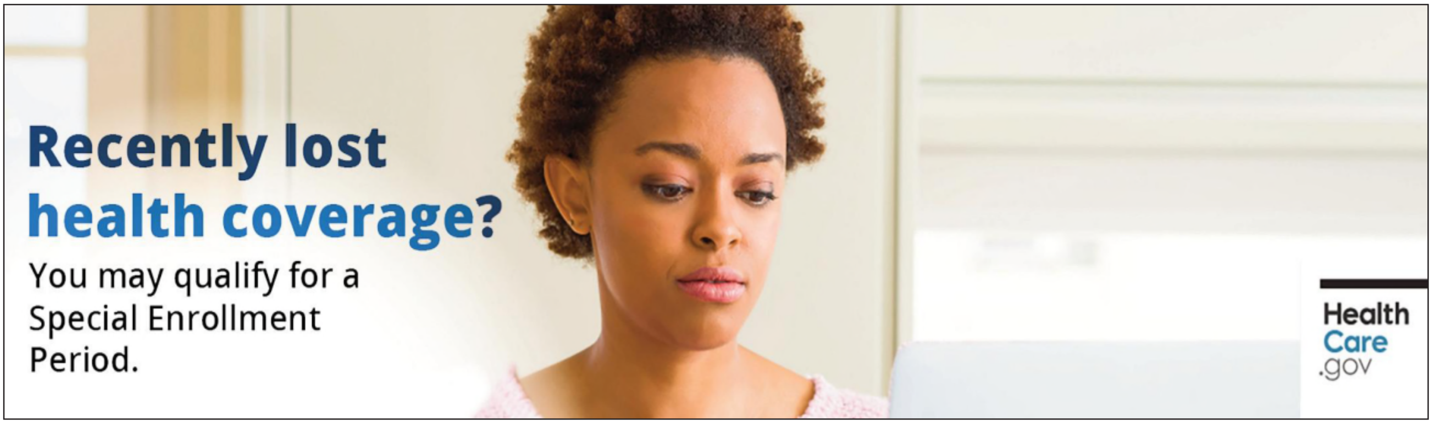
And that's it! Even with a physical disability, you can now perform these adaptive exercises at the comfort of your own home and become fit even without hitting the gym!

Just don't forget that before you do any exercise, it's a rule of thumb that you do warm-up exercises first like stretching. This is to help you avoid injuring or straining your muscles unnecessarily when you do the actual exercises, especially if it's your first time or it's been a while since you performed any exercise routines. •

ABOUT THE AUTHOR:



Daniel Stein is the CEO and Founder of Special Strong, a gym franchise that offers adaptive and inclusive fitness training to people with special needs including those with autism, Down's Syndrome, Asperger's, ADD/ADHD, cerebral palsy, stroke victims, obesity, spinal cord injuries, and many more. Daniel has certifications from the National Academy of Sports Medicine (ACSM) and the National Federation of Personal Trainers (NFPT). He is also a Certified Inclusive Fitness Trainer (CIFT). He also offers adaptive and inclusive fitness training certifications to those who are interested in becoming part of the Special Strong family. For more information, visit **SpecialStrong.com** or **CertifyStrong.com**



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UNDERSTANDING AUTISM

The future of autism begins with you.

WHAT IS SPARK?

SPARK is a groundbreaking study that aims to speed up autism research. Together with parents, autistic adults, and researchers, we aim to better understand autism to help improve lives.

WE DO THIS BY:

- Studying behavioral, medical, and genetic information from over 275,000 participants
- Partnering with leading research universities and autism centers
- Committing to research for the long term to advance understanding
- Inviting all individuals with a professional diagnosis of autism and their families to join

LJS Fac/X

WE CAN HANDLE YOUR PROJECT

HOME ELEVATORS • STAIR ELEVATORS • AUTOMATED SYSTEMS

Bring together more than thirty professionals, each a craftsman in his or her former industry, in one organization and no industry, situation, or challenge will be new to us. Not to say that we've seen it all. Technology adds novel challenges daily, making a flexible organization – one willing to grow in those new disciplines – invaluable.

LJS Fac/X, a twenty-two year old company, has undergone its own evolution since the 1990s. Larry Smith began as an individual electrical contractor, founding the company as LJS Electric as his commercial clients grew his business. Larry saw the need to expand his capabilities, and, over the next two decades, he brought talented professionals together to complement each other's unique skill set. Together the staff of LJS Fac/X offers practical, hands-on experience in a broad array of specialties.

The staff forms two teams, each offering comprehensive expertise in one of the company's two main divisions of facility services. The "Electrical Team" and the "HVAC/Mechanical Team" can cope with any situation an client or homeowner might encounter.

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summer FUN

THE GREAT OUTDOORS

PLAYING IT SAFE: Experiencing the great outdoors is an essential part of life. With proper precautions, preparation, and safety awareness, the risks of outdoor activities can be minimized so enjoyment can be had by all.

WARM WEATHER TIPS AND PRECAUTIONS

BY CRAIG ESCUDE, MD, FAAFP, FAADM

As we move into the warmer months, we are all but assured to be spending more time outside. Taking measures to ensure a safe experience will help ensure an enjoyable experience with minimal discomfort for everyone. IntellectAbility has created a document specifically for people with intellectual and developmental disabilities to help make the great outdoors more enjoyable for all. It's called The Great Outdoors! Warm Weather Edition. Here are some of the document's highlights, which can be freely downloaded at **https://replacingrisk.com/idd-resources**

BEATING THE HEAT : TAKING MEASURES TO ENSURE A SAFE SUMMER

IntellectAbility created a document titled "The Great Outdoors! Warm Weather Edition." (https://replacingrisk.com/idd-resources), specifically for people with intellectual and developmental disabilities to help make the great outdoors more enjoyable for all.

SUN PROTECTION

The sun's rays can cause sunburn in as little as 10 minutes. Here are some precautions to conder:

- *Limit exposure, especially during the hottest parts of the day between 10 AM and 2 PM*
- *Use SPF (sun protection factor) of 30 or greater*
- *Reapply sunscreen at least every 2 hours, more frequently if sweating or swimming*
- *Utilize clothing that has an SPF rating when available*
- *Many Medications that can increase light sensitivity of the skin and/or eyes. Examples include some antibiotics, antidepressants, antihistamines, blood pressure medications, antipsychotics, anti-seizure medications, and others. Discuss these with your pharmacist or physician.*

HYDRATION

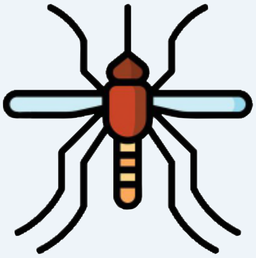
Fluid loss is greater when people are in warmer climates, participating in physical activities, and actively sweating. Maintaining proper body fluid levels is essential.

- *Encourage fluid consumption regularly*
- *Popsicles, sno-cones, and frozen juices can assist in maintaining hydration*
- *Fruits and vegetables with lots of juice can help, like watermelon, peaches, plums, salad greens, radishes, cauliflower, and others*
- *Consider intake of extra fluids before going outside or participation in physical activities*

It's important to know the signs of dehydration and to act fast. Signs include:

- *Skin dryness and tenting (not quickly returning to shape when gently pinched upward)*
- *Eyes sunken*
- *Dry mouth, lips*
- *No tears*
- *Darker colored urine*
- *Decreased urine output*
- *Change in level of consciousness*

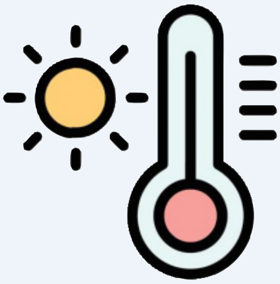
If any of these are noted, it's important to seek medical attention right away.



INSECTS

Biting and stinging insects are an outdoor nuisance. Consider these steps to reduce the likelihood of interference with your fun:

- *Use insect repellent per the manufacturer's instructions. Take caution not to overuse as too much DEET can be harmful to a person*
- *Cover exposed skin when hiking as possible to reduce tick bites*
- *Bright colored clothing attracts bees. Light clothing attracts ticks but repels mosquitoes*
- *Inspect skin after outdoor activities looking for ticks and other insect bites*
- *Avoid areas with fire ants*
- *Have epi-pens available, if prescribed, for people who have severe allergic reactions*



HEAT EXHAUSTION AND HEAT STROKE

The most important things to do to reduce heat exhaustion and heat stroke are staying hydrated and limiting exposure to the sun and to indoor spaces that lack adequate air conditioning. People with disabilities and those over 65 years old are at particular risk. Freezing damp towels and placing them around a person's neck can help one keep cool. Light-colored clothing absorbs less heat and is cooler than dark colors. Certain medications can block the body's ability to cool down naturally, and extra precautions should be exercised. Here are signs of heat-related conditions:

Heat Exhaustion

- *Nausea*
- *Light-headedness*
- *Fatigue*
- *Muscle cramps*
- *Dizziness*

Heat Stroke
(THIS IS A MEDICAL EMERGENCY!)

- Headache
- *Confusion*
- *Absence of sweating*
- *Rapid heart rate*
- *Nausea and vomiting*
- *Loss of consciousness*
- *Elevated body temperature*

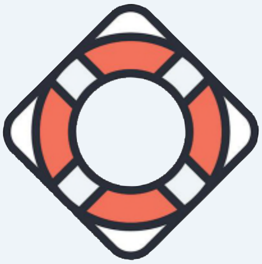
A heatstroke is a medical emergency! Here is what to do:

- *Call 911 immediately*
- *Have the person lie down*
- *Move the person to a shady, cooler area or an air-conditioned room or vehicle*
- *Remove tight clothing or extra layers to facilitate cooling while maintaining dignity*
- *Wipe exposed skin with cool cloths*

to reduce body temperature

- *Do not give oral fluids unless the person is alert and fully conscious*

Untreated heat exhaustion can lead to heatstroke. When signs are noted, seek medical assistance and help the person cool down using the steps above. Medications that can affect the body's ability to cool down include certain diuretics, blood pressure medications, antidepressants, asthma drugs, antipsychotics, and others; it's a good idea to consult with your pharmacist or physician to determine if they might have this property.



SAFETY

Here are some general safety items to consider:

- *Uneven ground increases the risk of tripping and falling*
- *Wear proper footwear for the activity (for example, do not wear flip-flops for a hike)*
- *Pool areas can be slippery, as can mossy rocks near a lake or stream*
- *Avoid poisonous plants such as poison ivy, oak, and sumac*
- *Do not ingest plants and berries as many are poisonous*
- *Pay attention to pollen counts when people have allergies*
- *When humidity is higher, it is harder for a person to cool off, which can increase the risk of dehydration and heat exhaustion*
- *Check on people who live alone to make sure their home is staying cool*
- *Never leave a person in a vehicle alone or without appropriate supervision for any period of time*
- *Blisters can occur from shoes or ill-fitting clothing. Ensure correct fit and monitor for their appearance*
- *Be aware of hazardous wildlife, including snakes, spiders, bears, scorpions, and others in your area*
- *Have epi-pens available whenever someone is known to have severe allergic reactions. Always have two pens in case you need to repeat a dose before emergency help arrives*
- *Review medications with a pharmacist regarding their effects on light sensitivity and body temperature regulation*
- *Have a cell phone available and remain in areas of good signal unless other arrangements have been made for emergencies*

Experiencing the great outdoors is an essential part of life. With proper precautions, preparation, and safety awareness, the risks of outdoor activities can be minimized so enjoyment can be had by all. For additional tips and information, visit https://replacingrisk.com/idd-resources to download this and other free resources, including the cold weather edition of The Great Outdoors! •

ABOUT THE AUTHOR:

Dr. Craig Escudé is a board-certified Fellow of the American Academy of Family Physicians and the American Academy of Developmental Medicine, and is the President of IntellectAbility. He served as medical director of Hudspeth Regional Center in Mississippi and is the founder of DETECT, the Developmental Evaluation, Training and Educational Consultative Team of Mississippi. He has more than 20 years of clinical experience providing medical care for people with IDD and complex medical conditions and is the author of "Clinical Pearls in IDD Healthcare" and the "Curriculum in IDD Healthcare."

GOING INTO THE SUMMER

BY RICHARD SELZNICK, PH.D

Whenever I assess children, one of the ice-breaker tasks to start the evaluation, I ask the kids to write three things they like to do. Almost without fail, at the top of the list is, "I like to play video games."

As we approach summer, I will also ask children what they are going to be doing in the summer. Often, I get a quizzical look that communicates something like, "What do you mean?" The way I read it, I think in the child's mind, they see the summer ahead as a couple of months of virtually endless screen time.

As a psychologist specializing in children struggling in school, I have one piece of parental advice. Whether your child has some type of exceptionality or not, do what you can to get them outside and off their iPads, phones or game systems.

Summer is a great time for children to be doing old-school socializing, whether in day camps or playing in and around a local pool or just playing in the dirt.

Too often, this translates to parents as organized sports such as soccer, little league or other such activities. While these are great, in my experience children need time not being steered by adults. Sadly, to many of the children this means playing in their basements or rooms, not with other children around them, but through their gaming systems with friends (or people they don't know) on-line.

I don't know if there is legitimate research on this or not, but my sense is children are driven by one thing and one thing only. That is their screen usage.

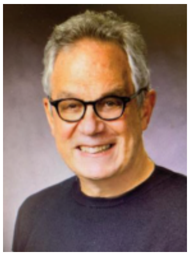
I urge you to break this habit, especially in the summer. To the extent possible, go on family outings – hiking in the woods, fishing in local lakes, exploring the outdoors and other similar day trips.

For school struggling children parents will also use the summer to try and fill in some of the academic gaps with some type of tutoring.

Tutoring in the summer can be great for kids, so can going to the library. Libraries in local communities often have fun programs for children. and these should be actively encouraged.

Take advantage of the unstructured time in summer, but take a firm stance in limiting the screen time and get kids outside and engaged. They might protest at first, but don't weaken. Years later, they will remember the family trip to the local lake more than playing five hours of Fortnite.

ABOUT THE AUTHOR:



Dr. Richard Selznick is a psychologist and the director of the Cooper Learning Center, Department of Pediatrics, Cooper University Health Care. The author of *The Shut-Down Learner: Helping Your Academically Discouraged Child,* as well as *What to Do about Dyslexia: 25 Essential Points for Parents,* and three other related books, he can be contacted through email: **selznick-r@cooperhealth.edu.** To learn more about his books, blogs and podcasts, go to **www.shutdownlearner.com** and **www.cooperlearningcenter.org.**


FEELDOM
ONE BAG FOR ALL
FEELDOM

5 SIMPLE IDEAS TO KEEP KIDS BUSY IN THE SUMMER

BY JENN ADAMS

It can be hard to find summer activities for kids. I know that it can be full of questions for families, especially for families of students with special needs. So I try to ease the tension and worry for my families with some of the ideas I've listed below. Working as a team to support students even in the summer is crucial to helping them.

When it's the end of the school year, we often are so focused on just getting to the end. Teachers and related service providers can do more to help! This can be a stressful time of year for families after an entire school year of routine and structure. Now it's summer and students have lots of downtimes.

Some students have support in the summer if they attend either summer school or an extended school year program. However, research has shown that many of us benefit from some structured activities. Who doesn't love a schedule and a plan to set the tone of their day? Let's read a few ideas that work well as summer activities for kids!

SKILL DRILLS: Life skills, the things we need to know how to do but don't learn about in most school settings, are a great thing to work on during the summer months.

MAKE A SUMMER ACTIVITY SCHEDULE

This can be a calendar on your fridge, a weekly chore list, or a daily set of tasks. As I stated before, routine is in our human nature and children are no different. So if they are capable; sit down with them before summer hits and fill that calendar in. Mark things like vacations, summer camp dates, and or other family activities you have planned. Find a few other things to keep students active, but not overwhelmed. Ask them for some input on things they would like to do too!

If a calendar isn't enough make a list of chores you would like your child to do around the house. This could be things like taking out the trash, walking the dog or reading for 15 minutes. Setting a simple routine can ease the question for many children, of what they should be doing. It also saves families the time of coming up with things last minute. Making a simple checklist could provide more visual support also! The child can check off the things they have completed as they go.

Of course, I also love a good daily visual schedule. It can have words, pictures, or a combination of both. They typically are interactive and students can take the visuals off as they are completed. Listing out a child's whole day can provide them with the predictability they crave. Additionally, it helps to know when a break or reward is coming for the work they are completing.

FIND FUN AROUND THE COMMUNITY

Check the local newspapers. Many communities have a summer guide with activities going on. This could be firework shows, community days, outdoor movies, farmer's markets, or story time at the public library. Many of these are free and are great for families that want to get out in the community.

Children need these opportunities, even if they are in small doses, to be out in their community. It provides them time to practice skills they have learned and generalize them. Things like being social, using their manners, paying for items, and safety skills. We teach these skills at home or at school, but summer is a great time to test them in the community.

Summer camps for short or long periods of time are also a great summer activity for kids. Some might be free and others cost money. You can find summer camps with themes and all degrees of participation from half-day, full-day, or even overnight camps. Check with your local area to see what is available through youth programs, schools, or camps. You might find something that interests your child in areas such as sports, art, theatre, and more!

USE SUMMER TO TACKLE LIFE SKILLS

We talked about generalizing skills in the community. The summer can also be a great time to work on life skills. The things we need to know how to do, but don't learn about in most school settings. Instead of or in addition to: working on academics in the summer, try teaching your child to do some of these things:

- *Washing the dishes*
- *Vacuuming the house*
- *Putting away the groceries*
- *Washing the dog*
- *Getting dressed independently*
- *Putting away clothing*
- *Doing the laundry*
- *Sweeping the floor*
- *Mowing the lawn*
- *Getting the mail*
- *Tying shoes*
- *Making a phone call*

And you can see how I can easily go on and on. I do think that we can't just give a child the directive of "washing the dishes." You have to show and teach them the steps involved in that process. Most of us learn better by watching and doing.

It's important to take the time to model these activities and provide some coaching along the way. I like to use a task analysis to support. This is basically a "recipe" or list of directions on how to do that job. You can make a list with words, or use visuals with pictures (I prefer real photos) to help.

FIND VOLUNTEER OPPORTUNITIES

If the child is older or has an adult that can accompany them, volunteering could be fun! Volunteering is a great summer activity for kids because it can help the community. There are lots of places around the community that are always looking for others to help. Some of the places that come to mind are:

- *Animal Shelters*
- *Libraries*
- *Churches*
- *Hospitals*

Sometimes you can find a volunteer opportunity that is aligned with the child's interests. If they love to read then helping at the library could be perfect! You have found something that is super motivating for the child because they get to work with something they love. Many students I know love animals. Who wouldn't want to spend hours petting a cat or helping to walk a dog?

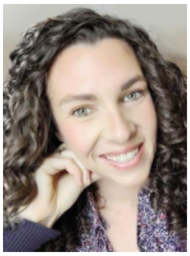
ASK THE IEP TEAM FOR HELP WITH SUMMER ACTIVITIES FOR KIDS

Lastly, why not ask the IEP team for ideas? Ask for an IEP meeting, get the minds together that know the student best and ask for help! There is nothing wrong with asking for help. There are also agencies that can help find opportunities and ideas for children to do in the summer.

The IEP team can help with vocational opportunities, academic materials, and ideas for working on IEP goals. Working to maintain skills learned during the school year is important. As a teacher myself, I have provided summer packets of materials, visual schedules, and lists of educational websites. Most are short activities students have used in the classroom. Don't ever hesitate to reach out to the team and get help!

In conclusion, you can see there are lots of ideas and opportunities for summer activities for kids. Ask around your community and the people that work closely with the child during the school year. They can provide valuable information that can guide you into making this summer the best one yet for your child! •

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.

summer FUN

HOW TO CREATE STRUCTURE DURING THE SUMMER

BY LISA PLASTINO, M.ED.

For many children with special needs, particularly those with Autism, classroom schedules and routines provide structure, which is critical in helping students manage behaviors and have successful days academically and behaviorally.

As the school year ends and summer break gets under way, you may start to notice the impact, that not having a schedule has on your child. Even if your child is in a summer school or camp program, there are likely to be more breaks and disruptions to routine than during the school year.

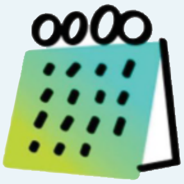
Because of this, you may recognize an increase in your child's anxiety. They may have a lower tolerance for handling unexpected situations.

Your child may be craving that sense of structure. Sure, you may be thinking that summer break should be a time to relax and enjoy the longer days, not having to schedule every moment! And you're right, you don't need to schedule every second of the day, but you can still provide some structure while having fun!

MOTIVATION THEORY: If your child has chores to complete, you could create a visual checklist. Be sure to include their reward at the end of the checklist, so they know that they will receive the desired item or activity once they've finished the other tasks.

A FRAMEWORK FOR SUCCESS : INTRODUCING EVERYDAY STRUCTURE

Here are a few tips to help you and your child navigate the breaks that may occur in the summer like a pro!



1. CREATE DAILY ROUTINES

Many Individuals with Autism Spectrum Disorder (autism) thrive in structured settings, where expectations are made clear and they can anticipate what will happen next in their day.

When a child with autism doesn't have the benefit of the structure that the classroom schedule offers, they may feel overwhelmed by their surroundings and may react when placed in unexpected situations. These feelings of stress and anxiety can often escalate into challenging behaviors.

By creating routines, even if it's just one routine for each day, you are providing the structure that your child may be craving.

Sit down with your child and talk through a typical day. Encourage them to help you build out the schedule if they are able to. For example, you could prompt them with "What is the first thing you should do to get ready for the day?" to which they may respond, "First, I brush my teeth, wash my face, and get dressed."

Lead them through the various routines they typically follow in a day: eating breakfast, completing chores/tasks, working on goals, eating lunch, etc.

If your child uses visual prompts, you could create a visual schedule, itinerary, or checklist for them to follow along with. You can ask your child's teacher for a sample visual schedule or materials that can be customized.

If they can work through the routine independently, encourage them to do so! This is a great way to boost your child's confidence and abilities to complete tasks independently.

2. CONDUCT A DAILY CHECK-IN

At the start of each day, do a quick rundown of any events or appointments that are on the schedule. Having an outline about the plans for the day can help you gauge if there are things that you'll need to prepare your child, and can help you anticipate any potential stress points for them.

During a daily check-in, you can give your child opportunities to make choices about the activities. This may give your child a feeling of control over the day.

3. USE VISUALS AND SOCIAL STORIES

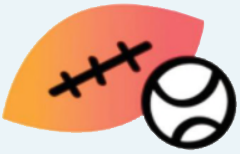
If your child has more success following visual prompts or schedules, try to create one or use a customizable template! Visual prompts could include a mini-schedule which uses graphic representations of tasks for your child to complete. Your child's teacher will likely be able to supply you with the pictures or graphics that you will need.

For example, if you're creating a mini-schedule to help them get ready in the morning, you could include visual representations for brushing your teeth, bathing, and putting on clothes.

If your child has chores to complete, you could create a visual checklist to make sure they've completed everything before moving on to a fun activity. Use photos or graphics to represent each chore, such as washing the dishes or taking out the trash. Be sure to include their reward at the end of the checklist, so they know that they will receive the desired item or activity once they've finished the other tasks.

Another great tool that can help your child maintain control and feel prepared is a social story. A social story, sometimes also called a behavior story, is an explanation of an upcoming event or situation to guide children through a situation. Within the story, include examples of appropriate responses and reactions to the situation. This offers your child a road map to follow when they are in a particular scenario.

For example, if you are going on a family vacation, you could prepare a social story about the vacation, explaining how your child will travel to the location and what types of activities they can expect to participate in while away. If you aren't sure how to write your own social story, find a customizable template online and adjust it to fit your situation!



4. LEAVE ROOM FOR FUN!

It's easy to get bogged down by the details and feel overwhelmed by the need to account for every minute of your child's day. But remember, it's summertime! Leave room in the day for your child to choose activities independently. If your child loves to color or draw, make sure they have time each day to doodle, be it indoors on paper or outside with sidewalk chalk.

By providing your child with choices and opportunities to select their own creative pursuits, you're giving them more control and autonomy. There are a number of ways you can prepare your child to have a fun and supportive summer break, if you plan in advance. Try out some of these tips and tools to provide structure for your child this summer! •

ABOUT THE AUTHOR:

Lisa Plastino, M.Ed. has worked in the field of special education for nearly thirty years, helping families, teachers, and students with special needs. In her current role as an Educational Consultant at the Watson Institute, Lisa provides training to educational teams working with students with disabilities in a variety of settings. She is an expert in early intervention, autism and related disorders, inclusive practices, structured teaching, and positive behavior supports

SPENDING YOUR SUMMER WITH THE AMERICAN KENNEL CLUB

BY MEREDITH SARACENO

Summer is all about getting out in the sunshine and enjoying the summer heat, but there are times when you and your children need a cool break inside. All our activities can be done at home and you don't need to be a dog owner to participate, just a dog lover!

- AKC Public Education has created our own page on the popular Teachers Pay Teachers online marketplace. Here it is easy to access all our educator resources as well as fun activities for parents to do at home with their children. Resources are easy and mostly free to download.
- Our AKC Math Agility App is a wonderful tool for children who are learning their math facts or may just want to sharpen their skills. Geared toward children ages five to ten, the app combines the sport of agility with basic math equations. Players navigate their dog through an agility course. The faster they can correctly answer the math equation, the faster the dog jumps through the course. AKC's goal is to provide parents and teachers a mobile learning game that educates about purebred dogs and the sport of purebred dogs. The app, for Apple or Android devices, is $2.99.
- Our two online newsletters, AKC Canine Corner and AKC Kids News, feature a variety of content for teachers, parents and children. Each newsletter is themed, and we provide a version specifically for exceptional learners. Issues are free and sent to you via email.
- Our AKC Museum of the Dog offers online activities and even a virtual summer camp broken up into 11 weeks of fun! Activities include arts and crafts, games and lessons on famous canine paintings. The AKC Museum of the Dog is in New York City, but their website includes many virtual exhibits.

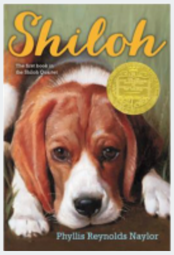
Children may be out for summer break, but they can still keep their academic skills sharp with AKC's excellent resources. For more information and activities, please visit: https://www.akc.org/public-education

ABOUT THE AUTHOR:

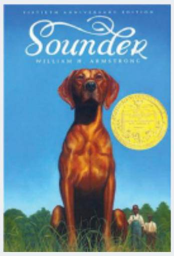
Meredith Saraceno is the AKC Public Education Manager. She has worked under the title since 2018. In that time, the department has created many programs to help reach diverse audiences to understand the importance of the human-canine bond. Most recently, she has dedicated her efforts to reach educators with over 100 lesson plans and resources in their library.

DOG DAYS OF SUMMER : KEEPING UP WITH READING SKILLS DURING VACATION

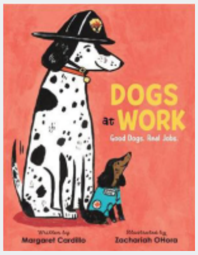
Check out our list of dog-themed books for students PreK-8th grade and get your children reading this summer!



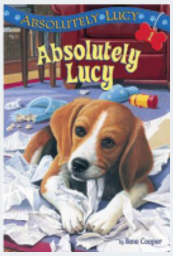
SHILOH
Phyllis Reynolds Naylor
(4th - 7th)
ISBN: 0689835825



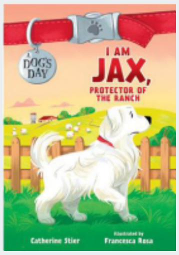
SOUNDER
William H. Armstrong
(4th - 8th)
ISBN: 0064400204



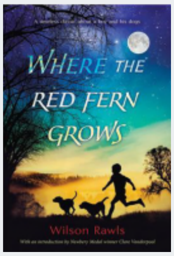
DOGS AT WORK
Margaret Cardillo
(K -3rd)
ISBN: 0062906313



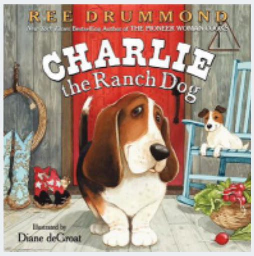
ABSOLUTELY LUCY
Ilene Cooper
(1st - 3rd)
ISBN: 0375855599



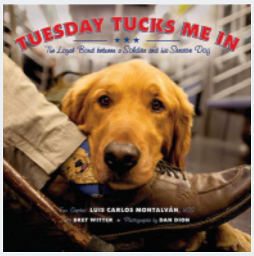
A DOG'S DAY SERIES
Catherine Stier
(3rd - 5th)
ISBN: 0807516767



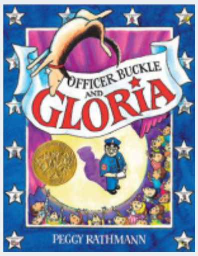
WHERE THE RED FERN GROWS
Wilson Rawls
(3rd - 8th)
ISBN: 0307742539



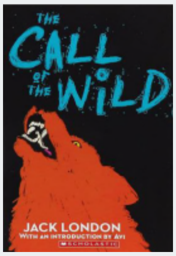
CHARLIE THE RANCH DOG
Ree Drummond
(PreK - 3rd)
ISBN: 0061996556



TUESDAY TUCKS ME IN
Luis Carlos Montalvan
and Bret Whitter (K -3rd)
ISBN: 1596438916



OFFICER BUCKLE & GLORIA
Peggy Rathmann
(1st - 4th)
ISBN: 0399226168



THE CALL OF THE WILD
Jack London
(5th - 8th)
ISBN: 1954839146

summer FUN

CHOICES FOR SUMMER ACTIVITIES FOR STUDENTS WITH DISABILITIES

BY LAUREN AGORATUS, M.A.

Children with specials needs may require continued learning in the summer months, particularly due to learning loss from the pandemic.

IS EXTENDED SCHOOL YEAR NEEDED?

Some students with disabilities may be eligible for “extended school year” services, or ESY. This is a discussion held each year with the IEP (Individualized Education Program) Team, which includes families. ESY may be needed to prevent a student from losing skills, especially if they are learning a new one, to prevent regression. This is even more important as students with disabilities were most impacted during COVID 19. If the school district disagrees but the family thinks ESY is necessary, families can contact their Parent Center for information on how to appeal the denial of ESY services *(see Resources).*

KIDS NEED TO BE KIDS: All children learn through play. There are some fun recreational options out there that include adapted sports such as Little League, Miracle League, and Special Olympics and their inclusive sports programs under Project Unify.

PHOTO COURTESY LITTLELEAGUE.ORG

WHAT ABOUT COMPENSATORY SERVICES?

Courts and guidance from the US Department of Education have identified students' rights to compensatory services under IDEA (Individuals with Disabilities Education Act) and Section 504 of the Rehabilitation Act (504). If students miss services and supports, such as instructional time or related services like speech/occupational/physical therapy, they may be entitled to additional services to make up this loss. This is true at any time, but it is especially important to address loss of services during the pandemic. Compensatory services can take place during the regular school year, or extended school year, or both as needed. Please note that some states have instituted deadlines for requesting compensatory services solely due to the pandemic (for more information see **www.epmagazine.com/blog/deadline-to-request-compensatory-special-education-and-related-services-due-to-the-pandemic**). Also, for younger children, IDEA protections for compensatory services also apply to early intervention. Again, if families think their child needs compensatory services but the district or early intervention provider doesn't, they can call their Parent Center to get info on how to challenge this decision.

IS CAMP A GOOD SUMMER OPTION?

Camps are a great choice for all students to increase their knowledge during the summer months. There are many different types of camps:

- *Recreational*
- *Special needs or integrated*
- *Academic/tutoring*
- *Overnight*

Some states have financing to help families afford camps. This includes camps for students with developmental and other disabilities and even one-to-one aides to help with inclusion in typical camp programs. State and local offices on disabilities sometimes offer financial help, too. Some students who are eligible for compensatory or ESY services can access them via support for their participation in camp programs. Students with disabilities can also benefit from, and participate in, summer camps regardless of the need for ESY or compensatory services. For more information on summer camps, see **www.eparent.com/education/transitioning-into-summer-finding-camps-for-children-with-special-healthcare-needs**.

SHOULDN'T SUMMER BE FUN?

Sometimes kids just need to be kids! All children learn through play. There are some fun recreational options out there that include adapted sports such as Little League (**www.littleleague.org/play-little-league/challenger**), Miracle League (**www.themiracleleague.net**), and Special Olympics and their inclusive sports programs under Project Unify (**www.specialolympics.org/program_locator.aspx**).

Accessible Playgrounds are another great option for children with disabilities (see **www.accessibleplayground.net/playground-directory**). Families should have time to be their child's parent or coach, not necessarily a home health aide or therapist. Although it's important for families to follow up with what teachers and therapists are doing in the home, down time is equally essential for both parents and children.

Children with disabilities should have all the learning opportunities they need including extended school year, compensatory services, camp, and just plain fun. •

ABOUT THE AUTHOR:

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 2 academic journals (**https://pubmed.ncbi.nlm.nih.gov/?term=agoratus+l**). Lauren was recently named a Hero Advocate by *Exceptional Parent Magazine*

A PLACE IN THE SUN : EXTENDED SCHOOL YEAR, COMPENSATORY SERVICES, CAMP, & JUST PLAIN FUN

U.S. DEPT. OF EDUCATION
Extended School Year
https://sites.ed.gov/idea/regs/b/b/300.106

Compensatory Services:
"Return to School Roadmap:
Development and Implementation of
Individualized Education Programs in the Least
Restrictive Environment under the Individuals
with Disabilities Education Act."

See section D "Determining Appropriate
Measurable Annual Goals & Considering the
Child's Need for Compensatory Services"
https://sites.ed.gov/idea/idea-files/return-to-school-roadmap-development-and-implementation-of-ieps/#_Toc83713879

COPAA

COUNCIL OF PARENT ATTORNEYS AND ADVOCATES
COVID-19 Compensatory Education Resource page
https://www.copaa.org/page/CompServ

State dashboard
https://www.copaa.org/general/custom.asp?page=CompEdStateDash

CENTER FOR PARENT INFORMATION AND RESOURCES
Extended School Year
www.parentcenterhub.org/esy-services-beyond-the-school-year-for-students-with-ieps/

Compensatory Services: Webinar on returning to school
www.parentcenterhub.org/webinar-doe-iep-oct2021

PTIs in each state
www.parentcenterhub.org/find-your-center/

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Our social media channels are a significant part of our digital strategy as well; please like us at www.facebook.com/exceptionalparentmag and follow us on www.instagram.com/epmzine and share our compelling posts.

We're really proud of our website and feel it will create the experience you're looking for when you pay us a visit at www.epmagazine.com

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CONTACT: Faye Simon at fsimon@epmagazine.com

EPMAGAZINE.COM: **AN ALL-INCLUSIVE DIGITAL HOME FOR THE SPECIAL NEEDS COMMUNITY**

STEPPING INTO SUMMER

BY JOSHUA FIELDS AND LISA BUTLER

Summer time is a time to kick off your shoes, relax and have a good time with friends and family. For families with children with disabilities, this break from the hustle and bustle of everyday life can become even more challenging and stressful. We want to provide you with some quick activity suggestions and ways to create a meaningful summer experience for your children or young adults.

LISA'S EXPERIENCE

As a mother, I want the best for my children. I want them to be safe, healthy and happy. As a mother of a young lady with significant complex needs, I want the same things, plus I want to ensure that she is not only cared for by people, but also cared about. This goal led me to my position as Program Manager at The Next Step Programs. My daughter was receiving home-based instruction during the important transitional period of school for a young adult. We were struggling with staffing and providers to get her the support she needed and ensure she had engaging days. The traditional route was just not meeting our needs.

It's not that easy with my daughter Sophia. Sophia is a young adult with significant disabilities that began at birth. Sophia was born at just 27 weeks weighing in at 2 lbs 8 oz. and even taking care of her basic needs required adaptations and modifications. So, as Sophia gets ready to turn 21, we have a plethora of tips for families to, as Sophia says, "keep me busy" this summer.

SUMMER ACTIVITIES MADE EASY

Many folks get held up or intimidated by the terms; adapt and modify, especially when thinking through the lens of disability. We like to remind folks to think about someone who might be left-handed when you are right-handed. If you are sitting next to them at dinner, you may want to sit on the right side of that person to avoid getting an elbow in the ribs. It can be that simple. Don't focus on the barriers in place, focus on creativity and accessibility. These activities are by no means an exhaustive list, but they might be a good place to start for some summer fun!

PHOTOS PROVIDED BY THE NEXT STEP PROGRAMS AND LISA BUTLER

SUMMER SMILES: *(Opposite page)* Lisa Butler and daughter Sophia share a warm moment; Sophie *(above, left)* and TNS program participants *(middle, right)* keeping busy and having fun during the summer months.

ADAPTIVE BOWLING

Make your own ramp with a light piece of wood and an outdoor chair. Lean the piece of wood against the cushion to create the ramp. Purchase a small light weight ball from Walmart, Target, or Five Below. Find one that your child can hold with one hand or that is light enough to gently grip on both sides. Have your child stand behind the chair and push the ball down the ramp.

For a child in a wheelchair, the same ramp can be used but the chair may need to be turned to the side or put the ramp to the left or the right of the wheelchair.

ADAPTIVE BASEBALL

A child may not have the hand-eye coordination to hit the ball that is being thrown to them by a pitcher. Use a road cone as the "pitcher" and place the ball on top of the cone and let the swinging begin! Another adaptation for an athlete who is non-ambulatory or lacks the stamina to run the bases, is having a peer be his/her legs, like a pinch hitter. One person will hit the ball while the other does the running.

BEACH VOLLEYBALL

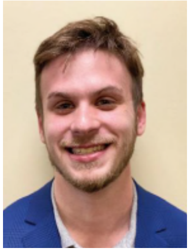
Instead of using a net, simply throw, you guessed it, a beach ball, high in the air for the kids to catch. Challenge them to count how many times they can clap before catching it! (Hint: If they have trouble gripping the ball, simply deflate it a bit.) You can probably guess that this game teaches counting and social interaction skills. Catching a ball using both hands, also teaches bilateral integration, a necessary skill for learning tasks such as cutting, buttoning and tying shoes.

GARDENING

Sorry, but did I mention I love gardening? My daughter is a quadriplegic, with very limited control of her arms and legs. She loves to help me in the garden, especially when it comes to watering the plants. It is hard for her to use a standard watering can, so I use a half gallon milk jug to give her the independence to water the garden on her own.

She painted the milk jug while I poked a few holes in the cap. She can grasp the handle as tight as she needs, and the water comes out without her struggling to have her wrist at a specific angle. See, pretty simple.•

ABOUT THE AUTHORS:



Josh Fields has been advocating for people with disabilities since he was in middle school. In 2015, he co-founded The Next Step Programs, a non-profit that aims to break down the barriers that prevent people with disabilities from finding educational and employment opportunities after high school. Now, he serves as CEO of the organization advancing opportunities for all.

Lisa Butler is Program Manager for The Next Step Programs; as well as a United States Air Force Veteran, a professional advocate and an avid gardener. Lisa says her "most important role is as a mother to two children with significantly different needs."

ABOUT THE NEXT STEP PROGRAMS

THE NEXT STEP

The Next Step Programs (TNS) was created in 2015 to break down barriers withholding people with disabilities from finding educational and employment opportunities post high school. TNS creates dynamic skill and community building programs for young adults and adults with disabilities. Our community programs focus on bolstering participants skills in: communication, employability, self-advocacy, independent living and teamwork. To learn more, visit **www.tnsprograms.org**

CALL FOR HELP

BY ROB WRUBEL, CFP®

Take this easy test. I promise, it's easy. There won't be any calculations regarding trains leaving from Station A or B.

1. *Your glasses break. Who do you call to fix them?*
2. *You need soap and shampoo. Where do you go to get more?*
3. *You have a letter to mail (I know, a letter). Where do you go for a stamp?*

Ok, those are easy ones, so easy I won't bother with the answers. For the first two you have choices – you can head to your supermarket, pharmacy or order online to get soap and shampoo. Still, you have a clear idea of where you buy these products and services and do not have to think too hard about it.

Future planning for our families includes aspects of life that require consideration of what steps to take when, who to engage, how the parts fit together and then how to measure success. Knowing who to call and when can be challenging and the answers you get from one professional or another might be different depending on where you are in your life and their experiences and training.

CALL TO ACTION: Future planning is different than buying soap or a stamp. Once you've built your team, the answers to difficult questions are much easier to find.

Knowing the roles of each professional you talk to or engage is important and it seems like there's confusion about who to contact and when. Often, I act like an air traffic control person sending people in the right direction for the help they need at the time.

Your legal, tax, investing, retirement savings, insurance, trust funding and debt reduction savings, ideally, work together. So, who do you call when?

The lawyer. Estate planning attorneys (lawyers) help with the documents needed if you become incapable of handling your own affairs or deceased. These are your will, powers of attorney and different types of trusts. For families with a member with a qualifying disability, a special-needs trust is almost always used. Some lawyers have experience in future planning and tax and they can be valuable resources with the other members of your team in thinking how to leave legacies efficiently.

CPA. We have to file taxes and your CPA can be a helpful resource in this basic and required activity. Additionally, CPAs are important in helping decide how and when to give assets to others – through trusts, gifting and charities donations. A good CPA helps decide which retirement accounts to use and should be involved in decisions about funding strategies for future benefits (like trusts). Tax penalties for errors can be high and the tax savings from certain strategies can be priceless.

Financial planner. This role seems to cause the most confusion. Once we get to planning and money, the job duties from different professional sometimes overlap or can be handled by one person. Financial planners help you envision the future and map out strategies for the financial funding you need to accomplish your goals. Investment advisors can help invest and manage your money so you can concentrate on daily living and not the markets. Insurance agents can help put coverage in place to cover lost income and pay for future expenses through life and disability policies. Not all of these people have experience with special-needs issues so make sure you find someone that does.

Future planning is different than buying soap or a stamp. It's a complex process that takes time. For most people, it also means learning new concepts and finding professionals to help. Once you've built your team, the answers to difficult questions are much easier to find. You can call your attorney, CPA or financial advisor when something arises. You don't have to struggle alone and worry about making a wrong choice.

Planning for the future means more than increasing the size of your investments. Having a plan in place and key people to support you means you can focus on today, live with less stress and enjoy the present knowing plans are in place for a secure future. •

ABOUT THE AUTHOR:

Rob Wrubel is a CFP who has a daughter with Down syndrome. He is recognized as a leading expert on financial planning for families with special needs members. Wrubel has written two books about financial planning and special needs families – *Financial Freedom for Special Needs Families: 9 Building Blocks to Reduce Stress, Preserve Benefits, Create a Fulfilling Future* and *Protect Your Family: Life Insurance Basics For Special Needs Planning* – and he has been published recently by Law360.com and The Good Men Project. Wrubel holds the Certified Financial Planning (CFP®) designation, the Accredited Investment Fiduciary® (AIF®) designation from Fi360, and the Accredited Estate Planner (AEP®) designation from the National Estate Planning Council.


DR. PRIYA LALVANI

DISRUPTING ABLEISM THROUGH EDUCATION

BY ANDREW MEES

More than at any point in America's history, there is an acknowledgement – and an expectation – that anti-bias education be part of a school district's curriculum.

But there is one group typically not included in these critical discussions; individuals with disabilities.

Even in progressive social justice education, the topic of disability is often left on the sidelines, rendering it irrelevant to nondisabled people, perpetuating stigmas, and allowing ableism to go unmentioned. With more states requiring disability education to be appropriately infused into standard curriculums, it is more important than ever to empower teachers with the tools needed to truly educate students – and to deconstruct ableism from the classroom.

Priya Lalvani, a professor of teaching and learning at Montclair State University and co-author of *Undoing Ableism: Teaching About Disability in K-12 Classrooms* (**www.amazon.com/Undoing-Ableism-Teaching-Disability-Classrooms/dp/1138545597**) is working to bridge this gap by providing a conceptual understanding of ableism, "the persistent devaluing of disability, or viewpoints in which life with a disability is understood as an entirely undesirable existence" and ways to introduce students to anti-ableism content and disability as a natural form of human diversity.

The goal? To empower teachers with ways to recognize and disrupt ableism, and position themselves as agents of change in building inclusive communities.

"There is a considerable gap in the curriculum in schools throughout the K-12 system," said Lalvani. "We have a system in which we prepare teachers to work with students with disabilities and their families, but we do not prepare them to understand and to educate their students about disability history and where this group has been. It would not be OK for a teacher to go before any other group and not have that contextual understanding. Many teachers feel unequipped to tackle this subject in their classrooms, so we are providing a framework that provides the tools needed to have meaningful conversations."

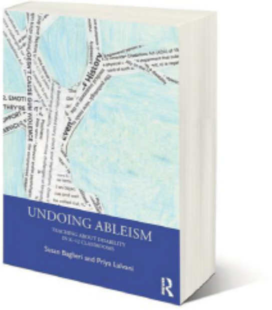
MISSED OPPORTUNITIES: By not acknowledging others who may have disabilities around them, children may learn to silence their natural curiosity about some differences they observe.

CHILDREN UNDERSTAND - AND THAT'S OK

The first step for educators is to understand that children notice – and even comprehend – disability, and they actually want to learn more about it.

The belief that children "don't notice" is not only incorrect, it can be potentially harmful, akin to striving to be "colorblind" when not noticing race. By not acknowledging others who may have disabilities around them, children may internalize that certain differences are valued while others should not be mentioned. They may learn to silence their natural curiosity about some differences they observe, creating an environment where educational opportunities are missed.

"We give children many messages about which differences are valued and which are not in society," said Lalvani. "In the context of disability, we tell them not to look, not to stare, not to point out something that looks different. Children pick up on that; if they are not supposed to mention it, it cannot be a good thing. This is often a lesson learned through interaction with parents, but it is perpetuated when a child comes to school, and the same things are not allowed to be questioned and are not discussed."



Title: **Undoing Ableism: Teaching About Disability in K-12 Classrooms**

Authors: **Susan Baglieri** and **Priya Lalvani**

Publisher: **Routledge**
Publication Date**: September 2019**
Paperback: **214 pages**
ISBN-13: **978-1138545595**
Available at: amazon.com and www.barnesandnoble.com

ABLEISM AT WORK

Ableism, Lalvani says, is at the root of this dynamic. If schools do anything regarding disability programming, it is most likely the standard "awareness days" in which community members wear a certain color, read about a famous person with a disability, or do activities that place children in the shoes of someone who is disabled (such as place children in a wheelchair).

All of these efforts, while well-intentioned, paint disability as something that needs to be overcome (the famous person is billed as a "hero" because they "overcame" their disability to achieve great things, for example), or reinforce negative stereotypes. Perhaps most importantly, though, they do not present teaching moments for children to learn about ableism and their own roles in it, and do not truly educate them about access, accommodations, or what they're seeing in their everyday lives.

"All of these initiatives are actually reinforcing ableism, not what they're trying to accomplish," said Lalvani. "If they want children to truly understand what it is like to have a disability, school districts and teachers must entirely rethink the experiences they are providing."

WHAT CAN BE DONE

Educators can begin to reverse this dynamic by inviting children, with and without disabilities, to learn about disability, disability rights, and disability pride and culture by providing them with the language and tools necessary to recognize all forms of oppression.

When beginning to design lessons surrounding disability, educators should ask themselves a series of questions.

First, if using a particular piece of educational content, determine from whose perspective the experience is being presented. Teachers, Lalvani says, should select materials that emphasize positive or neutral depictions of people with disabilities, particularly those written by such individuals to provide a more authentic educational experience.

Second, what dominant narratives or assumptions about disability are presented? Are there any counternarratives present? There is a lot of content available to teach disability, but teachers must be critical consumers, and spot content that is ableist in and of itself before administering it.

But that isn't enough. Lalvani urges teachers to seek out content that introduces ableism through counternarratives, such as the reclaiming of language and history of disability, questioning what is "normal", highlighting social and attitudinal barriers, or drawing attention to lack of access and acceptance.

Also, children should be given the tools necessary to spot problematic content and conversations, and examine them to learn *why* it is an issue. Popular culture is rife with negative stereotypes and ableist narratives, similar to the experiences created for children when they are taught about disability. Children should be given the space to analyze the content they see in TV, movies and books, and discuss why it may further perpetuate negative stereotypes.

Perhaps most importantly, these changes should be made across the entire curriculum, across all subjects, throughout the year. If this framework is infused in all areas of the educational experience, Lalvani says that children will be infinitely more informed - making conversations about disability easier for parents, as well.

"By implementing a framework like this, teachers are empowered to create change in the classroom. But that change will be felt at home, as well, because both children and their parents will be able to have better conversations about disability not rooted in ableism. Parents can take these recommendations and begin to shift the conversations they're having with their children about disability, whether or not they are disabled. By doing so, they're laying the groundwork to disrupt ableism – and, if it is then supported in schools, we can begin to change the way disabled people are viewed in our society." •

ABOUT THE AUTHOR:

Andrew Mees is the Media Relations Director at Montclair State University.

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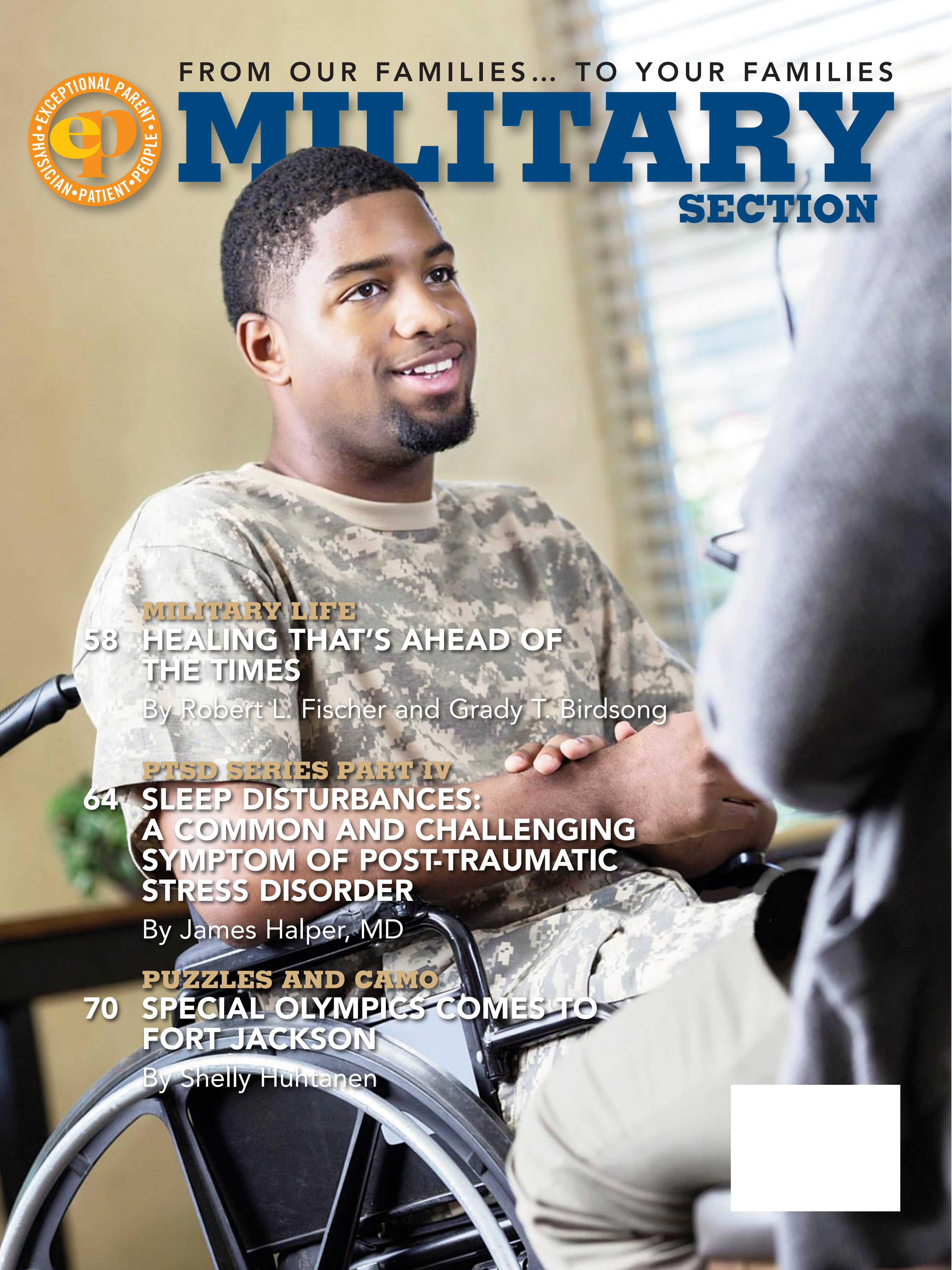

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FROM OUR FAMILIES... TO YOUR FAMILIES

MILITARY SECTION

U.S. MILITARY ★ BOOK EXCERPT PART I

HEALING THAT'S AHEAD OF THE TIMES

BY ROBERT L. FISCHER AND GRADY T. BIRDSONG

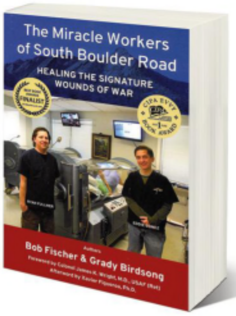
Editors Note: ***The Miracle Workers of South Boulder Road: Healing the Signature Wounds of War*** *tells a dramatic story of how a severely disabled young stroke victim healed himself using an element that only nature can provide: oxygen. It also describes how he and three other "Miracle Workers" began to help others. He learned how to render this important treatment therapy to veterans returning home from the Middle East with traumatic brain injuries and related post-traumatic stress.*

These Miracle Workers are healing lives with one of America's most successful integrated hyperbaric oxygen treatment and PTSD counseling programs. The following is the introductory segment in a series of articles about this process.

CHAPTER 1

BRAIN INJURIES – COMMON OCCURRENCES

Unfortunately, traumatic brain injuries are common occurrences and are ranked as one of the most prevalent injuries in our society today. As it is termed, TBI is a significant public health concern, especially in younger males and people in their elder years. Some of the most common causes of TBI for civilians include falls, motor vehicle crashes, being struck by objects or hitting against an object, and assaults. In 2010, 2.5 million TBI-related emergency room visits, hospitalizations, or deaths were recorded (Centers for Disease Control and Prevention).



Title: **The Miracle Workers of South Boulder Road: Healing the Signature Wounds of War**

Authors: **Robert L. Fischer** and **Grady T. Birdsong**

Publisher: **BirdQuill LLC**
Publication Date: **June 2016**
Paperback: **212 pages**
ISBN-13: **978-0997606805**
Available at: amazon.com and www.barnesandnoble.com

THE SIGNATURE WOUNDS OF THE CURRENT WARS

TBIs have also become one of the signature wounds of our combat veterans in military deployment in the Middle East. Of the approximately 2.5 million U.S. troops who deployed to Afghanistan or Iraq, it is estimated by study teams that a significant percentage suffer from some degree of concussion and post-traumatic stress. TBIs, PTSD, and accompanying depression generally follow deployment. Almost thirty percent of combat veterans experience TBI and PTSD, the signature wounds of our present-day wars – and what yesterday's combat veterans knew as "shell-shock" and "battle-fatigue." Unfortunately, most of these wounds remain untreated and misunderstood.

One of the more deadly weapons devised, IEDs, causes scores of mild to severe traumas for returning combat veterans. Those veterans who experience these wounds are familiar with IEDs and other concussive blasts. The author's son, Marine Sergeant Shane Birdsong, an infantryman, recorded two such blasts while on his first tours in Iraq.

The photo on the following page *(Figure 1)* shows a controlled blast by Marine combat engineers to destroy enemy ordnance found in an area while patrolling. This photo shows the magnitude of explosives in an IED cache typically discovered.

FIG. 1

FIG. 2

SIGNATURE DAMAGE: Author's son Sergeant Shane Birdsong (*Above, left*) in Afghanistan. He photographed two concussive IED blasts while on his first tours in Iraq – a controlled blast by Marine combat engineers (*Fig. 1*), and IED blast damage to a mobile patrol in Anbar Province, Iraq (*Fig. 2*).

The next photo *(Figure 2)* depicts a less fortunate mobile patrol in Anbar Province, Iraq. This squad, while on patrol, took the full impact of a buried command-detonated IED that destroyed the vehicle and wounded all occupants – the driver, the squad leader, the A-gunner, and eight Marine infantrymen in the rear of the truck. All were medically evacuated with moderate to severe physical wounds and TBIs. All the Marines survived. The IED consisted of an explosive wired to a 155 artillery round and propane tank. The propane tanks used in these IEDs are like a standard American BBQ grill propane tank, which can produce horrendous concussive force if ignited by explosives.

Brain damage from such blasts results in physical and psychological injuries that regular, pill-driven medicine attempts to treat and heal. Yet, rather than prescribing drugs, we believe there are better ways to address these injuries, which are done at the Rocky Mountain Hyperbaric Institute. However, before we continue to present the benefits and success of HBOT, it is essential to consider the brain and its complexity. Only then can we examine just how oxygen treats and heals TBI and also facilitates the treatment of PTSD.

HEROIC MARKER: TBI-PTSD Signature Wound logo design, courtesy of Rick Baum, USMC Veteran, Minister and Veteran Advocate for the Rocky Mountain Hyperbaric HBOT clinic.

THE HUMAN BRAIN: INJURY AND RECOVERY

The most fragile, complex, and vulnerable organ in the body is the human brain. It controls our thoughts, emotions, behavior, movements, and sensations. It processes what we think, feel, and create with billions of neurons and their dendrite forest. They work together to receive and exchange data and then act as the interpreter of our senses to control and direct all our movements. Even our sleep and breathing depend on this healthy condition. Each of the brain's five lobes has specific functions that we rely on to live, function, and experience life.

The brain's gelatinous mass is encased in a rigid skull for protection *(see Figure 3, next page)*. It wards off mild concussions and blows to the head that injures us when we fall or "have our bell rung" in a boxing ring. In his description of the human brain and how it functions, hyperbaric treatment pioneer, Dr. Paul Harch employs a brain-sized stalk of broccoli *(see Figure 4, next page)*. as he shows its many thousands of tendrils and then describes how a brain's dendrite forest reacts to a hard blow or a serious IED blast *(see Figures 1 and 2)*.

If we carefully examine broccoli, we see these many tiny tendrils *(Figure 4)* similar to the brain's dendrite forests *(Figure 5)*. The brain has billions of neuron cells that anchor their branched projections, the dendrites. They, in turn, propagate – sending and receiving electrochemical stimuli – and act as antennae or receptors of signals from other nerve cells.

The human body and all its physical and emotional functions depend on the healthy performance of these critical brain elements. They either die or shut down when they are damaged from a blow or concussive brain injury. Recent brain studies have confirmed that the brain has an amazing capacity to recover. The brain's plasticity generates brand new dendrites that replace the dead ones or revitalize the dormant ones. Spectrographic scans were taken of a veteran's concussion-damaged brain show areas of injury to the lobes and their dendrite forests. As we confirm with our HBOT treatment, concentrated oxygen not only treats and heals a damaged brain but stimulates and activates the brain's own ability to heal itself. Recent Israeli neuroplasticity studies of veterans with TBI confirm this process.

THE VETERAN'S BRAIN SUFFERS A CONCUSSION

The brain is composed of eighty billion dendrites anchored in their neuron bodies. They are the primary receptors for our brain's information, and together they control and coordinate our body's many functions. In effect, they are the main elements of the brain's computer.

The human brain is designed to ward off minor blows, such as from a fall or being shaken in an accident. This is because the brain mass bounces off the inside skull wall and is saved from any injury in most cases. However, a severe blast or concussion sends shockwaves through the brain mass with such intensity that many dendrites and neurons either shut down or die due to the extreme shock. Frequently, these dendrites survive serious damage and go dormant until the proper type of medical treatment revives and restores their lost functions. *(Figure 6)*.

FIG. 3

FIG. 4

FIG. 5

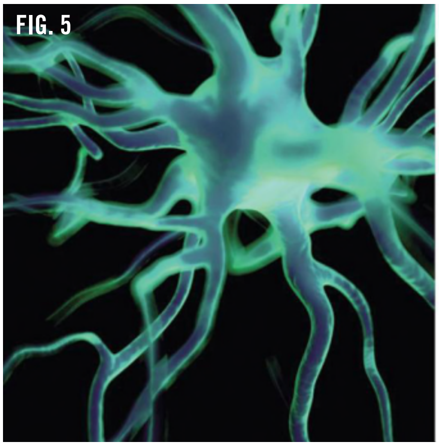
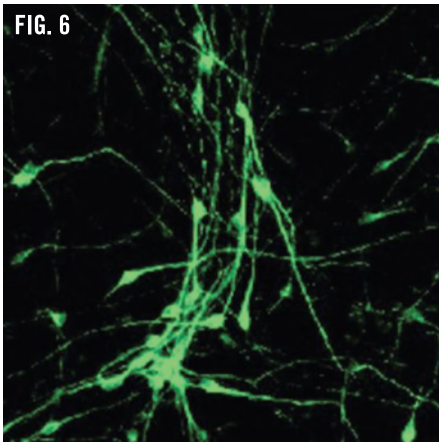


FIG. 6



BUILDING BLOCKS : The brain's gelatinous mass is encased in a rigid skull for protection *(Fig. 3)*; If we carefully examine broccoli, we see these many tiny tendrils *(Fig. 4)* similar to the brain's dendrite forests; The brain has billions of neuron cells that anchor their branched projections, the dendrites *(Fig. 5);* Frequently, these dendrites survive serious damage and go dormant until the proper type of medical treatment revives and restores their lost functions. *(Fig. 6).*

For several centuries, it has been proven that oxygen heals wounds and destroys parasites. Oxygen has been employed for more than 100 years by the U.S. Navy to treat and cure nitrogen narcosis, or the "bends," as it is better known. Major hospitals today employ hyperbaric chambers for a large number of FDA-approved maladies, as shown in the following list: air or gas embolism, carbon monoxide poisoning, gas gangrene, crush injury, decompression sickness, arterial insufficiencies (category of diabetic foot ulcers), severe anemia, intracranial abscess, necrotizing soft tissue infections, osteomyelitis, delayed radiation injury, comprised skin graphs and flaps, thermal burn injury, and idiopathic sudden sensorineural hearing loss.

An important Israeli study, documented and published in 2013 by a distinguished team of researchers drawn from Tel-Aviv University, The Assaf Harofeh Medical Center, and the Institute of Hyperbaric Medicine, Zerifin, Israel, tested and documented the brain's capacity to heal itself in at least two cases.[1, 2] Called neuroplasticity, the brain's unique ability to overcome and eliminate injuries and tissue damage with the right stimulus, such as the brain's exposure to hyperbaric oxygen, which heals and restores life to damaged cells.Blood flow is critical to human life and bodily functions. The brain is no exception, and its complexity requires even greater attention than other organs and wound areas. Interruption of blood flow to parts of the brain can result in strokes, seizures, and other impairments, which is why the timely HBOT treatment of veterans who suffer from TBI and PTSD is extremely critical, especially when there is proof that oxygen-based therapy does heal and restore the combat veteran's body and mind.

FIG. 7

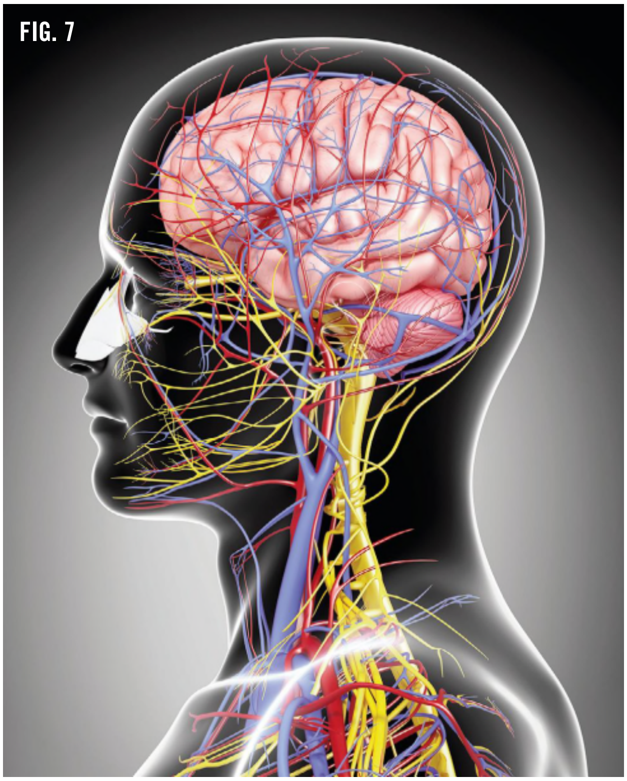
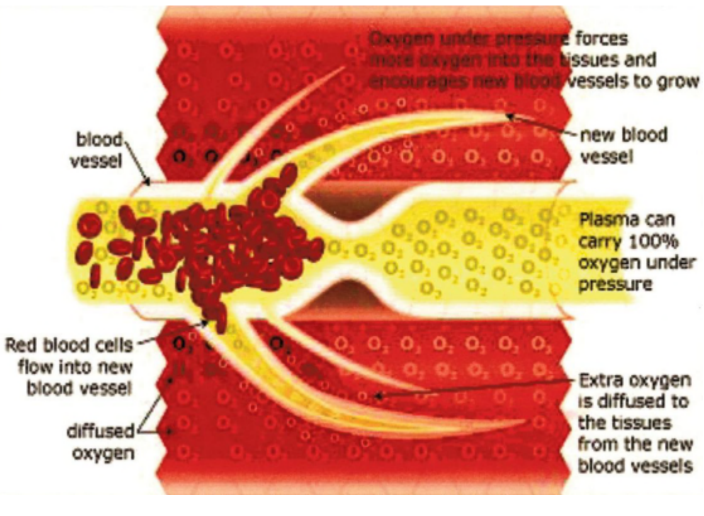


FIG. 8



FLESH AND BLOOD: Blood flow in the brain *(Fig. 7)*; An adequate supply of oxygen and nutrients is critical for all human cells and tissues; Neovascularization is the formation of functional microvascular networks with red blood cell profusion. Angiogenesis is mainly characterized by the protrusion and outgrowth of capillary buds and sprouts from pre-existing blood vessels (*Fig. 8)*.

HOW NEW BLOOD CELLS AND PATHWAYS ARE CREATED

An adequate supply of oxygen and nutrients is critical for all human cells and tissues. Nurturing the proliferation of the below processes with pressurized oxygen has accelerated the healing of traumatized areas in the brain.

Angiogenesis: The development of new blood vessels from preexisting vessels. It occurs in the healthy body to heal wounds and restore blood flow in damaged tissues after injuries.

Neovascularization: The formation of functional microvascular networks (blood paths) in red blood cell perfusion. It differs from angiogenesis, characterized by profusion and outgrowth of capillary buds and sprouts from preexisting blood vessels. Hyperbaric oxygen stimulates both.

THE INJURED VETERAN'S OPTIMAL COURSE OF TREATMENT

Each veteran treated at the Rocky Mountain Hyperbaric Institute receives a concentrated oxygen brain bath for forty hours, one hour at a time. The following schematic shows what happens inside the damaged brain when oxygen is introduced at 1.5 atmospheres (the equivalent of 17 feet below sea level at a 5,000-foot altitude). The oxygen healing process includes both angiogenesis and neovascularization, as defined above. In addition, the damaged dendrites and neuro pathways are either bypassed if the cell or dendrite is dead or can be revitalized if in a dormant state *(see Figure 8)*.

While there may be few exceptions, virtually every combat veteran who suffers from TBI has PTSD. The American Journal of Psychiatry and the Mayo Clinic have a similar definition: "post-traumatic stress disorder (PTSD) is an anxiety disorder that may develop after exposure to a terrifying event or ordeal in which severe physical harm occurred or was threatened. Traumatic events that trigger PTSD include violent assaults, natural or unnatural disasters, accidents or military combat."

They further define the signs and symptoms of PTSD and group them as follows:

1. **Re-experiencing symptoms:**
   - *Flashbacks – reliving the trauma repeatedly, including the experience of physical symptoms like a racing heart or sweating. Words, objects, or situations can trigger these symptoms.*
   - *Bad dreams and frightening thoughts that may cause problems in everyday life.*
2. **Avoidance symptoms:**
   - *Staying away from places, events, or objects that trigger experience reminders.*
   - *Feeling emotionally numb, with strong guilt, depression, or worry predominant.*
   - *Little interest in enjoyable activities in the past – before the trauma.*
   - *Having trouble remembering or recalling the dangerous or terrifying event.*
3. **Hyperarousal symptoms:**
   - *Easily startled, to the extent that a person may change their routine.*
   - *Feeling tense or "on edge," leading to more stress and angry outbursts.*
   - *Inability to function normally to do basic daily tasks, usually with little sleep.*

When the injured veteran arrives for treatment, it is common to find that they suffer from many symptoms listed above. Their disrupted sleep, profound memory loss, mood swings, and withdrawal-depression require the immediate attention of the clinic staff. Many do not communicate or lack the ability to speak clearly or even pay attention to their first instructions. They must be counseled and gently led through each TBI and PTSD treatment step until they become familiar with and trust the clinic's medical director, the HBOT technicians, the PTSD counselor, and the chamber operators. At first, it is a foreign environment and can be quite intimidating.

POISON PILLS: Prior to the program, many veterans were doped up on useless off-label medicine, the majority of which had not yet been approved or tested by the FDA.

Today, more than 450 healed veterans can now attest to the professional and successful TBI and PTSD therapy they experienced in the only integrated TBI and PTSD treatment program in America. When each veteran started the program, it was apparent that they suffered some degree of brain damage from their combat concussions or other injuries. In too many cases, they had suffered their signature wounds for far too long, and their families and friends had suffered. Their brain injuries went unhealed until they sought help at the Rocky Mountain Hyperbaric Institute. Unfortunately, when they arrived at the clinic, a large segment of them were actual "basket cases." Most were doped up on useless off-label medicine, aka "black drugs," the majority of which had not yet been approved or tested by the FDA. Some veterans arrived with many different prescriptions as if more of these pills would somehow help them feel better.

The need for additional health services, especially for neurotrauma, has skyrocketed in recent years. And it likely will increase even more significantly as time goes forward. Invisible wounds have become the signature wounds of this generation and these combat veterans. This brings us to our story… the miracle on South Boulder Road in Louisville, Colorado.

Ryan Fullmer, the program director of Rocky Mountain Hyperbaric Institute, has partnered with Eddie Gomez, President, Patient and Nonprofit Services, Rocky Mountain Hyperbaric Association for Brain Injuries, to treat and heal traumatic brain injuries. They also integrate PTSD counseling within the same TBI treatment period, usually over forty days. This is one of the most innovative and successful programs in the United States and combines the treatment of the two maladies under one comprehensive treatment process (in parallel). •

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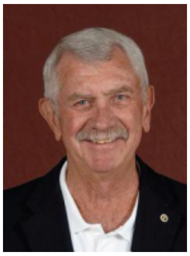
ABOUT THE AUTHORS

Bob Fischer is a 1955 Naval Academy graduate and career Marine Corps officer who retired in 1982. He was Captain of Marines on the U.S.S. Saint Paul CA-73, the 7th Fleet Flagship, from 1961 to 1963, when he studied four guerrilla wars in Southeast Asia and obtained the Malaya Jungle School Syllabus at Johore Bahru. He used the syllabus to establish the 2nd Marine Division Counter-guerrilla Warfare Center at Camp Lejeune, North Carolina. 20,000 Marines, Navy Seal, and Special Forces Teams were also trained there. His CIPA award-winning book Guerrilla Grunt documents this experience. He was also a task force advisor (Covan) for the Vietnamese Marine Corps from 1966 to 1968 and wrote his book Covan about this experience. From 1977-to 80, as Commander of the Defense Electronics Depot, Kettering, Ohio, his workforce set the Defense Logistics Agency's all-time performance record. For this, he was awarded the Defense Superior Service Medal. In 2010, he attended a presentation by the Rocky Mountain Hyperbaric Institute and its nonprofit Rocky Mountain Hyperbaric Association for Brain Injuries, where he learned about their recently established Healing Our Heroes fund. His involvement with other Marine veteran organizations motivated him to become a Veteran's Advocate for the clinic. Joining Grady Birdsong, they filmed the first veterans who received hyperbaric oxygen therapy (HBOT) in the original Boulder clinic and raised funds by presenting the unique HBOT story to groups in the Denver area. He was named Colorado American Legion's Veteran Advocate of the Year for his efforts in 2012.



Grady T. Birdsong was raised in Kansas before enlisting in the United States Marine Corps in 1966. After serving two tours in the Northern "I-Corps" region of Vietnam during Tet of 1968 and the DMZ in 1969, he traveled the world, enjoying a successful career in engineering, business development, marketing, and technical sales in the telecommunications/data systems, information technology systems, and the optical and fiber systems test industries. Additionally, Grady is the author of A Fortunate Passage, To the Sound of the Guns, and Echoes of Our War, with nine EVVY awards from the Colorado Independent Publishers Association (CIPA). In 2010, Grady and Bob Fischer became Marine Corps Veteran Advocates for the Rocky Mountain Hyperbaric Institute, at a time when Ryan Fullmer and Eddie Gomez were struggling to establish their brand new HBOT clinic in the industrial area of Boulder, Colorado. His early filming of the clinic's first successful TBI-PTSD veteran's treatment generated the first significant donor funds, earning $135,000. These funds enabled the HBOT clinic to move to its current site in the Professional & Medical Center in Louisville, CO, and provide a nearby home for the forty-day treatment of out-of-town veterans. Now retired, Grady lives with his wife, Pamela, in the Denver area, where he enjoys his grandchildren and spends his time writing, volunteering, and hunting big game. Grady is a graduate of Regis University in Denver, Colorado. Both authors have an ongoing commitment to veterans of all wars and continue to advocate, inform, educate, and raise nonprofit funds. Both remain Semper Fidelis.

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U.S. MILITARY ★ PTSD SERIES PART IV

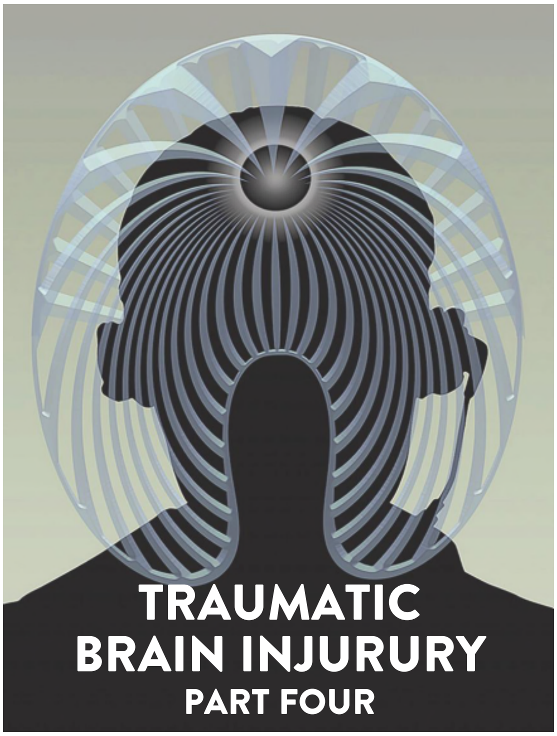
Sleep Disturbances:

A Common and Challenging Symptom of Post-Traumatic Stress Disorder

BY JAMES HALPER, MD

Editors Note: EP continues its exploration of the effects of combat on servicemembers who have returned home and are attempting to cope with traumatic experiences while reintegrating into the daily life of family, community, and work. This series focuses on traumatic brain injury, post-traumatic stress disorder, and related health issues. This month's article explores the issue of substance abuse, some of its effects, and some options and thoughts for recovery.

Sleep disturbances are a major sympton of post-traumatic stress disorder (PTSD). In the DSM-IV-TR (Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition, Text Revision), the official diagnostic manual of the American Psychiatric Association (APA) in the diagnosis of PTSD, the presence of nightmares (recurrent distressing dreams of an event) is part of the DSM's Criterion B (reexperiencing of the traumatic event) and difficulty falling or staying asleep are part of Criterion D (increased arousal) – i.e., sleep disturbances comprise two of the five criteria required for the diagnosis of PTSD.



One or both of these features is experienced in up to 90 percent of patients with PTSD. These symptoms are considered particularly distressing by patients and have a highly negative impact on their quality of life (QOL). Additionally, there is evidence that impaired sleep contributes to physical and mental disorders associ-" "ated with PTSD and is a contributor to the development and/or is a perpetuator of PTSD itself.

Sleep disturbances also play a role in substance abuse—especially alcohol abuse—as people attempt to self-medicate to avoid the distress associated with disturbed sleep and/or nightmares. Patients also respond to disturbances such as nightmares by engaging in behaviors in which they avoid sleep, resulting in insomnia. These sleep difficulties have a major adverse impact on patients with PTSD. The effective treatment of sleep disturbances is associated with beneficial consequences that go beyond improved sleep and decreased nightmares.

SEEKING EFFECTIVE TREATMENTS

A variety of treatments have been tried, and some have shown greater results than others.

Unfortunately, sleep disturbances frequently do not respond to selective serotonin reuptake inhibitors (SSRIs), the major treatment for PTSD. Indeed, SSRIs may, at least initially, make insomnia more severe. The new generation of "atypical antipsychotics" (e.g.: quetiapine, olanzapine, and risperidone) may be helpful but are associated with side effects that include sedation and weight gain. Recently, however, new treatments have been developed that are more effective for sleep disturbances. These new treatments have been developed, in part, because of increased understanding of the pathophysiology (the accompanying functional changes) of PTSD.

UNDERSTANDING SLEEP

Sleep is divided into a variety of stages. The major division is that between rapid eye movement (REM) sleep and non-REM sleep. Most, but not all, dreams occur during REM. Additionally, during REM, the body is essentially paralyzed. The paralysis is useful in that it prevents people from acting out their dreams. The brain waves in REM are very rapid and desynchronized. NonREM sleep is divided into three stages. Here, we look first at the third stage. It is the deepest sleep and is known as slowwave sleep (SWS), because the brain waves recorded during this type of sleep by electroencephalogram (EEG) are slow. They are also synchronized. It is thought that slow-wave sleep is the major restorative sleep. The amount of this sleep will determine whether you"

"feel you have obtained a good night's rest when you awake in the morning. Stage 1 and 2 sleep is intermediate between REM and slow-wave sleep with respect to rate and degree of synchronization. While the majority of dreaming occurs during REM, it also occurs during other stages, particularly if the sleep is light and the sleeper can be easily awakened.

UNDERSTANDING PTSD AND SLEEP

It is thought that PTSD is associated with a failure to process and neutralize frightening memories. This failure allows frightening memories to push in during waking and sleeping hours. Because processing normally occurs during sleep, particularly REM sleep, and nightmares disrupt sleep, a vicious cycle begins, in which the processing of frightening memories is compromised. This has led to the use of a variety of psychotherapies to enhance processing and neutralization of frightening memories to decrease their ability to disturb sleep and to enhance sleep-mediated processing of disturbing thoughts. Alternatively, there are medications that decrease disturbing dreams. The effect of medications on processing frightening memories is unclear, but the two approaches may be complementary since medications may be helpful in breaking the vicious circle noted above."

ALL SYSTEMS NOT GO: SOME OF THE DIFFICULTIES

Stress in general, and PTSD, in particular, is thought to be associated with activation of the noradrenergic system (NAS). The noradrenergic system consists of the neurotransmitter norepinephrine and its receptors, which are found in the central nervous system and throughout the body—on nerves, blood vessels, and organs, including the heart. There are many types of noradrenergic receptors, alpha (alpha1 and alpha 2) and beta. The noradrenergic system is thought to play a role in the transition from acute stress disorders to chronic stress disorders and to be central to the symptoms in established cases of PTSD. Alpha receptors are believed to have the predominant role in these symptoms, including sleep disruption and intrusions of unwanted and frightening thoughts while patients are awake or asleep. The understanding of the role that the noradrenergic system plays has led to the use of medications that block the noradrenergic system as a way of treating sleep disorders and nightmares.

Evidence for the role that the noradrenergic system plays includes the following: Many of the areas of the brain thought to be associated with PTSD symptoms are heavily stimulated by noradrenergic (NA) neurons and express a high density of nordrenergic receptors. They are very responsive to activation of the system. Furthermore, concentrations of noradrenergic neurons in the cerebrospinal fluid (CSF) are highly correlated with the severity of symptoms of PTSD, and excretion by noradrenergic neurons of Norepinephrine and its metabolites are increased in the urine of patients with PTSD.

Laboratory studies show that increased noradrenergic activity has a variety of bad effects on a person's REM sleep. These include the diminishing of REM-associated paralysis, leading to increased movements during REM, which may lead to waking up. In addition, shifts from REM to other stages are increased. Thus, noradrenergic system activation is associated with REM fragmentation (waking up throughout the night, reducing the total amount of time spent in the deeper levels of sleep). Poor-quality REM sleep, in addition to leading to awakenings, also prevents a person from processing stressful memories. This leads to waking up more often and decreased processing. In addition, NA stimulation is associated with the lightening of types of sleep other than REM and increased levels of corticotrophin releasing factor (CRF). Corticotrophin releasing factor is a hormone produced by the hypothalamus that leads to anxiety, including an increase in a person's primitive internal alarm system. Furthermore, it leads to release of Norepinephrine by noradrenergic neurons, which in turn leads to further release of corticotrophin releasing factor, again, increasing a person's anxiety level.

THE ROLE OF MEDICATIONS

All this suggests that medications that interfere with the noradrenergic system might be useful in PTSD. Clonidine is one such medication. It is an activator (agonist) of the type 2 alpha receptor, a receptor that decreases noradrenergic neuron release of Norepinephrine. Thus, clonidine causes the noradrenergic system to regulate down. Its major use in medicine is to treat hypertension – hence, hypotension is one of its side effects. Its peak effect occurs one to three hours after it is taken by mouth, and a usual dosage is .2 to.4 mg. Aside from hypotension, bad side effects are dry mouth, drowsiness, and constipation. The beneficial effects may wear off in time, requiring an increase in the dosage. There have been a number of reports of its successful use for those with PTSD, particularly in children.

Recently, most studies of medications to regulate the noradrenergic system have focused on prazosin, which blocks the alpha1 receptor. It is used for hypertension and urinary difficulties that are secondary to a non-life threatening enlargement of the prostate. Multiple studies of this medication have shown its use for the treatment of PTSD, particularly for the treatment of nightmares and sleep disturbances. Interestingly enough, it specifically decreases the abnormal nightmares that occur with PTSD. Normal nightmares and normal dreams have been reported to increase after its administration, as stress-related nightmares decrease. In addition, using it has led to a decrease in difficulties falling asleep and staying asleep. A decrease in PTSD symptoms other than those associated with sleep and decreased ratings of depression have also been reported. One study reported that prazosin was associated with increased total sleep as well as more REM sleep (consistent with return of normal dreaming) as well as an increase in the number of eye movements during a period of REM sleep and less time between falling asleep and the first period of REM sleep. Patients who had failed to respond to other treatments (e.g., SSRIs tricyclic antidepressants (TCAs)) have responded to this drug, which may indicate the superiority of prazosin to these other treatments. On the other" "hand, since in many trials patients continued on previous medications, these results may indicate prazosin's use as an additional medication to SSRIs, tricyclic antidepressants, and others.

While many of the trials have been open trials, a number of them have been placebo-controlled and crossover, providing compelling evidence for the effectiveness of prazosin. While protocols using up to 20 mg have been described, most studies have shown good results with 2 to 6 mg. Higher doses are divided, but doses of 2 to 6 mg are given at bedtime. A test dose of one mg is given, with the dosage increased every 3-7 days as needed until effective or until side effects decrease. While some patients experienced a drop in blood pressure when standing, many of these were also on anti-hypertensives or other cardiac medications. Prazosin's peak effect occurs 1 to 3 hours after being taken by mouth, its half-life is 2 to 3 hours, and its effect lasts 4 to 6 hours. The most common side effect is nasal congestion, with hypotension and sedation being rare. Dosage increases may occasionally be required. A return of sleep problems occurs when a person stops using prazosin, consistent with prazosin suppressing nightmares rather than helping in the processing of the underlying traumatic memories.

Thus, prazosin has demonstrated effectiveness in treating sleep disturbances and nightmares and has had a favorable effect on other symptoms of PTSD. Whether or not the decrease in symptoms, other than sleep symptoms, is secondary to improved sleep or primary, prazosin should be considered a first-line medication for sleep disturbance. It avoids the potential disadvantages of other agents such as tricyclic antidepressants, monoamine oxidase inhibitors (MAOIs), and benzodiazepines (used especially as tranquilizers), which include suicide risk, medical adverse effects, and in the case of benzodiazepines, substance abuse, and only has variable effectiveness.

> **"Medications may improve sleep and decrease nightmares while psychotherapy may help with the reprocessing of traumatic thoughts. Since at least some good-quality sleep is required for optimal reprocessing, the two techniques are likely complementary."**

THOUGHTS IN THE FIELD

Despite the attention paid to sleep disturbances as symptoms that occur with PTSD, certain investigators think the importance of sleep disturbances may have been downplayed and that certain types have been neglected. They contend that insomnia and nightmares should be considered core symptoms of PTSD, which may actually cause and perpetuate the disorder. Furthermore, they suggest that sleepdisordered breathing (SDB) (abnormal breathing patterns that interfere with sleep) and periodic arm and leg movements in sleep (PLMS) are important contributors to PTSD sleep disturbances and have been largely ignored.

In support of the idea that sleep disturbances may cause PTSD, they cite studies reporting that sleep disturbances occurring during the period of the stress reaction right after the stressful event are strong predictors of the development of PTSD. There is even a report that sleep disturbances occurring before the stressor may predict the later occurrence of PTSD. The plausibility of these reports is supported by observations that sleep deprivation is well known to interfere with a person's ability to cope in general and to impair mood. Furthermore, as discussed, normal sleep, including REM, is thought to play a role in processing memories of trauma, which are central to PTSD. All of these may increase a person's vulnerability to PTSD. Consistent with this possibility, there are reports that early treatment of sleep disturbances during periods of acute stress may prevent the development of PTSD, and a number of studies have shown that treatments directed at sleep disturbances and nightmares may decrease other symptoms of PTSD. While treatments that focus on traumatic memories may decrease symptoms of PTSD, unless attention is paid to sleep disturbances, patients often continue to suffer from insomnia and nightmares, which, according to these models, may perpetuate PTSD. The possible interactions of sleep disturbances and PTSD are compatible with several models of the relation of stress, sleep, and PTSD, each of which may hold for different patients:

1) Sleep abnormalities, regardless of cause, predispose one to the development of PTSD after an acute stressor;
2) Sleep abnormalities resulting from acute stressors may cause PTSD—i.e., sleep disturbances mediate the relationship between acute stress and PTSD; and
3) Sleep disturbances and other PTSD symptoms develop in response to the acute stressor, and sleep disturbances may be resistant to standard PTSD therapies that do not explicitly deal with them. If any of these three relationships hold, it is clear that treatments must explicitly focus on sleep disturbances to obtain optimal results with PTSD.

FINE-TUNING UNDERSTANDING

Recent studies have indicated that PTSD is often associated with sleep-disordered breathing. Two explanations for this association have been advanced, both of which are plausible and may cooccur. As has been described, sleep, including REM sleep, is broken up in patients with PTSD. It has been shown in experimental settings that such sleep fragmentation is associated with an increased tendency for airway collapse. While such airway collapses may not be of magnitude to cause sleep apnea (a temporary suspension of breathing occurring repeatedly during sleep), with its easily observable arousals, gasping for breath, snoring, etc., they can cause hypopneas (abnormally slow, shallow breathing), which trigger microarousals that serve to restore sufficient airflow—i.e., hypopneas lead to further sleep fragmentation. This is known as upper airway resistance syndrome (UARS). These apneas or hypopneas have been shown to lead to nightmares or at least to impart negative emotional tones to the dreams associated with them. Thus, it is clear how a vicious cycle could result, leading to both nightmares and fragmented sleep.

Disruptions of other phases of sleep lead to lack of restorative sleep (sleep that leaves a person feeling that he or she has had a good night's rest). This decrease is often associated with daytime sleepiness and/or a lack of energy. Other signs of sleepdisordered breathing include: morning headaches, dry mouth, nocturia (waking up to urinate), and cognitiveaffective disturbances, which include depression, anxiety, attentional problems, and memory disturbances, among others. Since upper airway resistance syndrome may require state-of-the-art technology for its detection, sleep-disordered breathing often remains undetected and hence ignored. Aside from the technical difficulties associated with the detection of subtle forms of sleep-disordered breathing, their neglect in part results from the tendency of both doctors and patients to focus most on the psychological aspects of PTSD as the explanation of symptoms, including sleep disturbances.

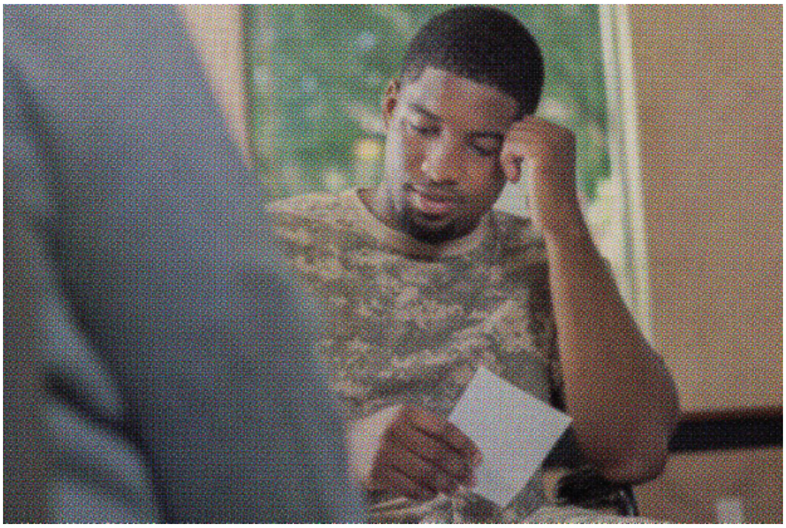
It has been proposed that in at least some cases, sleep problems that persist after psychological and/or pharmacological treatments result from sleep-disordered breathing continuing. Indeed, it has been shown that in some cases, treating PTSD by continuous positive airway pressure (CPAP) alone, which is the gold-standard treatment for sleep-disordered breathing, and without any psychological intervention, not only alleviates sleep problems but can also cause a dramatic relief from other PTSD symptoms, underscoring the potential causal or mediating role of sleep problems, including sleep-disordered breathing in the genesis of PTSD. Since many patients with PTSD find that continuous positive airway pressure may produce claustrophobia and anxiety, conservative approaches such as instruction to sleep on the side instead of the back, attention to nasal hygiene, or the use of nasal dilator strips may be used first. The latter techniques clear the nasal passages, thus decreasing airway resistance and, hence, mini-collapses. Periodic limb movements in sleep, which disrupt and fragment sleep are also increased in patients with PTSD, probably due to increased noradrenergic tone.

PSYCHOLOGICAL TREATMENTS

In addition to medication and treatments for underlying sleep-disordered breathing, there are a variety of psychological approaches to the treatment of sleep disturbances. One of these, imagery rehearsal therapy (IRT), focuses on the symptom of disturbing nightmares. In this treatment, patients are taught techniques of imagery and how to apply these to their nightmares. Two types of instructions have been employed that are equally effective.

In one of these, patients are asked to remember a nightmare, write it down, and then change the ending in any way they deem helpful and rehearse the new "dream." This is often done in group sessions. This technique has been shown to have ongoing positive effects on the number of nightmares per week and the number of nights without nightmares. Furthermore, insomnia is often improved because of the decrease in sleep disturbances resulting from nightmares and a decrease in protective behaviors adopted in attempts to ward off nightmares. (These protective behaviors include: delaying bed time, getting out of bed when waking rather than trying to get back to sleep, sleeping with lights on, substance abuse, and others). PTSD symptoms often decrease as sleep improves. Some patients find that imagery rehearsal is stressful and may increase fears. These negative effects may be decreased by first teaching patients how to employ pleasant imagery and having them start with less fear-inducing dreams (e.g., those not dealing explicitly with the traumatic events and limiting imagery rehearsal therapy to one dream per week).

A second form of psychotherapy dealing with sleep issues is Sleep Dynamic Therapy® (SDT), which includes a multitherapeutic focus on sleep issues in addition to imagery rehearsal therapy for nightmares. Sleep Dynamic Therapy consists of six two-hour sessions given weekly in a group format with an emphasis on psychoeducation and sleep-directed cognitive behavioral therapy (CBT). Sleep-directed cognitive behavioral therapy involves identifying stimuli that either interfere with or help with sleep, together with identification and abandonment of maladaptive habits that interfere with sleep. The psychoeducation includes identification of" "symptoms of sleep problems, including lack of restorative sleep, daytime sleepiness, and frequent awakenings, etc., which are often ignored because of the other obvious symptoms of PTSD. In addition, proper bedtime habits (good sleep hygiene) are taught.



INCREASING UNDERSTANDING

While the importance of nightmares and insomnia as symptoms of PTSD has long been appreciated, it is increasingly becoming apparent that this may be only the tip of the iceberg. Other types of sleep abnormalities such as sleep-disor- dered breathing and periodic limb movements in sleep are apparently common and may play a role in insomnia or nightmares. Importantly, not only are sleep disturbances major sources of distress for patients with PTSD, but they may play key roles in causing or perpetuating the disorder. They may also contribute to substance abuse, particularly of alcohol. While alcohol may help patients fall sleep, there is a rebound awakening. Furthermore, sleep worsens during withdrawal. These factors lead to increasing amounts of alcohol consumption. Fortunately, there are an increasing number of treatments available for sleep disturbances (e.g., imagery rehearsal therapy, Sleep Dynamic Therapy, pharmacotherapy, and, in some cases, continuous positive airway pressure). Yet in order for these treatments to be effective, the sleep problems must be noted. While it is hoped that cli- nicians are becoming more aware of the prevalence and importance of sleep dis- turbances, it behooves the patient to bring them forward if the clinician does not focus on the issue.

Patients' descriptions of sleep dis- turbances are the gold standard for their identification. While polysomno- grapy (EEG, eye movement, and mus- cle activity measurements obtained during sleep) may be helpful in identi- fying and/or confirming some cases of sleep disturbances, there are many" "false negatives. This is because sleep laboratories, and even home monitoring, induce feelings of safety in many patients with PTSD. The partner may supply invaluable information regarding sleep-disturbance symptoms.

> **"Not only are sleep disturbances major sources of distress for patients with PTSD, but they may play key roles in causing or perpetuating the disorder. Fortunately, there are an increasing number of treatments available for sleep disturbances, such as, imagery rehearsal therapy, Sleep Dynamic Therapy, pharmacotherapy, and, in some cases, continuous positive airway pressure."**

DETERMINING A PERSON'S OPTIONS

Further studies are required to determine how to optimally use the great variety of treatments now available for sleep disturbances, including night- mares, associated with PTSD. Among the questions requiring answers is this one: Is there one "best" treatment or, as is more likely, are different clinical pat- terns associated with different respons- es to a given treatment? Medications may improve sleep and decrease night- mares while psychotherapy may help with the reprocessing of traumatic thoughts. Since at least some good- quality sleep is required for optimal reprocessing, the two techniques are likely complementary. In view of this, should medications and psychological therapies then be used at the same time or in sequence? These and many other questions need to be answered.

Since it is likely that different treat ments and/or their combinations may be required for a given patient, patience and persistence will be required while sequential trials are performed. But it is fair to say that this should be done with a spirit of optimism and conviction that an effective treatment regimen will be found. Not only may such treatments alleviate a decreased quality of life for individuals due to sleep disturbances, but they may also improve other PTSD symptoms. •"

ABOUT THE AUTHOR:

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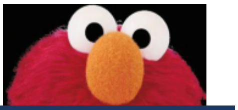

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PUZZLES & CAMO SHELLY HUHTANEN

Special Olympics Comes to Fort Jackson

All of Fort Jackson was there to support. Everyone was there to celebrate these athletes. They were seen as having value and purpose.

It's been three years since Fort Jackson has had the opportunity to host the State Special Olympics Games. Last weekend was the first time that our cadre had the opportunity to experience and support this amazing event. My husband, Mark, is in the brigade who was selected to host the event and frankly, we didn't know what to expect. "We'll have to experience it to understand it's impact." I think all us who have been here for three years or less needed to observe this past weekend and personally find ways that we could support. I saw so many smiles. Not just smiles of those who were competing, but smiles on the cadre and trainees who came out to support the Special Olympics. People with different abilities have a way of doing that to people around them.

FIRED UP: From left, Fort Jackson Post Command Sgt. Maj. Jerimiah Gan, Fort Jackson Deputy Commanding Officer Col. Douglas Walter, 2019 South Carolina Summer Special Olympics athlete Madelyn Haag, South Carolina Lt. Gov. Pamela Evette and Civilian Aide to the Secretary of the Army Kevin A. Shwedo bear the Olympic torch to the ceremonies.

PHOTO COURTESY US ARMY

On Friday night, the Special Olympics ascended on Fort Jackson like a seismic bolt. The torchlight running team started at the Capital building in downtown Columbia. Mark said, "Come to Solomon Center around 7:30 pm. That is where we'll be ending our run with the torch to start the games." When I arrived and slowly walked up to the building, I couldn't believe my eyes. Hundreds of athletes and their families and friends were culminating around the facility. Mark's operations sergeant major, Mike, met me at the door full of excitement, "Shelly, have you been inside? You have to see this. It's amazing." I follow him into the Solomon Center towards the music and cheers. Basic Training trainees filled the stands and Army cadre circled the participants. They were cheering "USA" as the athletes were smiling and cheering. Mark was right. To truly understand how special these games are, we had to experience it.

Mike and I ran back outside to witness Mark and the rest of the runners come up the street with the torch to start the games. Sirens were blaring as the team with the torch was escorted by the Richland County sheriff's department. Mark was on the right flank as BG Michaelis, the commander at Fort Jackson, ran with a participant. I saw the excitement and awe on the cadre's faces running up to the facility. They were experiencing something special. Fort Jackson was connecting and building relationships with a special group of people. This group of people had pure hearts and have been looking forward to this event for three years, and it was time for these games to begin.

As the team walked into the Solomon Center, they heard the cheers coming from the gym. More people had arrived to kick off the celebration. BG Michaelis said it best, "Look in these stands. This is your Army and we are here to serve you! Let the games begin!" The athletes stayed the night in the barracks and started their competitions early the next morning. There was aquatics, bocce ball, softball, bowling, powerlifting, track and field, and gymnastics. In between the events, Mark and I visited the Olympic Village where there was food being served, a music DJ with dancing and other vendors.

I met Sue Manor, the Vice President of Special Olympics South Carolina, "Have you seen our program called Healthy Athletes?" As Mark and I shook our heads, Sue escorted us down the hall to show us that this is not just an event where their athletes compete, but they also have an opportunity to receive much needed healthcare, "This may be the only opportunity where an athlete might receive an eye exam or a dental exam." According to Sue, this program started with Eunice Kennedy, the founder of the Special Olympics, "Eunice thought, if my sister has a difficult time receiving dental care, what about the rest of our population with special needs?" This is how the Healthy Athletes Program was born. This is a service provided by Special Olympics that is free of charge to the athlete.

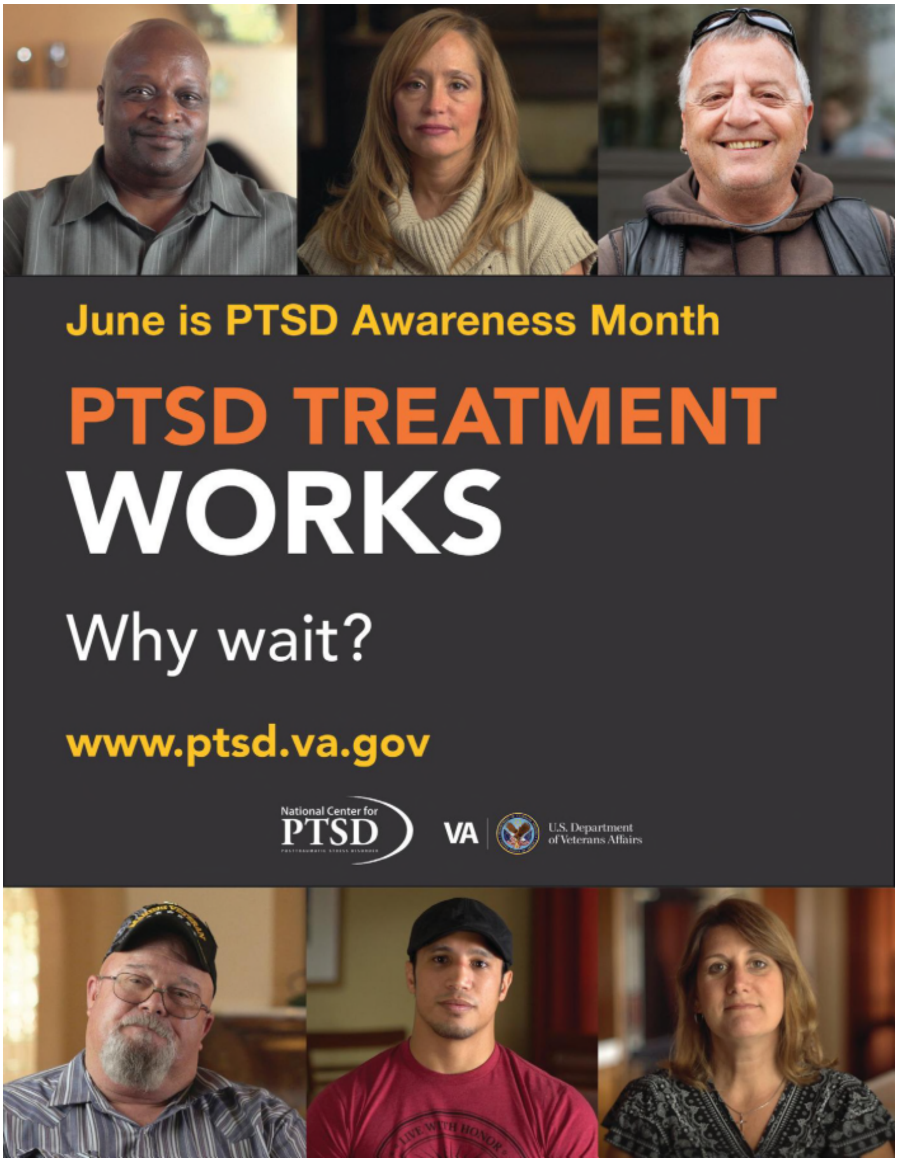
That night, Mark and I brought our boys to the closing ceremony. We wanted them to witness and experience this special event. I lured Broden out onto the floor as the music was playing and we started to dance. I looked over and watched athletes dancing with soldiers and an athlete with autism dancing with his service dog. This was true inclusion at its finest. A cadre member came up to Mark to talk to him about his experience, “This is the first time I’ve ever spent time with people with disabilities. This is the first time for a lot of us. They are amazing people. We want to participate next year.” The 2-60th command team who provided support to the event told us that this was the most fun they had had and were already building an AAR (After Action Report) to find more ways to support this event next year. It wasn’t just Mark’s brigade that was there to support this momentous occasion, all of Fort Jackson was there to support. I watched my friend’s daughter, Summer, yell, “Let’s do this!” as an athlete approached her asking her to dance. Everyone was there to celebrate these athletes. They were seen as having value and purpose.

> “As Mark and our friends continued to dance with the athletes and celebrated their accomplishments, I couldn’t help but feel grateful. I was grateful for having the opportunity to witness a celebration for people who have different abilities.”

As Mark and our friends continued to dance with the athletes and celebrated their accomplishments, I couldn’t help but feel grateful. I was grateful for having the opportunity to witness a celebration for people who have different abilities. As our son, Hayden, says over and over again, “Different does not mean less.” This weekend was not just about celebrating those athletes, but it was providing an opportunity for Fort Jackson to see how special these athletes truly are. As the event drew to a close, I witnessed an athlete come up to BG Michaelis to shake his hand, “I didn’t leave the bed as neat as when I got here to Fort Jackson.” BG Michaelis smiled and teased him by saying, “You can fix that bed before you leave!” The athlete replied, “I figured you could take care of that for me.” Yes indeed. We will take care of that bed for you and we’ll have a bed ready for you next year. The Special Olympics will be an experience that we will remember and we are already looking forward to supporting them next year. •

PUZZLES & 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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