PLUS: UNITED STATES MILITARY SECTION

EXCEPTIONAL PARENT
PHYSICIAN • PARENT • PEOPLE

EXCEPTIONAL PARENT
MAGAZINE
AUGUST 2022
$7.95

EP's ANNUAL HEALTHCARE ISSUE:

ATTAINING DISABILITY COMPETENT HEALTHCARE

PLUS:

THE ANXIOUS CHILD: A NEW ORIENTATION

AND:

WHAT DOES "MEDICAID UNWINDING" MEAN?

UNIQUE, BEAUTIFUL & BRAVE:

LILY D. MOORE

STATS; MYTHS; RESOURCES:

TRAUMATIC BRAIN INJURY

ALSO • FINANCIAL PLANNING:

ENSURING HEALTH CARE *and* GOVERNMENT BENEFITS UPON REACHING THE AGE *of* 18

EP MAGAZINE
1971 2022
51
YEARS
CELEBRATES

CONTENTS

AUGUST 2022 VOLUME 52 ISSUE 8

EP'S ANNUAL HEALTHCARE ISSUE

FEATURES

ON OUR COVER

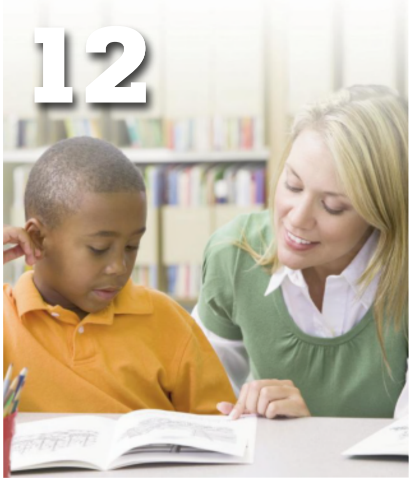
The hard working and talented Lily D. Moore, a 19-year-old actress and advocate who can truly inspire all of us to "find our inner star." EP's Annual Healthcare issue also explores sensory integration therapy, holistic approach interventions, and traumatic brain injury treatments, and presents two new contributors to our publication whose unparalleled knowledge and experience in the fields of law and finance will be invaluable to our audience. *Coverage begins on page 22.*

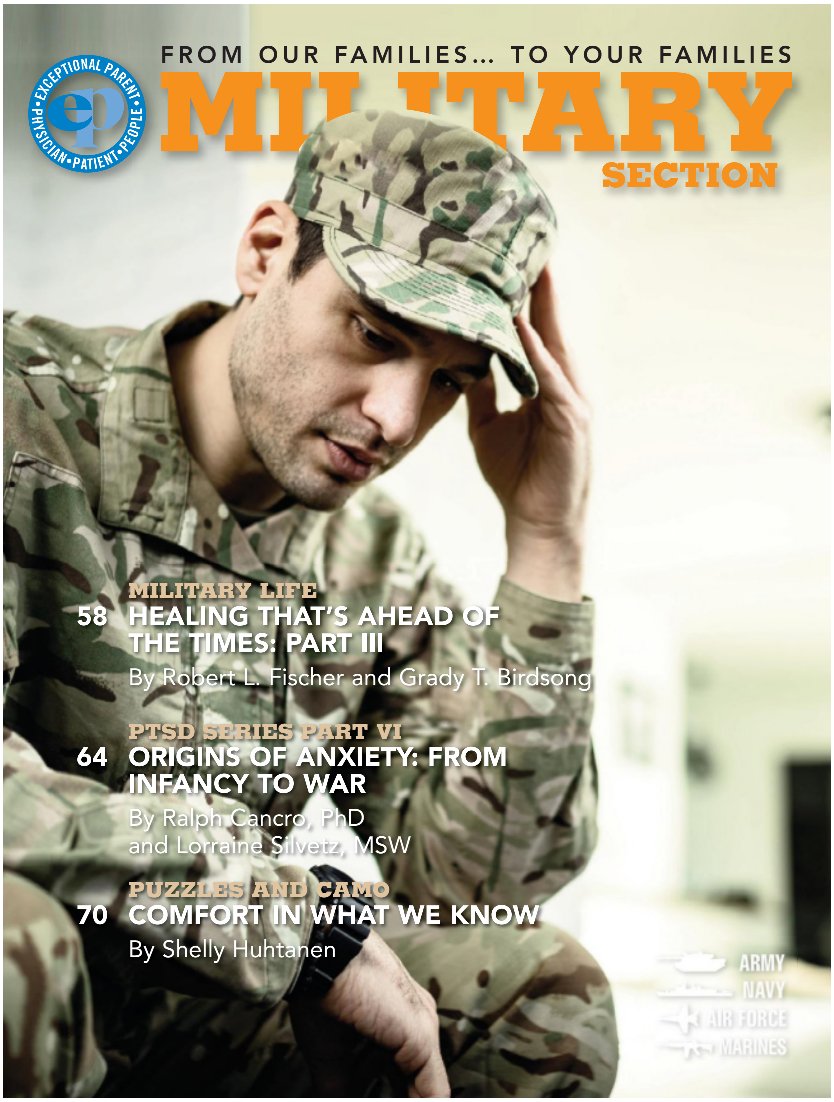
CONTENTS

AUGUST 2022 VOLUME 52 ISSUE 8

DEPARTMENTS

MILITARY SECTION





The contents of *EP Magazine*'s Military Section are not necessarily the official views of, or endorsed by, the United States Government, the Department of Defense, or the Department of the Army. The appearance of advertising adjacent to the Military Section does not constitute endorsement by the United States Government, the Department of Defense, or the Department of the Army of the products or services advertised.

HELPING YOU COMBAT COVID-19

BANTEC SANITIZING

COMMERCIAL AND RESIDENTIAL CLEANING PRODUCTS & SERVICES

Bantec Sanitizing is your ally in the fight against Covid-19. With efficient and affordable solutions for cleaning and safely sanitizing residential, school and business settings, Bantec Sanitizing can help you prepare for living, learning and working in a safe and healthy environment.

HOME

SCHOOL

OFFICE

Bantec Sanitizing offers a wide selection of industry-leading products for all of your sanitizing needs. In addition, we are introducing groundbreaking technological innovations that can be custom tailored for your particlar specifications. Visit **bantec.store/pages/bantec-sanitizer-service** for more information.

Our products are easy for anyone to use in multiple environments to protect themselves by disinfecting surfaces they encounter throughout the day.

CLEANING PRODUCTS
www.bantec.store/collections/all

Our service provides the safest, most environmentally friendly hygiene strategy. Easy to use and implement while being efficient and cost effective.

CLEANING SERVICES
www.bantec.store/pages/bantec-sanitizer-service

EXCLUSIVE OFFER!

BANTEC DISINFECTING KIT

Easy for anyone to use in multiple environments to protect themselves by disinfecting touch surfaces they encounter throughout the day. Perfect for use between cleanings. Featuring Enviro-Pro ® products which meet the EPA's criteria for use against the novel coronavirus. Each kit contains:

- 3 gallons CleanSmart Enviro-Pro
- 1 1 oz. dispensing pump
- 1 1/8 oz. dispensing pump
- 2 each 32-oz. Enviro-Pro labeled spray bottles
- 2 each spray bottles triggers
- 1 box of disposable gloves
- 1 pack of 12 machine washable microfiber cloths
- 2 each disposable, non-medical face masks
- 1 pack disposable dusting sheets
- Directions, tips and more.

www.bantec.store/products/bantec-disinfecting-kit

**Bantec Sanitizing is committed to providing their customers the most comprehensive cleaning products and services that are safe, environmentally friendly, easy to use, efficient and affordable.
Contact us today!**

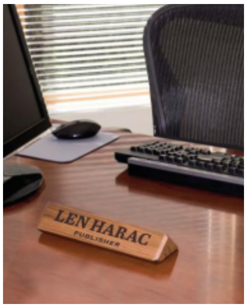
A DIVISION OF
BANTEC

HELPING YOU COMBAT COVID-19
BANTEC SANITIZING

www.bantec.store

To Your Health

Our Annual Healthcare Issue contains thoughtful pieces on sensory integration therapy, holistic approach interventions, and traumatic brain injury treatments – and much more.



Every August, *EP Magazine* presents its Annual Healthcare Issue, featuring educators, researchers, specialists and medical professionals who deliver topical news, advice and a wide range of general information to our audience in the special needs community. This edition contains thoughtful pieces on sensory integration therapy, holistic approach interventions, and traumatic brain injury treatments. You will also find helpful articles on establishing effective hygiene routines, guidance on maintaining Medicaid coverage, and attaining disability competent healthcare.

In addition, this issue offers a special section highlighting the topic of genetic disorders, including an interesting examination of emerging developments in newborn screening technology.

> "The wonderful Lily D. Moore caught up with our Editor in Chief Faye Simon for this issue's exclusive interview."

Also this month, we are very pleased to introduce our readers to the wonderful Lily D. Moore, a hard working and talented 19-year-old actress and advocate, who, along with her mom Natalie, caught up with our Editor in Chief Faye Simon for this issue's exclusive interview. You will be very impressed as this charming young woman, soon to be a freshman at Clemson University, discusses her achievements in movies, modeling, and charitable missions. Lily can truly inspire all of us to "find our inner star."

EP is also very proud to present two new contributors to our publication whose unparalleled knowledge and experience in the fields of law and finance will be invaluable to our audience. Both Beth C. Manes, Esq. and Joshua Fishkind, J.D., MBA offer a well informed way forward to families seeking financial advice and careful estate planning. We welcome their helpful and practical articles this month and look forward to many more in the future!

We would like to remind our readers that we are always interested in your comments, input and feedback as it pertains to all aspects of the publication. *EP Magazine* is intended to be an open forum for all members of our community; please submit all correspondence to Faye Simon at **epmagazinevp@gmail.com.**

EP is experiencing a sustained period of growth and new interest, as more and more members of the special needs population learn about our publications and digital presence. To find out more about our unique sponsorship opportunities and the great value in our advertising rates, contact *EP Magazines*'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

VOLUME 52 ISSUE 8
ESTABLISHED 1971

Publisher
Len Harac
lharac@epmagazine.com

Editior In Chief
Faye Simon
fsimon@epmagazine.com

Art Direction & Design
Leverett Cooper
lev@foxprintdesign.com

Subscriber Services
1360 Clifton Avenue, Ste. 327, Clifton, NJ 07012
www.epmagazine.com

Customer Service/New Orders
Faye Simon fsimon@epmagazine.com
(973) 726-6218

Publishing & Editorial Office
1360 Clifton Avenue, Ste. 327
Clifton, NJ 07012

EXCEPTIONAL PARENT MEDIA

Exceptional Parent (ISSN 0046-9157) is published monthly 12 times per year including the special January EP Guide - Navigating Special Needs Resources by Exceptional Parent Magazine, 1360 Clifton Avenue, Ste. 327, Clifton, NJ 07012 Internet address: www.epmagazine.com. All rights reserved. Copyright ©2022 by Exceptional Parent Magazine,. Exceptional Parent™ is a registered trademark of Exceptional Parent Magazine. Postmaster: Please send address changes to: Exceptional Parent,1360 Clifton Avenue, Ste. 327, Clifton, NJ 07012. Any applicable periodical postage paid at Clifton, NJ and additional mailing offices (USPS 557-810). Basic annual subscription for EP Digital is free. Limited edition print subscription $95.00. Subscriber Service: Direct all inquiries & address changes to: Exceptional Parent, 1360 Clifton Avenue, Ste. 327, Clifton, NJ 07012 08758. Customer Service/New Orders: E-mail: fsimon@epmagazine.com or call (973) 726-6218. Back issues incur a charge of $10.50 each with shipping, (January issue $12:50 when requested) and depend upon availability. Call (973) 726-6218. Agreement #1420542

WHAT'S HAPPENING

DOT INTRODUCES BILL OF RIGHTS ENSURING A BETTER FLYING EXPERIENCE FOR PEOPLE WITH DISABILITIES

As the busy summer travel season continues, U.S. Transportation Secretary Pete Buttigieg announced actions taken by the U.S. Department of Transportation (USDOT) to help protect airline passengers. USDOT has published the first-ever Airline Passengers with Disabilities Bill of Rights and issued a notice to airlines to seat young children next to a parent.

FLY RIGHT: The DOT has announced actions taken to help protect airline passengers and has published the first-ever Airline Passengers with Disabilities Bill of Rights

"Today's announcements are the latest steps toward ensuring an air travel system that works for everyone," said U.S. Transportation Secretary Pete Buttigieg. "Whether you're a parent expecting to sit together with your young children on a flight, a traveler with a disability navigating air travel, or a consumer traveling by air for the first time in a while, you deserve safe, accessible, affordable, and reliable airline service."

These announcements come at a time when consumer complaints against airlines are up more than 300% above pre-pandemic levels. The actions announced by the Department include publishing the first-ever Bill of Rights for Airline Passengers with Disabilities:

The Airline Passengers with Disabilities Bill of Rights, an easy-to-use summary of the fundamental rights of air travelers with disabilities under the Air Carrier Access Act, will empower air travelers with disabilities to understand and assert their rights, and help ensure that U.S. and foreign air carriers and their contractors uphold those rights. It was developed using feedback from the Air Carrier Access Act Advisory Committee, which includes representatives of passengers with disabilities, national disability organizations, air carriers, airport operators, contractor service providers, aircraft manufacturers, wheelchair manufactures, and a national veterans organization representing disabled veterans. The Bill of Rights provides a convenient, easy-to-use summary of existing law governing the rights of air travelers with disabilities.

The 10 protected rights include: the right to be treated with dignity and respect, the right to receive information about services and aircraft capabilities and limitations, the right to receive information in an accessible format, the right to accessible airport facilities, the right to assistance at airports, the right to assistance on the aircraft, the right to travel with an assistive device or service animal, the right to receive seating accommodations, the right to accessible aircraft features, and the right to resolution of a disability-related issue.

Wheelchair damage and loss are frequent occurrences in airports these days. *The Washington Post* reported in July 2021 that the largest U.S. airlines have lost or damaged more than 15,000 wheelchairs or scooters since they were required to start reporting those numbers to the government at the end of 2018.

Kurt Fearnley, an Australian wheelchair racer and paralympian, tweeted last week that a fellow athlete's chair went missing during a trip to Atlanta.

"A mate arrived in Atlanta a week ago. No race chair. No day chair. That means no life for the week," he tweeted.

The Transportation Department said that information in the document applies to all flights run by U.S. airlines as well as flights to or from the U.S. that are operated by foreign carriers. Federal officials note that there are some exceptions to airlines' obligations as described in the bill of rights in order to comply with safety and security laws and in cases where airlines have been approved to use an alternative method to comply.

While the bill of rights doesn't provide new rights for disabled travelers, it does make the ACAA more accessible to passengers. It condenses lengthy regulations into a more easily digestible format — one that disabled people can print out and reference during a trip.

WHAT'S HAPPENING

DOJ COMMEMORATES THE 32ND ANNIVERSARY OF THE AMERICANS WITH DISABILITIES ACT

FACING HURDLES: To prevent discrimination against people with disabilities, the ADA sets out requirements that apply to many of the situations you encounter in everyday life. Employers, state and local governments, businesses that are open to the public, commercial facilities, transportation providers, and telecommunication companies all have to follow the requirements of the ADA.

On July 26, 2022, the Department of Justice commemorated the 32nd anniversary of the Americans with Disabilities Act (ADA), the preeminent civil rights law requiring equal opportunity for people with disabilities. Recently, the ongoing COVID-19 pandemic and the opioid epidemic have exacted a steep toll on many people with disabilities and shed light on the continued urgency of ADA enforcement.

"The Americans with Disabilities Act embodies a national promise to eliminate discriminatory barriers and support full participation, community integration, independent living and economic self-sufficiency for people with disabilities," said Assistant Attorney General Kristen Clarke of the Justice Department's Civil Rights Division. "We will continue using this bedrock civil rights law to eliminate barriers and safeguard the rights of people with disabilities across the country."

PROMOTING WEB ACCESSIBILITY

The COVID-19 pandemic has shown, for example, the vital importance of equal access to the web. This year, the department published guidance on the ADA requirements for website accessibility and announced it is also undertaking a rulemaking concerning standards for web accessibility for state and local government entities. The department's enforcement efforts have removed barriers that prevented people with disabilities from booking vaccine appointments on the web and finding critical vaccine information. Since November 2021, the department has reached settlement agreements with CVS Pharmacy Inc., Hy-Vee Inc., The Kroger Co., Meijer Inc. and Rite Aid Corporation to ensure that people with disabilities can book COVID-19 vaccine appointments and obtain vaccine information online.

WARNING ABOUT THE RISKS OF ARTIFICIAL INTELLIGENCE IN HIRING

The department has also prioritized ensuring that state and local government employers do not use new technologies to discriminate against job applicants or employees with disabilities. In May, the department, partnering closely with the Equal Employment Opportunity Commission, issued guidance about disability discrimination when employers use artificial intelligence and other software tools, including algorithmic decision-making tools, to make employment decisions.

ENSURING FAIR TREATMENT OF PEOPLE WITH OPIOID USE DISORDER

The department has also enforced the ADA to safeguard the rights of people with opioid use disorder (OUD) who are in treatment or recovery. In April, the department published guidance explaining how the ADA protects individuals with OUD from discrimination. The department is working to ensure that people in treatment and recovery have an equal opportunity to receive services and to participate in their communities and the workforce. For example:

- *In February, the department filed a lawsuit against the Unified Judicial System of Pennsylvania, alleging that it prohibits or otherwise limits participants in its court supervision programs from using medication for OUD. And in March, the department entered into a settlement agreement to resolve similar allegations concerning Massachusetts' drug courts.*
- *The department also issued a letter finding that the Indiana State Board of Nursing violated the ADA by denying a nurse the opportunity to participate in a rehabilitation program, required to reinstate her nursing license, because she takes medication for OUD.*
- *The department secured a settlement agreement with a Colorado-based employment, residential and social services program resolving allegations that the program denied admission to an individual because she takes medication for OUD.*

PROMOTING ACCESS TO TRANSPORTATION INCLUDING RIDESHARING SERVICES

After filing a lawsuit in November, the department entered into a multi million-dollar settlement agreement with Uber Technologies Inc. Under the agreement, Uber committed to policy changes and will offer several million dollars in compensation to more than 65,000 Uber users who were charged discriminatory fees due to disability.

FIGHTING SEGREGATION AND CRIMINALIZATION OF PEOPLE WITH DISABILITIES

Finally, the department continues to prioritize enforcement of the Supreme Court's decision in *Olmstead v. L.C.*, a landmark case ruling that the ADA prohibits unnecessary segregation of people with disabilities. The department's enforcement of *Olmstead* has enabled thousands of people with disabilities to live in their homes and communities instead of in institutions. For example:

- *In June, the department issued a letter finding that Maine unnecessarily institutionalizes children with mental health or intellectual and developmental disabilities in psychiatric hospitals, residential treatment facilities and a juvenile justice facility. In March, the department issued a letter finding that Colorado unnecessarily segregates adults with physical disabilities in nursing homes.*

> ***"The DOJ's enforcement of Olmstead v. L.C. has enabled thousands of people with disabilities to live in their homes and communities instead of in institutions."***

- *The department also launched statewide Olmstead investigations in response to complaints. In May, the department opened an investigation into whether Kentucky unnecessarily segregates people with serious mental illness in the Louisville/Jefferson County Metro area in psychiatric hospitals and places them at risk of law enforcement encounters. The department is also investigating the Louisville/Jefferson County Metro Government and the Louisville Metro Police Department concerning their systems for responding to people experiencing behavioral health crises.*

For more information about the ADA, please visit **ada.gov** or call the department's toll-free ADA information line at 800-514-0301. For more information on the Civil Rights Division, please visit **justice.gov/crt**

ABOUT THE AMERICANS WITH DISABILITIES ACT

ADA
Americans with Disabilities Act

The Americans with Disabilities Act (ADA) is a federal civil rights law that prohibits discrimination against people with disabilities in everyday activities. The ADA prohibits discrimination on the basis of disability just as other civil rights laws prohibit discrimination on the basis of race, color, sex, national origin, age, and religion. The ADA guarantees that people with disabilities have the same opportunities as everyone else to enjoy employment opportunities, purchase goods and services, and participate in state and local government programs. Learn more at **ada.gov**

WHAT'S HAPPENING

'SO RUDDERLESS': COUPLE'S QUEST FOR AUTISM TREATMENT FOR SON HITS REPEATED OBSTACLES

BY MICHELLE ANDREWS

When Sebastian Rios was a toddler, he hardly talked. "Don't worry," his pediatrician told Amparo and Victor Rios, Sebastian's parents. Kids who grow up in households in which both Spanish and English are spoken are sometimes slower to develop language skills, she said.

Plus, Sebastian was developing well in other ways: When he was just 18 months old, for example, he could identify the magnetized letters of the alphabet on the refrigerator at their home in Bronxville, a short train ride north of New York City.

But by the time Sebastian was a little over 2 years old, his skills weren't keeping up with those of other kids his age: He spoke only simple words, like "mama" and "dada," and had problems interacting with people, Amparo Rios said. He didn't know how to play with other kids and didn't care about showing people his toys or sharing them. He made eye contact less and less.

The Rioses worried their son might have autism but didn't know how to get a definitive diagnosis for his lagging skills or how to get him help.

HARROWING JOURNEY: The Rios family discovered that getting an autism diagnosis and any subsequent help can be a long, winding, nerve-wracking, and sometimes costly road. Parents can wait months for appointments with a developmental pediatrician or other specialists.

One in 44 children have been diagnosed with autism spectrum disorder by age 8, according to federal estimates. It is a developmental disability that affects people's social and communication skills and their behavior to varying degrees. About a third of children with autism have intellectual disabilities as well, according to the federal Centers for Disease Control and Prevention.

As awareness of the autism spectrum has grown, new diagnostic criteria that cover milder forms of the disability have helped draw attention to the needs of children, like Sebastian, who may benefit from ongoing treatment and need significant support to go to school and participate in activities like sports.

Autism can't be diagnosed with a blood test or scan. Instead, professionals generally rely on in-depth interviews with parents or caregivers about a child's development, as well as evaluations of a child's behavior during one-on-one sessions. Those may require out-of-pocket payments as insurance companies impose stricter coverage standards. Parents can wait months for appointments with a developmental pediatrician or other specialists.

"There are significant provider shortages, especially with the number of children who are diagnosed or suspected to have autism these days," said Kelly Headrick, senior director of state government affairs and grassroots advocacy at Autism Speaks, a research and advocacy organization.

As a result, the Rioses discovered, getting a diagnosis and any subsequent help can be a long, winding, nerve-wracking, and sometimes costly road.

Although parents may notice developmental problems during a child's first 18 to 24 months, children aren't diagnosed with autism, on average, until they are more than 4 years old, studies show. That means missed opportunities for intervention: Research shows that early treatment of autism leads to better outcomes.

Eager to get help for Sebastian, the Rioses asked their pediatrician for help when their son was 2. The doctor referred them to their school district, so Sebastian could be assessed for special education services. But he was too young for the district to help.

The Rioses learned that children under age 3 need to connect with services through the federally mandated early intervention program that requires states to provide services to children with developmental delays or disabilities.

The family waited more than three months for the battery of tests and appointments to be completed, and the gap between Sebastian's development and that of other kids his age continued to widen. In addition to his language and social developmental delays, he struggled with imaginative play and was intensely self-directed, focused completely on what he wanted to do when he wanted to do it.

Although the staff members of the early intervention program didn't have the specialized skills necessary to provide a medical diagnosis, they recommended Sebastian begin occupational therapy, speech therapy, and applied behavior analysis, a widely used

ILLUSTRATION COURTESY OONA TEMPEST / KHN

technique in which therapists work intensively with children who have autism using positive reinforcement to achieve goals related to communication, learning, motor, and other skills. For example, a therapist might encourage a child to play a game the therapist has chosen before playing the game the child prefers. If the child does that, he might be praised by the therapist or get something else he values, like a toy or playground time.

The early intervention program paid for someone to go to the Rioses' home six hours a week to do ABA therapy. But Amparo Rios said the therapist didn't focus on Sebastian's problem areas, such as transitioning from one activity to another without having a meltdown, so she wanted a different ABA therapist.

The Rioses had health coverage through a plan administered by Trustmark, which set coverage policies in consultation with Amparo Rios' employer, a local college. But Sebastian needed a medical diagnosis of autism from a provider the plan considered a qualified clinician before it would pay for ABA therapy – a diagnosis Sebastian still didn't have at age 3. At about this time, the Rioses noticed their son was "stimming," shorthand for self-stimulating behavior, often repetitive movements or sounds that help calm or comfort people with autism. In Sebastian's case, he made grunting noises.

> ***"Trustmark refused to pay for the ABA therapy, and in February the Rioses discontinued it. Now they're facing more than $11,000 in bills for the sessions. Without the therapy, their son's progress is slipping."***

Since there is no single standardized test required to diagnose the condition, providers use different tools — some of which specific insurers will not accept.

The family took Sebastian to a neurologist for an exam, but she said she wasn't sure he had autism. "We felt so rudderless," Amparo said. "We didn't know who to turn to to diagnose him or figure out what was wrong with him."

Six months later, in September 2020, the family found a clinical psychologist who specialized in autism spectrum disorders and was in their provider network. She tested Sebastian over three months, evaluating his cognitive abilities and his capacity to attend to tasks, follow directions, and pay attention, among other things. The pandemic slowed medical care to a crawl, and in May 2021 she finally diagnosed Sebastian, then 4, with Level 1 autism spectrum disorder, the least limiting form, and recommended he again begin ABA therapy.

The delay cost Sebastian. His stimming behaviors got worse, and he made eye contact with others less frequently. "We had very mixed feelings about the diagnosis," said Amparo. "It was a relief that we had a diagnosis we could rely on for medical care. But it was mixed because as parents we didn't know what he would grow up to be."

Two years after the Rioses noticed their son's atypical behaviors, they enrolled him in individual ABA therapy for 15 hours a week at a center near their home. It felt like the pieces were finally falling into place. Sebastian's language skills were getting better because of speech therapy, but he was very self-directed and still not good at making eye contact. He sometimes wandered off on his own, a terrible safety risk, and couldn't use the bathroom by himself.

Amparo's health plan administrator, Trustmark, confirmed that ABA therapy was covered, with a copayment of $25 per session.

It was tough for Sebastian at first, Amparo said, as he worked with a therapist to learn how to be less rigid and less focused on doing only what he wanted to do. But he gradually got better at skills like making eye contact and using the bathroom on his own.

The relief was short-lived.

In September, the Rioses started getting notices from the health plan administrator saying it wouldn't pay for the therapy because it wasn't medically necessary. Unfortunately, the therapist who had provided the diagnosis hadn't screened Sebastian using the Autism Diagnostic Observation Schedule (ADOS-2), a highly regarded test.

Sebastian's developmental pediatrician sent a letter to the health plan explaining the need, and the ABA therapy provider sent clinical notes from Sebastian's sessions.

It didn't work. Trustmark refused to pay for the ABA therapy, and in February the Rioses discontinued it. Now they're facing more than $11,000 in bills for the sessions. Without the therapy, their son's progress is slipping, Amparo said. He's stimming more and has been distracted and disruptive in his kindergarten class, needing constant reminders to stay focused.

Trustmark declined to comment for this article.

"It's just really frustrating" for parents, Amparo said, "but ultimately it's very sad for my son."

The Rioses appealed the denial but lost. An independent reviewer found in May that the ABA services weren't medically necessary and questioned whether Sebastian had autism. He noted that Sebastian hadn't been screened using the ADOS-2 test and said he needed it.

It was the last straw. Amparo quit her job, and the family switched their health coverage to her husband's plan. They began a new assessment process for Sebastian, now 5. They paid $500 to a provider to administer the ADOS-2 test, which confirmed his autism diagnosis in June. Now, three years after starting the search for help, they're trying to enroll Sebastian in ABA therapy again using the new health plan's coverage.

"You want your child to be assessed as early as possible to get as much help as possible," Amparo said. "This is a critical time in his development, and I just feel beaten down."

KHN (Kaiser Health News) is a national newsroom that produces in-depth journalism about health issues. Together with Policy Analysis and Polling, KHN is one of the three major operating programs at KFF (Kaiser Family Foundation). KFF is an endowed nonprofit organization providing information on health issues to the nation.

ABOUT THE AUTHOR:

Michelle Andrews is a contributing writer and former columnist for KHN. She has been writing about health care for more than 15 years. Her work has appeared frequently in The New York Times, where she wrote the Money and Medicine column and contributed regular news and features. Her work has also been published in Money, Fortune Small Business, National Geographic and Women's Health magazines, among others. Michelle previously worked as a senior writer at U.S. News & World Report and at SmartMoney magazines. She has a bachelor's degree from the University of Wisconsin and a master's in journalism from Columbia University.

WHAT'S HAPPENING

STUDY SHOWS CHANGES IN BRAIN'S VISUAL AREAS IN INFANCY MAY PRECEDE AUTISM DIAGNOSIS

Infants who were diagnosed with autism spectrum disorder (ASD) at 24 months old had differences in the visual processing areas of the brain that were apparent at 6 months old, according to a study funded by the National Institutes of Health.

The American Journal of Psychiatry

NEW CLUES: According to a new study, babies who were diagnosed with autism spectrum disorder at 24 months had differences in the visual processing areas of the brain at 6 months old.

The researchers theorized that disruption in visual processing could interfere with how infants see the world around them, changing how they interact with and learn from caregivers and their environment. These early changes could affect further brain development and play a role in ASD symptoms.

The study was conducted by Jessica Girault, Ph.D., of the University of North Carolina School of Medicine, Chapel Hill, and colleagues.

The study enrolled 384 pairs of siblings, the oldest of which had been diagnosed with ASD. Previous research by the team found that younger siblings were more likely to develop ASD if their older siblings had higher levels of ASD traits. Researchers performed Magnetic Resonance Imaging scans on the brains of the younger siblings at 6, 12 and 24 months of age.

Among the 89 younger siblings who developed ASD, those whose older siblings had severe ASD traits had greater volume and surface area of the cerebrum, which controls speech, thought, emotions, reading, writing, and learning; larger surface area in the part of the visual cortex important for recognizing objects; and less mature connections in the splenium, which connects the brain's left and right visual cortices and plays a role in visual attention.

NIH funding was provided by the Eunice Kennedy Shriver National Institute of Child Health and Human Development, National Institute of Mental Health, and National Institute of Neurological Disorders and Stroke.

The article, "Infant Visual Brain Development and Inherited Genetic Liability in Autism" appears in the *The American Journal of Psychiatry.* May 2022 issue. **ajp.psychiatryonline.org/doi/full/10.1176/appi.ajp.21101002?af=R.** •

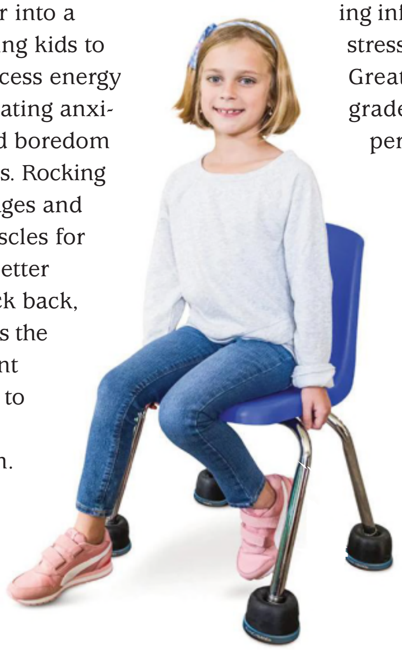
WHAT'S NEW READY TO LEARN

FEELINGS IN A FLASH EMOTIONS FLASHCARDS

Developing a strong and nuanced vocabulary of feeling words in children at a young age provides them with the tools necessary to properly label and express emotions. This set of 100 flashcards includes 50 open-ended scenario cards that ask children how they would feel in a certain situation, plus 50 emotion face cards. Each emotion face card features a list of practical coping suggestions to guide positive behavior and decision-making skills. The face cards also offer strategies for expressing and/or coping with the emotions. Cards measure 2-1/2 x 3-1/2". Perfect for counselors, teachers and parents. Ages 6 +.

UNITED ART AND EDUCATION
www.unitednow.com

WIGGLE WOBBLE CHAIR FEET



The Wiggle Wobble Chair Feet convert a standard school chair into a Wobble Chair; enabling kids to have an outlet for excess energy while working, alleviating anxiety, hyperactivity and boredom while increasing focus. Rocking in all directions engages and strengthens core muscles for stronger backs and better posture. Kids can rock back, forth and all around as the continuous movement increases blood flow to the brain enabling greater concentration. Continuous movement helps fidgety kids to expel excess energy and is a calming influence while seated, reducing stress and increasing time on task. Greater focus leads to higher grades and improved academic performance. This set of four feet is easy to install and do not require any tools – just snap right onto a standard round school chair glide (measuring between 1.125 and 1.25 inches in diameter), turning the seat into a Wobble Chair. Wiggle Wobble Chair Feet can be used on tile, wood and carpeted floors. Ages 5 +.

SCHOOL SPECIALTY
www.schoolspecialty.com

TIME TRACKER VISUAL TIMER

This visual timer and clock helps children learn to manage play time, homework, music practice sessions, independent reading – even time outs. It features unique light and sound cues to help keep tasks on track. Colored lights and sound effects can be quickly programmed to alert children of the time remaining. Easily program green, yellow and red sections and six sound effects to indicate that time is running out. Perfect for study sessions, tests, practice sessions, hearing impaired, projects, experiments, classroom assignments and more! Ages 5 +.

FUN AND FUNCTION
www.funandfunction.com

SENSY BAND

This amazing wearable sensory band is a great, stylish and discreet fidget. Soothing textured silicone is the secret behind Sensy Band's ability to calm and focus the mind. The bright orange band is easy to "slap" on and take off and adjusts to any wrist size. When not worn, Sensy Band is fun and satisfying to bend and curl. The soft silicone bristles are irresistible to the touch. Sensy Band makes the perfect travel gift and is great for tactile st.imulation and anxiety. Ages 5 + . up

AUTISM COMMUNITY STORE
www.autismcommunitystore.com

AN EXCERPT FROM

THE FLUENCY BUILDERS TEACHER TOOLKIT

RELATED TO THE HEREDITARY COMPONENT OF DYSLEXIA AND HISTORY OF EARLY LANGUAGE DELAY

BY GEORGIE NORMAND, M.A.

THE RIGHT TOOL: The Fluency Builders Digital Kit contains the Teacher Toolkit, which presents the foundational research for the program and teacher resources, including video.

FAMILY HISTORY OF READING DIFFICULTY

The Fluency Builders Dyslexia Screener first collects information as to whether there is a family history of either parent having had reading problems (or a confirmed diagnosis of dyslexia) and/or a child history of early language delay. This information may help to substantiate other information acquired through the screening.

A family history of dyslexia is known to be a predictor of literacy outcome from the preschool years (Thompson, Hulme, Nash, Gooch, Hayiou-Thomas, & Snowling, 2015, p. 976; Gaab 2017). In fact, dyslexia occurs in up to 50% of individuals who have a first degree relative (parent or sibling) with dyslexia (Pennington, 1991). While the family history risk factor is most significant when one or both parents, or one or more siblings have a history of dyslexia, even an aunt, uncle, or grandparent with dyslexia presents as a risk factor for the student.The risk and severity is greater when both parents are affected (Wolff & Melngailis, 1994).

AN EP FOCUS ON GENETIC DISORDERS

STUDENT HISTORY OF EARLY LANGUAGE DELAY

In the case of a young child, the parents should be asked whether s/he has ever been diagnosed with an early language delay. When one or both of these risk factors (family history of dyslexia and/or early language delay) are identified in a 5-year-old child, this child is at risk for dyslexia (Raschle, et al., 2015). This information is just as important when an older student is being screened. •

Coming in EP's September Back to School issue: ***Georgie Normand's Dyslexia by Grade Level***

References

Thompson, P.A., Hulme, C., Nash, H.M., Gooch, D., Hayiou-Thomas E., & Snowling, M.J. (2015). Developmental dyslexia: predicting individual risk. Journal of Child Psychology and Psychiatry, 56(9), 976-987.

Gaab, N. (2017). It's a myth that young children cannot be screened for dyslexia. Baltimore, MD: International Dyslexia Association. https://dyslexiaida.org/its-a-myth-that-young-children-cannot-be-screened-fordyslexia/

Pennington, B.F. (Ed.) (1991). Reading Disabilities: Genetic and Neurological Influences. Kluwer.

Wolff, P.H., & Melngailis, I. (1994). Family patterns of developmental dyslexia: Clinical findings. American Journal of Medical Genetics, 54(2), 122-131.

Raschle, N.M., Becker, B.L.C., Smith, S., Fehlbaum, L.V., Wang, Y., & Gaab, N. (2017). Investigating the influences of language delay and/or familial risk for dyslexia on brain structure in 5-year-olds. Cerebral Cortex, 27(1), 764-776.

ABOUT THE AUTHOR:

Georgie Normand, M.A. holds a Master's degree in Reading Education and has spent many years working with students with dyslexia. She is the founder of Early Literacy Solutions and the author of the Orton-Gillingham based Fluency Builders Dyslexia Program (**www.earlyliteracysolutions.com**). Designed for parents, tutors, and teachers, the Fluency Builders program utilizes the latest neuroscience in dyslexia. These new studies found that dyslexia is not a one-size-fits-all learning disability. Georgie has also developed the Certified Dyslexia Practitioner Program, a professional learning program that trains teachers and tutors to identify and succeed with multiple dyslexia profiles.

QUICK & EASY

NEW!

No More Embarrasing Mess!

P-GUARD BENEFITS:

- Keeps urine in the bowl where it belongs
- Keeps urine from getting on the floor and clothes
- Keeps toilet and bathroom clean and fresh
- Mild Fresh Linen scent is a pleasant addition to any bathroom
- Unique design looks sleek, like it is part of the toilet seat
- Totally hidden when seat is down
- Innovative design makes it easy to install and replace
- Easy to clean • Saves time • Disposable • Made in USA!
- Creates a much more sanitary environment for your loved ones
- Perfect for special needs or elderly family members

1. Peel the adhesive backing

2. Press into place under seat

3. Enjoy a more sanitary bathroom

Check out our informative video HERE

MADE IN THE USA

www.sweethomeventures.com

610-457-8596 | contact@sweethomeventures.com

Sweet HOME VENTURES
A Family Owned Company

ADVANCING NEWBORN SCREENING FOR RARE GENETIC DISEASES

Researchers, Industry, and Patient Advocacy Groups are Driving Efforts to Facilitate Early Diagnosis and Improve Babies' Long-term Outlook

BY CATHERINE A. NESTER, BSN

Newborn screening is unquestionably one of the most significant innovations in pediatric health. As screening panels become more sophisticated and incorporate a broader range of rare genetic diseases, they are helping more families in facilitating early diagnosis of their babies' conditions and in charting a course for survival and long-term health.

AN EP FOCUS ON GENETIC DISORDERS

Yet, despite the continuing evolution of newborn screening, some would argue that the evolution isn't happening fast enough. That is because it takes a lot of time, money, and effort to get a genetic disease added to a newborn screening panel. Additionally, screening panels may vary considerably from state to state, with certain conditions included in some states' panels, but not in others.

Consequently, if your family has a child living with a rare genetic disease, and if that disease happens to be on your state's screening panel, that is excellent news for you. It eases your family's diagnostic odyssey and allows your child to access treatment sooner. However, a number of rare diseases are still not included in screening panels, a limitation that leaves many families out in the cold.

Fortunately, there has been a growing recognition in recent years of the impact of rare genetic diseases, and of the need for improvement in newborn screening programs. That recognition has been accompanied by the development and introduction of numerous innovative therapies for rare diseases. However, if a family cannot access a therapy for their child's disease, that therapy is essentially useless to them. That conundrum encapsulates the challenge of connecting families to promising treatments, which is the key to improving long-term survival and clinical outcomes for patients.

HARNESSING THE POWER OF PARENTS AND ADVOCACY GROUPS

I feel fortunate to work for a company that is developing therapies for rare mineralization disorders, and that works closely with patient communities and advocacy groups to raise awareness of these diseases. A major focus of our efforts is on decreasing the time to diagnosis for babies and young children with ENPP1 Deficiency and ABCC6 Deficiency. These are disorders in which the infant mortality rate is 50% at six months of age, but the time to diagnosis can take many years. Including those disorders in newborn screening panels would significantly shorten families' diagnostic and therapeutic journeys, because it would allow babies to be diagnosed immediately at birth, and assuming there is an available treatment, to start therapy right away. That is the dream for all of us who advocate for people with rare diseases.

But it is not necessarily pharmaceutical and biotechnology companies, or even local health departments, that are securing the inclusion of rare diseases in newborn screening panels. If you look at the historical record of serious rare diseases added to screening panels, it is often because parents took up the charge. Indeed, parents of children with rare diseases tend to have the loudest and most effective voices in advocating for more advanced screening, faster diagnosis, and enhancing access to treatment.

To a great extent, change starts with raising awareness of a rare disease. Patient advocacy groups – many of them founded and led by parents of children affected by rare genetic diseases – have played an enormous role in enhancing public awareness of the impact of these disorders. GACI Global, a parent-led advocacy group, is just one example of the power of parents to raise awareness of a rare disease, shorten time to diagnosis, and hopefully find a treatment in the future.

PROGRESS THROUGH PARTNERSHIPS

For its part, the research community is increasingly looking toward biotechnology companies and patient advocacy groups as potential partners in efforts to facilitate the diagnosis of genetic diseases. An example is Inozyme Pharma's participation in the BeginNGS™ consortium, an initiative developed by Rady Children's Institute for Genomic Medicine, to evaluate a diagnostic and precision medicine guidance tool that incorporates rapid whole-genome sequencing to screen newborns for approximately 400 genetic diseases. The rapidity of sequencing is crucial to ensuring that infants with rare diseases can access treatment options, as quickly as possible. Such collaborations, therefore, hold great promise in scaling up advanced screening efforts, in a relatively short period.

Fundamentally, successful partnerships in the rare disease space are those that amplify the voice of the patient in research, development, and awareness-building. At Inozyme one of our most enduring partnerships is with GACI Global, which works on behalf of families affected by generalized arterial calcification of infancy (GACI) or hypophosphatemic rickets caused by ENPP1 or ABCC6 deficiencies. Our joint efforts with GACI Global have included collaborating on research publications and securing patient input into the design of our clinical trials. The partnership has reinforced the notion that if you do the right thing for the patient, all our other efforts tend to work themselves out.

> **"THERE HAS BEEN A GROWING RECOGNITION IN RECENT YEARS OF THE IMPACT OF RARE GENETIC DISEASES, AND OF THE NEED FOR IMPROVEMENT IN NEWBORN SCREENING PROGRAMS."**

HOPE FOR THE FUTURE

Despite the challenges inherent in securing the inclusion of rare genetic diseases in screening panels, I am incredibly optimistic about the future of newborn screening. If we can incorporate as many as a thousand diseases into screening panels, and if we can make these panels broadly accessible and widely used, that will change the game tremendously. We are years away from including that many diseases, but we are moving in that direction. The ability to find rare diseases will not only make a difference in children's lives; it will also allow families and patient advocates to tell biotech companies, "We can find this disease now, so you need to make an effort to find a treatment for it." That will be a fitting rejoinder to companies that claim, there is no reason to develop a drug if they can't identify patients who might benefit from it.

Additionally, widespread adoption of advanced newborn screening technologies may enable the discovery of new diseases we don't currently know about, due to the ability to rapidly sequence a broad range of samples. It may also give us a better understanding of the incidence and prevalence of rare diseases, and the ability to predict them due to certain mutations, possibly enabling the identification of specific sub-populations in which certain disorders are especially prevalent.

In the meantime, it remains vital for parents and patient advocates to continue raising awareness of rare genetic diseases, particularly those characterized by abnormal mineralization. A key reason why increasing numbers of doctors are familiar with ENPP1 and ABCC6 deficiencies, is that community members have been "making noise" about these disorders for years. In many cases their efforts are motivated by the loss of a child, but it shouldn't take a tragedy to effect meaningful change. Due to our work with communities affected by rare pediatric diseases, we commonly hear about the loss of babies, and every time the news is catastrophic, because the stories these families share give us a small sense of what they are going through. Their stories are what motivate us to try to save these babies and young children. To that end, the more noise families make, the more doctors will recognize these devastating diseases, and the sooner they can initiate therapeutic intervention. Advances in newborn screening may not end the cycle of sadness, but they can make a huge difference in children's and families' lives. That is what we are here for.•

ABOUT THE AUTHOR:

Catherine Nester, BSN is Vice President of Physician and Patient Strategies at Inozyme Pharma (**www.inozyme.com**) and is an accomplished leader in the biotech industry. With more than 25 years of clinical and pharmaceutical experience, Catherine previously served in leadership roles at Incyte and Alexion Pharmaceuticals.

ORGANIZATION SPOTLIGHT

BIG HEARTS, BIG ABILITIES : Lily Moore and Laura Whitaker, Big Hearts 2022 Pageant Emcees; Big Hearts is ESP's annual showcase event that shines a spotlight on the abilities of some of our community”s most big-hearted individuals while they leave their disability in the wings.

EXTRA SPECIAL PEOPLE, INC.

BY LAURA WHITAKER

ESP (Extra Special People Inc.) is a non-profit organization that exists to create transformative experiences for people with disabilities and their families, changing communities for the better.

In 1986 in Watkinsville, Georgia, ESP founder Martha Wyllie noticed a lack of opportunity for children with disabilities during the summer months, and she began ESP to provide one week of summer camp for only 21 participants. I entered as an 18-year-old college student volunteer and was captivated by this place of true belonging. A year later, Martha was diagnosed with pancreatic cancer and I took the helm as the director at the age of 19

Thirty-seven years into the organization's history, ESP continues to serve participants beginning at birth and with no upper age limit. Participants are welcomed with diagnoses of cerebral palsy, Down syndrome, autism, traumatic brain injury, spina bifida, and many more. At ESP, participants are never turned away because of their disability but rather celebrated for their ability. Our specialized programs enable our participants to experience activities that their neurotypical peers do and allows them to create meaningful and reciprocal relationships with volunteers, interns, and community members.

Since ESP's humble beginning, we have grown to now serve over 800 participants from over 30 counties in Georgia and fulfill our mission in three ways:

1. ***360*** *sparks connection through wrap around programs that enrich the lives of people of all abilities and their families. These include year-round enrichment programs offered in the fall and spring, as well as family support.*
2. ***Java Joy*** *is an ESP program that employs adults with disabilities and spreads unmatched joy as people of all abilities experience moments of engagement at a mobile coffee cart. Located in Athens, Atlanta, and Rome, GA, Java Joy is an extension of ESP's mission in the community, teaching businesses about engagement, inclusivity, and employing people of all abilities.*
3. *Empowered by ESP,* ***Hooray*** *welcomes people of all abilities and their families to a place of belonging where they experience boundless adventure. Hooray Day camps are offered in Athens and Rome, GA. Hooray's property in Jackson County represents ESP's dream of a 90-acre camp property, right outside of Athens, that will one-day become a universally-accessible camp. Here, anyone can spend the night on the top bunk, visit the dining hall with their friends of all abilities, and ride the zipline. It will also be a retreat and recreation park for families of all abilities, and a living laboratory for corporations to continue to learn about universal design and inclusion.*

IMAGES PROVIDED BY LAURA WHITAKER

A WORLD OF TALENT: *(Above, left)* A moment from the Big Hearts 2022 Talent Show; ESP showcases its deeply-rooted conviction that every person has abilities that are worthy of sharing and engaging with every corner of the community. *(Above, right)* Emcee Lily Moore takes the stage. "Celebrities, movie stars, NFL Players, ESPN analysts – none of them shined the way she did."

You see, ESP was founded for the children and young adults with disabilities, but then the mission was expanded to include people of all abilities. ESP began to serve the families, and extended then further to the thousands of volunteers and college students who are changed by the mission. Now, ESP is breaking barriers by engaging everyone in the beautiful exchange of what it looks like to live in a community of belonging.

One of the ways we began bringing the community into the conversation is through Northeast Georgia's most anticipated yearly event: Big Hearts. Big Hearts is ESP's annual showcase event that shines a spotlight on the abilities of some of our community's most big-hearted individuals while they leave their disability in the wings. ESP participants with all levels of ability become performers for the evening and show off their abilities in a fun-filled talent show. They are celebrated not for who they aren't but for who they are. What started in a high school auditorium in 2008, has grown to sell out Athens' Classic Center Theater and Conference Center with thousands in attendance each year

Along with the talent show, Big Hearts also hosts a Gala event where ESP supporters and community members come together for a night to watch ESP participants walk the red carpet, enjoy dinner and dancing, and support the ESP mission. This past year over a thousand people dressed to the nines in support, raising over $400,000.

The event requires months of planning, script writing, rehearsals, and celebrity wrangling. Events in the year 2020 challenged the question: is it worth it?

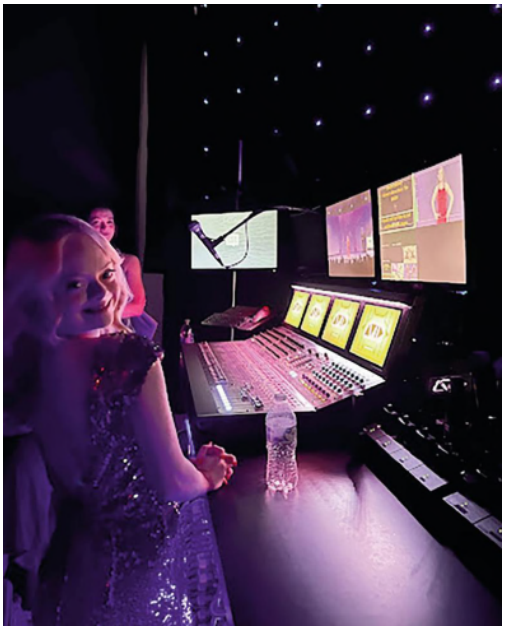
If we were going to carry on with the Big Hearts magic in spite of the pandemic, we needed to get creative, once again, and figure out how to translate our experience-based advocacy (and raise funds for our vital programs) to a screen in peoples' homes. In previous years, the emcees have mostly been celebrity football players and TV personalities; this year, we knew we needed to step up the game to appease watchers from home, and bring in national talent. That talent would include an introduction from Ryan Seacrest and participant interviews with Tom Holland. But more importantly, we needed to increase the engagement of our mission with those home screens. How could we continue to push the human connectedness of experiencing people of all abilities? We decided the dimension we needed was a participant emcee. As a public speaker myself, I wanted this experience to not only be of benefit to the audience, but for the participant we chose.

Ms. Lily Moore, a beautiful, well-spoken light of a teenager, began attending ESP programs at the age of 16. She was born as a natural performer, but she was also born with Down syndrome. If you know much about Down syndrome, you know that there are many beautiful characteristics that come along with the diagnosis. The CDC describes Down syndrome (**www.cdc.gov/ncbddd/birthdefects/downsyndrome.html**) as "a condition in which a person has an extra chromosome. Typically, a baby is born with 46 chromosomes. Babies with Down syndrome have an extra copy of one of these chromosomes, chromosome 21. Even though people with Down syndrome might act and look similar, each person has different abilities. People with Down syndrome usually have an IQ (a measure of intelligence) in the mildly-to-moderately low range and are slower to speak than other children."

ABOUT EXTRA SPECIAL PEOPLE, INC

esp

ESP exists to create transformative experiences for people with disabilities & their families, changing communities for the better. ESP envisions a world where every person, of every ability, in every community has universal access to transformative experiences. Learn more at **www.espyouandme.org**



OPPORTUNITY TO SHINE: *(Above, left)* Lily Moore and Laura Whitaker appear as Big Hearts 2021 Pageant Emcees; *(Above, right)* Lily waiting in the wings in 2022; "The Big Hearts event is a celebration of all big hearts – people labeled with a disability who have the opportunity to shine for their abilities, like Lily."

We approached Lily with an offer to be emcee for our Big Hearts Talent Show and Gala. Everyone was nervous; I was nervous – I hoped we could shine light on Lily. Most of her professional roles were completely scripted, while emceeing involved some set scripts and some impromptu gestures. Lily was excited but nervous, hoping to make ESP proud. I remember the numerous texts from her mom, with everyone working to ensure that Lily had every chance to be successful.

As Lily and I took the stage – hand in hand, girl to girl – both working to use our abilities to shine the spotlight on others, Lily and I found a deep bond under the lights of that stage and the stare of the camera. It was natural, it was beautiful. There were hiccups and redos. That is what made it successful. We were both human, real, not over-rehearsed, but a reflection of what we were created to be. Truth be told, I learned from Lily's stage presence and ability to capture an audience more than she learned from me. It would not have been an ESP experience any other way.

So, was it worth it? If you measure by the funds raised the last two years with Lily by our side? Yes. If you measure by the views from all over the country and every continent in the world? Yes.

But more importantly, what makes Big Hearts worth it is, whether on screen or in a banquet hall, that Big Hearts is expression of a human experience: love, belonging, and connection. Lily made that possible from screen to couch. Ability-focused living calls for all of us – disability or not – to look at ourselves and those around us with the ability filter. When we do this, remarkable things happen, connections are formed, and fears of differences melt away.

One of the most fascinating components of Big Hearts to me is that, at the end of it all, the people who make donations, buy tickets, and give so generously to help our organization run approached me and Lily and thanked us for the opportunity to be a part of something so special. You see, the Big Hearts event is a celebration of all big hearts – people labeled with a disability who have the opportunity to shine for their abilities, like Lily. In doing so, they offer perspective on life, joy, and the growth of each heart that is watching. In return, community members respond by giving back to the best of their ability, whether that be with time, energy, and/or their own resources, creating a beautiful cycle of ability-focused living.

We are not just talking about it, we are living it and bringing our communities along to experience it for themselves. The outcome of events like Big Hearts is a shift in perspectives, sharing with the world that people of ALL abilities not only belong, but are needed in every corner of the community. •

For more information on ESP, visit **www.espyouandme.org** *; and to watch us grow to other communities follow us on instagram at @esp_inc and @laurahopewhitaker*

ABOUT THE AUTHOR:

Laura Whitaker is an Athens, Georgia local, serving as the CEO of ESP, an organization that she became involved with as a freshman at the University of Georgia. It was impossible to know then that, at the young age of 19, she would become the organization's leader. Her team has grown from one to 30, from a handful of volunteers to thousands, from a budget of $70,000 to a budget of $3 million. She has identified the key, unique differentiators in leadership that translated into millions of dollars in fundraising for an underserved community of all abilities. She would tell you some of her highlights of leading ESP include taking four Joyristas ("Joy" + "Barista") on their very first business trip to serve coffee and hugs in San Francisco, California, helping kids in wheelchairs tube down the Chattahoochee, setting off a confetti cannon (nearly every day!), building a fully accessible Miracle League baseball field in ESP's backyard, or the simple joys of receiving any hug from an ESP participant. For more information on Laura Hope Whitaker, visit **www.laurahopewhitaker.com**

Abilities EXPO

Serving the Community Since 1979

“I always come to the Expo. It’s where I learn something new every year!” - Maria M.

Up your game and…

- Boost independence with latest products & tech
- Learn tips and tricks from community experts
- Get moving with adaptive sports & dance
- Build relationships with your community
- Find solutions for all ages and abilities

FREE ADMISSION

Houston
August 5-7, 2022

Phoenix
Sept. 9-11, 2022

Miami
Nov. 4-6, 2022

Dallas
Dec. 2-4, 2022

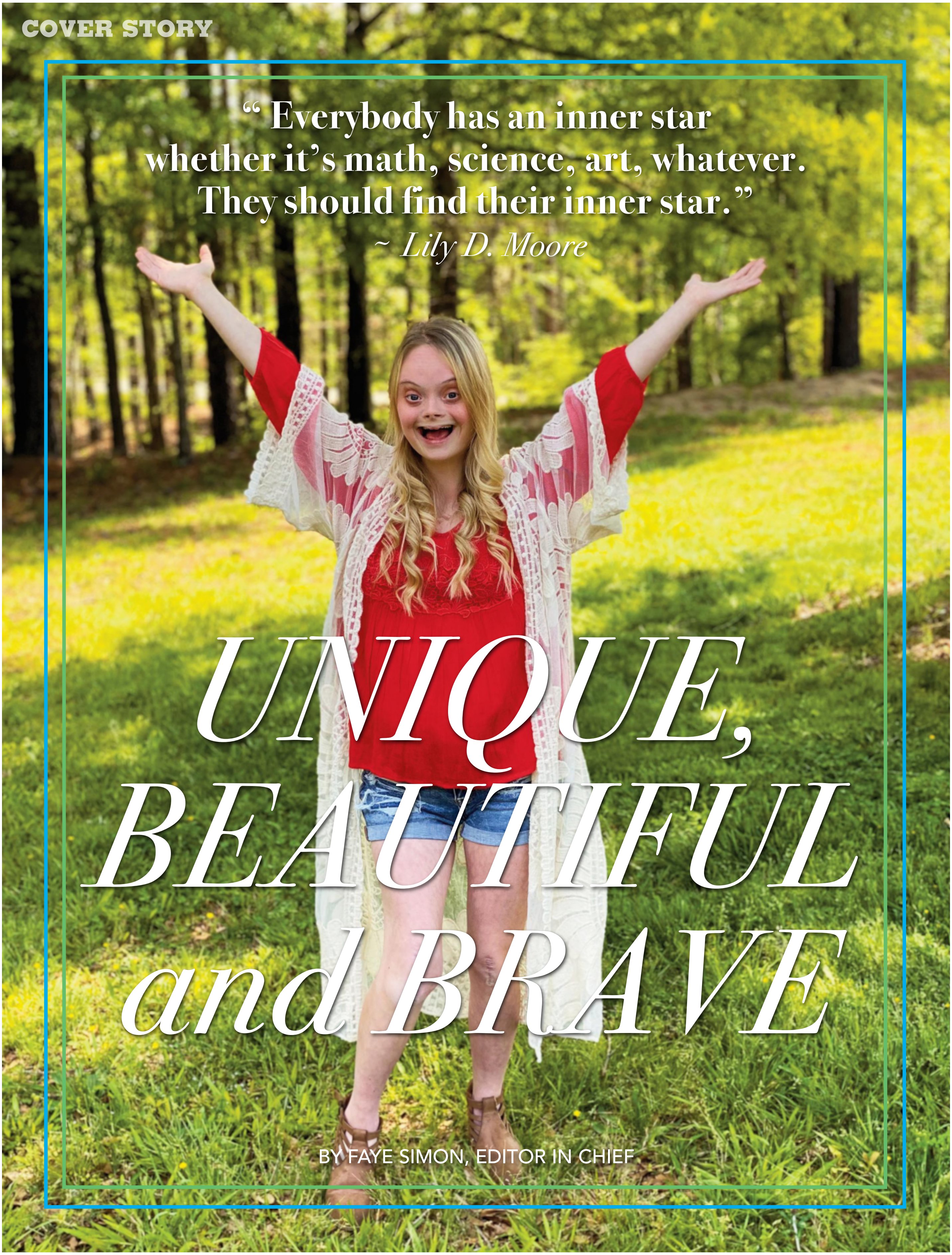
Los Angeles
March 10-12, 2023

New York Metro
May 5-7, 2023

Chicago
June 23-25, 2023

Abilities.com • Register online today.

@AbilitiesExpo @AbilitiesExpo @abilities_expo



> “ Everybody has an inner star
> whether it’s math, science, art, whatever.
> They should find their inner star.”
> ~ *Lily D. Moore*

UNIQUE, BEAUTIFUL and BRAVE

BY FAYE SIMON, EDITOR IN CHIEF

IMAGES COURTESY LILY AND NATALIE MOORE

Lily D Moore is an nineteen-year-old actress, model, and advocate for people with disabilities. She was born with Down syndrome, but she doesn't let that get in her way. She has starred in films, television and commercials. She has modeled on both coasts of the U.S. and traveled extensively in Asia and Europe.

Lily is involved with Special Olympics, Breaking Barriers, and Extra Special People. She also started H.E.L.P., an initiative that distributes packages of food and toiletries to the homeless. She will attend Clemson University this fall, and plans to pursue her career acting and modeling. Her ultimate long term goal is to win an Oscar.

She plans to continue to use her voice to advocate for people in all walks of life because she believes everyone is unique, beautiful, and brave. Recently I had the oppotunity to speak with Lily and her mom, Natalie Moore.

Faye Simon: Lily, why don't you tell me a little bit about yourself?

Lily D. Moore: I just graduated from high school. I'm planning to go to Clemson University to major in healthcare, but still do acting. I love to act, model, and also help homeless people.

FS: How did you pick that college?

LM: Mom, can you help with this answer?

Natalie Moore: Sure. We have three children. Our two oldest have gone to college: one just graduated with a master's, and the other one's getting her Ph.D. So, Lily has experienced seeing her two older sisters go to college, and Lily has always said, "I'm going to college, too."

As parents, we wanted to support that dream. So, we started doing our research and went on a whirlwind tour. Some were in person, some zoom because of COVID, but we did our research on about fifteen different campuses. We finally found Clemson, but we knew how competitive it is to get into Clemson. We didn't have the best of hopes, because I think several hundred people applied, and they only had twelve or thirteen spots. So, we had backups, but no other offers. Then Clemson offered. Of course, Lily was thrilled.

FS: What would you like to do in healthcare?

LM: It's between physical therapy and RN.

FS: Do you think you will still have time for acting?

LM: Hopefully. For the healthcare, I want to do that part-time.

FS: How and when did you start with acting and modeling?

LM: When I was about six years old, we used to live in Europe for three years, in Austria. I took a drama class in school. I loved it. Then when we moved back, I started getting involved with acting classes and workshops. I loved it more and I got an agent. It took a lot to get an agent, but finally one signed me, and then I started getting auditions and jobs.

FS: What was your first acting job?

LM: It was a commercial for a local hospital here.

FS: Were you nervous?

STAR POWER: *Color My World With Love,* Lily's most recent film project which tells a new kind of love story, will be broadcast on the Hallmark Movie channel this month.

LM: I was a little nervous at that time. Yes.

FS: What do you enjoy about acting?

LM: Meeting new people and traveling the world.

FS: When did you get started with modeling?

LM: Can you help me with this answer, Mom?

NM: That just kind of has happened along the way. There were certain projects, and people would reach out and say, "Hey, you know, just looking through your portfolio, and your daughter just really spoke to me." She had the opportunity to model for some famous photographers. For most of her modeling, people have reached out through her Instagram or contacted me through her website or her Facebook page.

FS: What's your most recent acting?

LM: The recent was the movie. That was my most recent, *Color My World With Love.*

FS: You just finished it or are you still doing it?

LM: No. We finished. I can't think how long ago we wrapped, but it was long ago.

NM: First week of April. I like the quote that she gave with the movie, when people asked her about it. Do you want to read that?

LM: Yeah. I hope viewers take away that *Color My Word With Love* is about painting your own story through your emotions, and that we all have endless possibilities.

FS: What's it like when you see yourself on TV?

LM: I like it. I enjoy it because seeing myself on TV is very fun.

NM: We didn't realize that the trailer for the movie was on. A friend of mine messaged me on Facebook and said, "Hey, I just saw the trailer for the movie."

LM: We were like, "Wait? What?"

NM: Yes. I turned on the TV and we saw it.

LM: It was perfect timing.

NM: She got pretty emotional about it.

LM: Yes. I do.

NM: It's very, very special. I had a lot of tearful moments myself.

FS: That is so exciting. What was your part in it?

LM: I was the main character of the whole movie. Her name is Kendall.

FS: Is it hard to remember the lines?

LM: Yes. Very.

NM: Lily has the gift of memorization, though. She really can memorize very quickly and easily.

FS: I'm shocked that she's saying that. I would have thought you would have said sometimes you have to do the scene over and over and over.

LM: That's pretty hard, too, doing the scene over and over and over.

FS: Do they feed you on the set?

LM: Yeah. They did. A lot.

FS: When you're filming, is it a whole day or is it just a few hours at a time?

LM: They can hold me up to twelve hours. I had very early call times to late nights.

FS: Where was it filmed?

LM: It was filmed in Canada.

FS: Did you get to see any of Canada?

LM: Yes. It was nice. When I had free days, we were able to go and explore and stuff.

FS: Did you like the other actors?

LM: Oh, yes, so sweet.

FS: Do you, you like acting better than modeling?

LM: I prefer it. Yes.

FS: But you'll do modeling if people ask?

LM: Mm-hm. Yeah.

FS: Growing up, what were some of your challenges?

LM: So, one of the biggest things was surgeries. I've had like a lot of bad legs and knees, open-heart surgery, back surgery. About thirteen surgeries. So, I'll say, one of my main challenges I've had was surgeries.

PUT TO THE TEST: Lily graduated from high school this past spring; "I enjoyed school. I had some really good friends there, but also there were some, obviously, mean people. It's like a combination. But I grew a lot of friendships and I enjoyed going to school. Going through classes was very fun."

NM: Yeah, they were long recoveries and they put her out of school for six to eight weeks. Because of that, she missed the social interaction with people, and certainly the bonding that can go with it. She was born with her knee on the righthand side on her right leg and with a kneecap growing on the outside of her leg. For the longest time they weren't sure if they could do anything, or what they could do. That took a long time, and on the other side, it dislocated all the time. So she's had multiple surgeries on those. Because of all that, she wasn't able to do sports, which broke me and my husband's hearts. We were athletes growing up. We just assumed that all three of our kids were going to be athletes.

LM: My two older sisters were athletes. I was the only one who was like, "No. I want to do acting."

FS: Can you swim?

LM: Yes. I can. We have a pool in our backyard. I was a cheerleader for four years for varsity basketball.

NM: She also has ridden horses for years. She can't do it at the moment, but, for seven, eight years, she's ridden horses.

LM: It's leg stuff. Possibly, another surgery is going to be happening.

NM: She had a surgery last May. She was getting bow-legged so they had to take out part of her shinbone to straighten her leg, and put in some hardware and a bone graft. The bone graft hasn't taken hold. That's why he said no horseback riding. Now, we're going to have another surgery.

FS: Did they feel all this is related to Down syndrome?

NM: Well, loose joints and ligaments have certainly to do with Down syndrome, and the dislocating of the knee repeatedly. But the knee that kept growing on the outside could have been in utero, just because the loosey-goosey joints shifted over and never went back. But certainly, loose ligaments and joints and all that, is associated with Down syndrome.

LM: Yeah.

NM: Like her heart, there's a lot of people with Down syndrome who have heart issues. Some don't. Lily was lucky enough to have seven different issues. She has a lot of hardware. She has these beautiful scars where she can show them off, all of her warrior wounds.

FS: Lily, you are a warrior for sure! How was going to school for you, when you could be there?

LM: I enjoyed school. I had some really good friends there, but also there were some, obviously, mean people. It's like a combination. But I grew a lot of friendships and I enjoyed going to school. Going through classes was very fun.

NM: She did have a time when she was bullied in middle school. Do you want to talk about that?

FS: *(Lily became emotional and shook her head no)* You don't have to. I see it still hurts.

NM: She doesn't mind me talking about it. She just feels emotional. In middle school, she got bullied by this one boy who was typical. The school did their very best to protect Lily, and keep her from him and him from her. But he just used every opportunity possible to throw stuff at her, slam her hand in the locker, and push her around physically.

LM: And punched.

NM: Yes, punched.

FS: Were any of the other children supportive?

LM: A lot of my friends, yes.

NM: This kid had a pattern of picking somebody each year and being relentless. The sad thing is that his mother didn't seem to have a problem with it. So, that made it difficult, because if she didn't have problem with it, then she didn't think anything was wrong with what her son was doing. So, the final straw was one time when the teacher called and said he was throwing stuff and hitting her repeatedly in the back with erasers. I immediately got Lily and went straight back to the school. I said, "I need to see the principal." "Oh, he's not around right now." I said "Well, you need to find him. I'm not leaving until I talk to him." So, we had a very strong conversation and, thank goodness, action was taken then. But it took a long time. It just shocked me to my core that his family thought that it was okay, for not only a young man to bully a girl, but to take it one step further to bully somebody with a disability. However, she learned a lot of good life lessons from it.

LM: Yeah, true.

NM: We've always tried to teach our kids in whatever situation, how to turn that around. So, it definitely helped Lily to use her voice, and to speak up for herself, and speak up for other people.

FS: Where did you find support throughout? I'm sure your mom. But are there other people who have been very supportive for you throughout getting your career, school, and everything?

LM: Yes. My two older sisters are very supportive, and my dad is as well. Also, my grandmother is inspiring.

FS: Do you have pets?

LM: I do. I have three. I have two cats and a dog. I have a goldendoodle, Charlie. Then I have two cats, Lester and Hazel.

FS: Do they get along?

LM: Yes. They do.

FS: Do you walk your dog or is that hard for you?

LM: It's hard for me sometimes, because he's really strong. But we've taken lots of walk and stuff.

FS: Lily you speak out, and you're an advocate. What would you like people to know about Down syndrome?

LM: We want to be like typical people. We want to do things like going to college, owning shops, and do our own businesses and do all that stuff. I think it's really important. Also, people want to fall in love and get married one day, just like other typical people. People with disabilities want to do that, too.

FS: What else would you like people to specifically know about you, Lily?

LM: Well, I started a homeless ministry called H.E.L.P. It stands for Helping Everyone with Love and Passion. I put snacks and toiletries into bags. Whenever I see homeless people, I give them out. I have given out over one thousand bags in five years.

FS: Tell me a little bit more about your advocacy.

LM: I'm a Special Olympic Champion Ambassador. I give a lot of speeches and stuff to different schools and all that. And I'm about to... What's those summer things?

NM: She's going to open the ceremony for the Georgia's Special Olympics.

FS: Do you have to speak?

LM: Yes. I have to speak, opening up the games and all that.

LOOKING AHEAD: "People with Down syndrome want to be like typical people. People have dreams, and whatever it is, I hope that they can achieve those goals."

FS: Do they give you a script, or you write your own?

LM: They give it to me.

FS: When you do other speaking, what message do you want to get across?

LM: Follow your dreams. Finding that inner star and let that inner star come out and shine. I encourage people to include people with disabilities.

FS: Yes. Very important. That's one of our hopes from this magazine, that as people learn more about all different disabilities, and see how they're wonderful people, like anybody else, and how inspirational so many of them are, we're hoping that inclusion will become a part of life. That would be a dream come true.

NM: During a commercial, I can't remember the question that they asked her but Lily ended up saying…

LM: Everyone is unique, beautiful, and brave.

NM: That's been her mantra. When people message her privately, and they're having a hard day, she always reminds them that they are unique, beautiful, and brave.

FS: Do a lot of people reach out to you, Lily, who have disabilities?

LM: Yes and no, it's between typical people and people with disabilities. I get a lot.

FS: Can you think of one or two interesting questions you've been asked?

LM: One of the funniest ones was this random person asking if I would marry them. You see, I said no. It was a very funny and interesting thing, for sure.

FS: Do you ever go to schools and talk to classes?

LM: Yes. I went to a school up in North Carolina once, talked to a school and stuff. It's fun. There is a thing at that school. It's called Reading with the Stars. It's where you pick a book. You read it to little kids. It was really fun.

NM: They have a lot of questions.

LM: One of them wanted to know if I was rich. I told them, "No." They also asked me what kind of phone I have.

NM: It's interesting. One of the classes: I think there were six different groups. One of the groups that came through wanted to talk only about animals and pets after she read the book.

LM: It was really cute.

FS: Do you have advice for others who have Down syndrome?

LM: Everybody has an inner star whether it's math, science, art, whatever. They should find their inner star. And also realize that other people have dreams, and whatever it is, I hope that they can achieve those goals.

FS: It's been wonderful talking to both of you. Congratulations, Lily, on graduating, on your movie, and everything you do, and being such a wonderful human being. It's so nice to meet both of you.

LM: Thank you.

NM: Thanks for the opportunity. •

Learn more about Lily and her career at **www.lilydmoore.com**

ALTERNATIVE THERAPIES FOR CHILDREN AND YOUTH WITH DISABILITIES

HOLISTIC APPROACH

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

Children and youth with disabilities are often involved in numerous traditional therapies, such as: physical, speech, occupational, psychological and behavior therapy. Most health care professionals regularly incorporate these recognized therapies into the patient's plan of care with helpful results.

Yet, there are alternative therapies available that are often overlooked by health care professionals and unknown to parents. The children and youth with disabilities are often over prescribed medicines to manage symptoms, which can provide short-term benefits, but there are many researchers that have shown these medications have long-term side effects.

Holistic approach emphasizes on "whole person" a balanced approach to healing mind, body and spirit. The alternative therapies when used "holistically" can offer numerous options for parents and professionals to consider on the basis of the unique needs of the child. These therapies have fewer to no side effects, can be used alongside other traditional therapies, with the consultation and guidance of the medical physicians, and can support the treatment outcomes.

NHIS data shows that about one in three U.S. adults (33.2 percent) used complementary health approaches in 2012, as did about one in nine children age 4 to 17 (11.6 percent).[1] This has increased in 2017, specifically in the areas of use of yoga, meditation, and chiropractic care.[2]

THE WHOLE PERSON : ALTERNATIVE THERAPY OPTIONS FOR CHILDREN AND YOUTH WITH DISABILITIES

The National Institutes for Health, National Center have documented the therapies below for Complementary and Integrative Health.

HOLISTIC HEALING

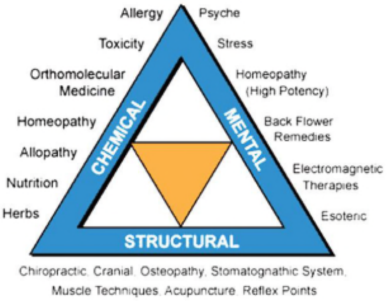
AROMATHERAPY/ ESSENTIAL OIL

A holistic healing treatment that uses natural plant extracts to promote health and well-being. It uses aromatic essential oils medicinally to improve the health of the body, mind, and spirit. It enhances both physical and emotional health. Previous studies have found beneficial effects of aromatherapy massage for agitation in people with dementia, for pain relief and for poor sleep. Children with autism often have sleep difficulties, aromatherapy massages enable more rapid sleep onset, less sleep disruption and longer sleep duration.[3]

APPLIED KINESIOLOGY

A non-invasive system that evaluates structural, chemical and mental aspects of health, using manual muscle testing combined with other standard methods of diagnosis. Treatments involve specific joint manipulation or mobilization, various myofascial therapies, cranial techniques, meridian and acupuncture skills, clinical nutrition, dietary management, counseling skills, evaluating environmental irritants and various reflex procedures. There is research to show that AK when used with other alternative therapies, has provided improvements in individuals with disabilities.[4]

The Triad of Health: The triad of health focuses on balancing three sides of health: structural, chemical, and mental. It works on the principal that an imbalance to any one or more of these areas leads to health challenges or diseases.



ACUPRESSURE AND ACUPUNCTURE

A mainstay of traditional Chinese medicine, which has been practiced for thousands of years. The Chinese healing tradition sees the body as a delicate balance of yin and yang, the two opposing, yet inseparable forces, and believe that disease occurs when these two forces of yin and yang are out of balance. **Acupuncture** is a technique that involves inserting very thin metal needles into the skin at precise points on the body to clear energy channels, with the aim of restoring and maintaining health, commonly used for pain. **Acupressure** is often called acupuncture without the needles, commonly used for nausea. Instead of needles, acupressure involves the application of manual pressure (usually with the fingertips) to specific points on the body. Acupressure has been used as part of treatment programs for children with developmental disorders including speech and language delay, cerebral palsy, ADHD, and autism with improvements reported in motor and/or language function in children with cerebral palsy, better language communication function and/or social interaction, reduction of repetitive behaviors, improvements in fine motor, self-care, and/or cognitive function in individuals with Autism.[5]

BIOENERGY THERAPIES

Bioenergy Therapies include a number of different therapeutic interventions where a therapist helps to harness or manipulate a patient's subtle energy, in order to help restore the body's balance and improve the body's ability to heal.

TRANSCRANIAL MAGNETIC STIMULATION (TMS) THERAPY

A FDA approved treatment for individuals diagnosed with Major Depressive Disorder

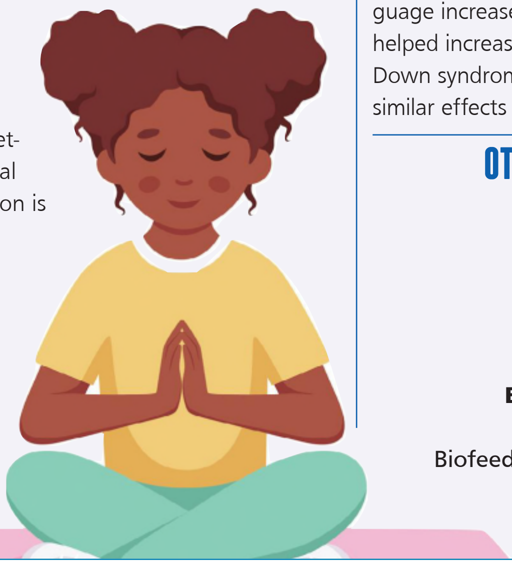
There are other interventions that have yet to be listed in the NIH research. These therapies include herbs, craniosacral, Reiki, auditory integration (Tomatis/Berard), and animal assisted therapies, such as: assistance/therapy dogs and hippotherapy (therapeutic horseback riding, often combined with physical/occupational therapy.) Many parents of children with special needs are using these and other therapies, but again, must consult with their pediatrician prior to use.

The Complementary and Alternative Medicines (CAM) are also used as alternative treatment for individuals with disabilities. Even though CAM therapies are considered "natural," with less side effects than conventional medications, they still lack scientific evidence. CAM therapies use: diet & dietary planning, nutritional supplements, Omega fatty acids, probiotics, enzymes and much more. These are easily available on the internet, but should be used only under medical supervision to monitor the side effects, since the individuals with disabilities are very sensitive, and many may not be able to report the side effects. On the other hand, Holistic ***approach*** emphasizes the "whole person," a balanced approach to healing mind, body and spirit. These have fewer to no side effects, can be used alongside other traditional therapies, but it is still recommended to consult and inform the healthcare providers before implementing. •

(MDD), and Obsessive Compulsive Disorder (OCD). TMS Therapy can be used as standalone treatment or used in conjunction with medication. It helps in relieving the symptoms of schizophrenia,[6] such as irritability and repetitive behaviors, and improve autism related issues in areas such as, eye-hand coordination and social skills.

CHIROPRACTOR VERTEBRAL SUBLUXATION REDUCTION

These techniques have helped improve symptoms of ASD and Sensory Processing Disorder. After the spine is adjusted, many patients and their families have reported that the patient is more relaxed, displays more eye contact as well as, an increased willingness to be social. It has also shown benefits in children with autism, with problems like digestive disorders, sleep disturbances, and bedwetting.[7] Spinal manipulation is commonly used for pain relief.



QIGONG SENSORY TREATMENT (QST)

Deep pressure massage developed by Dr. Louisa Silva. The fundamental *qigong* practice is the activation, development, and application of "qi." A subtle energy functions through an energetic network in the body for coherent communication between all the body's organs, tissues, and cells; between the mind and the body; as well as between the body and the living environment. The increased subtle energy plays an important role in restoring the functions of the body, and in addressing the miscommunications between the internal organs, tissues, and cells, thereby preventing and healing diseases and promoting health.

Research has shown that QST has helped children with Autism by improving Sensory problems by 38%, Autistic behaviors decreased by 32%, improved social skills as children became more affectionate, and receptive language increased up to 18%. It has also helped increase speech in children with Down syndrome.[8] Tai Chi has demonstrated similar effects on pain reduction as Qigong.[9]

OTHER THERAPIES

BIOFEEDBACK AND NEUROFEEDBACK

Biofeedback is a mind-body, non-invasive technique that involves using visual or auditory feedback that enables an individual to learn to gain control over involuntary bodily functions, such as: blood flow, blood pressure, and heart rate, to improve health and performance. **Neurofeedback**, also known as EEG (electroencephalogram) is a kind of biofeedback that uses sound or visual signals to reorganize or retrain these brain signals, and teaches self-control of brain functions. It has been effective in the treatment of various disorders:[10] **ADHD, Learning Disabilities** (helps children with Dyslexia, Dyscalculia), **Autism** (improved focus, attention, decreased anxiety and impulsivity, better sleep, increased social behavior, decreased behavior and better academic outcomes), **Epilepsy** (reduced the rate of seizures in severe and uncontrolled epilepsy), **Insomnia** (improved sleep) and much more. Bio- and neurofeedback are commonly used for pain relief.

MUSIC THERAPY

Music Therapy has been shown to help with anxiety, pain, sleep disorders, depression etc. Many children with special needs benefit from music therapy.[11]

For more information, visit:

NIH National Center for Complementary and Integrative Health

NATIONAL CENTER FOR COMPLEMENTARY AND ALTERNATIVE HEALTH

www.nccih.nih.gov

References

1 https://www.nccih.nih.gov/about/strategic-plans/introduction
2 https://www.nccih.nih.gov/health/statistics-from-the-national-health-interview-survey
3 https://www.ncbi.nlm.nih.gov/pmc/articles/PMC1513142/
4 https://pubmed.ncbi.nlm.nih.gov/25256020/
5 https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3235695/
6 https://www.autismspeaks.org/expert-opinion/transcranial-magnetic-stimulation-autism-evidence-benefit, https://www.greenbrooktms.com/tms_therapy.htm
7 https://asfca.com/health-and-wellness-resources/chiropractic-care-for-autism-spectrum-disorders/#_ednref1, https://www.princetonchiropractic.com/wp content/uploads/2019/01/publishedautismstudy.pdf
8 https://www.tandfonline.com/doi/abs/10.1080/03004430.2012.761607?journalCode=gecd20
9 https://www.nccih.nih.gov/health/tai-chi-and-qi-gong-in-depth
10 https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4892319/
11 https://search.usa.gov/search?utf8=%E2%9C%93&affiliate=nccih&sort_by=&query=music+therapy

ABOUT THE AUTHOR:

Dr. Garima Jain is Doctor of Naturopath (N.D.), Certified Nutrition Consultant (C.N.C.) and Community Health Worker (CHW). She is the co-author of the Book ***Healing Autism in the Kitchen.*** She has served at various Education and Health Projects at SPAN and is currently serving as Family Support Specialist at NJ Integrated Care for Kids (InCK) family-centered model aimed at improving care for children on Medicaid/NJ Family Care housed at Children and Family Health Institute.

IDD healthcare curricula must be incorporated into every clinical training program in the US and abroad.

ATTAINING DISABILITY COMPETENT HEALTHCARE

BY CRAIG ESCUDE, MD, FAAFP, FAADM

Have you ever accompanied someone with an intellectual disability to a medical appointment due to a new, concerning behavior, only to be told by the clinician that they are doing this just because of their disability? That's diagnostic overshadowing - a term that describes when clinicians attribute a new or untoward behavior to the fact that the person has an intellectual disability, rather than looking for some underlying medical or environmental cause. It is all too common in the medical profession. Why? The primary reason is the lack of training of clinicians to adequately meet the healthcare needs of people with intellectual and developmental disabilities (IDD).

The National Council on Disability released the Health Equity Framework for People with Disabilities in February of 2022. In it, the Council calls for 4 main changes that are needed to improve healthcare for people with disabilities, including those with IDD:

1. *Designating people with disabilities as a Special Medically Underserved Population (SMUP) under the Public Health Services Act*
2. *Requiring comprehensive disability clinical-care curricula in all US medical, nursing, and other healthcare professional schools and requiring disability competency education and training of medical, nursing, and other healthcare professionals*
3. *Requiring the use of accessible medical and diagnostic equipment*
4. *Improving data collection concerning healthcare for people with disabilities across the lifespan*

All four, along with the thirty-five additional recommendations in the document are important to achieve health equity for people with disabilities, but let's talk about number two in more detail.

DISABILITY COMPETENCY VERSUS CLINICAL COMPETENCY

Becoming disability competent should be a requirement of every clinician, hospital, and healthcare payor entity, including health maintenance organizations and fee for service payors. But, for clinicians, disability competency is not enough. A simple definition of disability competency is where the basic premises of the world of people with IDD is understood. Examples might include: understanding different ways a person may communicate, appreciating the network of support upon which many people with disabilities rely, and understanding the necessity of creating physical environments where people with disabilities have equal access. This would include: the availability of scales that can weigh people in wheelchairs, exam tables that can move to lower positions to allow access, and the like. But healthcare providers must go beyond this level of understanding to attain true disability *clinical* competency. They must acquire the clinical and diagnostic skills that foster the provision of competent healthcare to people with IDD.

Two main groups of clinicians must be trained to achieve disability clinical competency. The first group consists of clinicians in training such as medical students, nursing and nurse practitioner students, dental students, and allied health professional students. The second group is made up of clinicians that are already out in practice. Two different approaches must be taken to achieve clinical competency among both groups.

HEALTHCARE PROFESSIONAL STUDENTS

IDD healthcare curricula must be incorporated into every clinical training program in the US and abroad. There are two main components to achieving clinical competency: didactic education and hands-on clinical experience.

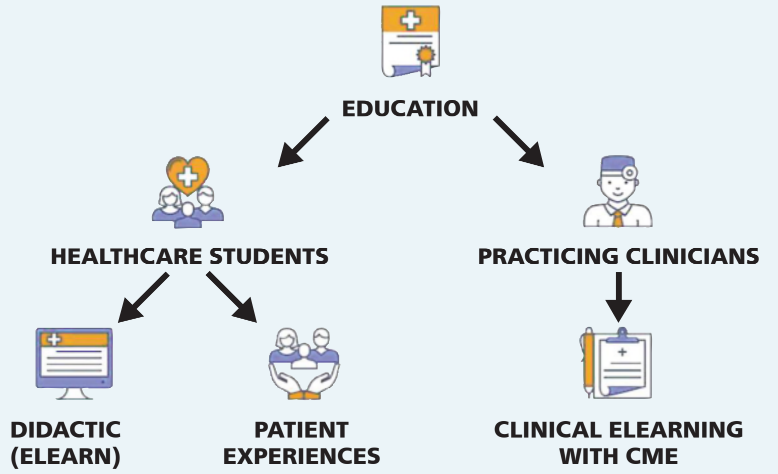
Didactic instruction should focus on teaching information such as: what behaviors might be pointing to specific, treatable, underlying medical or dental conditions in a person who does not use words to communicate, the steps taken to evaluate the cause of newfound aggressive behavior in a person with IDD, the most common causes of preventable illness and death in people with IDD, and other clinical and diagnostic lessons.

Didactic training should be accompanied by experiential training where students interact with people with disabilities on different levels, to gain insight into and appreciation of the lives of people with IDD. Standardized patient scenarios and real-life clinical experiences will help develop the skillsets needed to provide appropriate clinical assessments and medical treatments to people with IDD.

One of the challenges to teaching these skills is the limited number of currently available experts in this field to teach these courses. If every medical, nursing and allied health professional training program in the US wanted to employ clinicians with the expertise to teach this information in their schools, they would

ADEQUATELY MEETING NEEDS : STEPS TO ACHIEVING DISABILITY COMPETENT HEALTHCARE

Two main groups of clinicians must be trained to achieve disability clinical competency. The first group consists of clinicians in training such as medical students, nursing and nurse practitioner students, dental students, and allied health professional students. The second group is made up of clinicians that are already out in practice. Two different approaches must be taken to achieve clinical competency among both groups.



SYSTEMS CHANGE

1. **Move toward integrated care** (Primary Care, Emergency Care, Behavioral Health, and Dental)
2. **Specialty IDD Clinical Care** (clinical experts)
3. **Hospital and Clinic Physical Accessibility for all** (Universal Design)
4. **Payor Disability Competency** (Managed Care and Fee for Service to include disability competency in acute and Long Term Services and Supports (LTSS)

have a difficult time finding qualified clinicians to do so. Fortunately, with advances in eLearning courses, this type of information is more readily available than ever before. In a matter of days, a school could bring an IDD expert to their students through eLearning.

PRACTICING CLINICIANS

Society cannot wait until every school implements IDD training, all of their students graduate, and then replace every practicing clinician to attain a disability clinically competent workforce. Healthcare providers who have completed their training and are out in practice also must be trained, to improve the availability of IDD competent healthcare providers. The challenges here are a bit different. Many clinicians are not aware of their own need to develop clinical competency in this area. It's similar to the old saying, "we don't know what we don't know." However, once they begin to gain some insight into this world, it becomes clear that additional information and skills about IDD healthcare would be of great benefit to all patients in their practices with vulnerabilities, including: people who are aging, those with dementia, people with traumatic brain injury and others. But how do we get this information to practicing clinicians who are busy with, well, practicing?

To do this, the information must be concise, practical, and afford an opportunity to fulfill continuing medical and nursing education requirements. Adding "teeth" in the form of this type of training being required, by their professional accreditation academies or state licensing boards, would also provide incentives. Again, one of the best ways to deliver this type of training is through online eLearning courses. They are efficient and can be done on the clinicians' own time and at their own pace.

In recent years, there has been an increase in focus being placed, by different organizations, to increase clinical competency among healthcare providers. The American Academy of Developmental Medicine and Dentistry (**aadmd.org**) has fostered the National Curriculum Initiative in Developmental Medicine, which has cultivated the implementation of varying degrees of training, in over 20 medical schools. The Developmental Disabilities Nurses Association (**ddna.org**) credentials nurses to provide healthcare for people with IDD. The Institute for Exceptional Care (**ie-care.org**) is working to improve access to competent healthcare for people with IDD, addressing both educational, as well as, the payor components needed to achieve this goal. IntellectAbility (**replacingrisk.com**) is a company that focuses on health risk identification and prevention, as well as training of all levels of supporters, and has eLearning courses specifically geared to teaching physicians and nurses about IDD healthcare. One particular course, the Curriculum in IDD Healthcare, is used in medical and nurse practitioner schools, as well as, by practicing clinicians. It has demonstrated efficacy in improving clinical confidence in IDD healthcare for both students and practicing clinicians.

NON-CLINICIAN SUPPORTERS

What can non-clinicians do to improve IDD clinical competency? Here are a few thoughts: Educate healthcare providers about organizations and options to receive IDD clinical training. Work with medical licensure boards and specialty organizations to encourage or require IDD clinical training. Encourage and support health professional schools to incorporate IDD training into their curricula. Reach out to payors to encourage them to work to adjust payments, to help foster better healthcare provision for people with disabilities.

With the increase in interest in this area, and continued movement toward improving training opportunities for students and practicing clinicians, we will come to a place where anyone with any level of disability, will be able to present to any clinician's office or hospital, and receive a basic level of compassionate and competent healthcare. Let's work to make this sooner rather than later. •

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 (**https://replacingrisk.com**). He has more than 20 years of clinical experience providing medical care for people with IDD and complex medical and mental health conditions serving as medical director of Hudspeth Regional Center in Mississippi for most of that time. While there, he founded DETECT, the Developmental Evaluation, Training, and Educational Consultative Team of Mississippi. He is the author of *Clinical Pearls in IDD Healthcare* and developer of the "Curriculum in IDD Healthcare," an eLearning course used to train clinicians on the fundamentals of healthcare for people with IDD.

Dedicated to Your Comfort, Support and Style

CHILL-OUT CHAIR

ALTERNATIVE SEATING™

WHEN KIDS ARE COMFORTABLE, THEY'RE RELAXED.

Every Chill-Out Chair is built with a combination of high-grade foams to help relax spastic muscles, improve positioning and provide the most comfortable sitting experience possible.

AVAILABLE IN TWO UNIQUE STYLES:

Rock'er

Roll'er

chill-outchair.com | 1-800-661-9915

WHAT "MEDICAID UNWINDING" MEANS FOR PEOPLE WITH DISABILITIES

BY LAUREN AGORATUS, M.A.

During the pandemic, Medicaid coverage was continuous. There were also Medicaid flexibilities in benefits. What will happen once the public health emergency ends?

MEDICAID CHANGES DURING THE PANDEMIC

The Public Health Emergency (PHE) allowed for temporary but important changes in Medicaid. The most important was continuous coverage; no one was allowed to be "dropped" from Medicaid until the PHE was over. States also had flexibility in how benefits were administered. In NJ for example, these flexibilities included:

- *Zero premiums for all Medicaid plans*
- *Prescriptions and medical supplies expanded from 30 to 90 day coverage*
- *Access extended to telehealth appointments*
- *More HCBS (home/community based services) flexibility such as using paid family members for personal care assistance*
- *Elimination of requirements for prior authorization for inpatient procedures*

MEDICAID POST-PANDEMIC AND WHO WILL BE AFFECTED

Once the PHE is lifted, all of these protections and expanded services will likely disappear. Advocates are seeking to have some of these temporary protections made permanent, but this isn't guaranteed. The Families First Coronavirus Act requires coverage until the end of the month in which the PHE expires. Then states will have to decide who is still eligible for Medicaid. This includes over 80 million Medicaid enrollees, over 37 million of whom are children.[1] The Urban Institute estimates that in the first 6 months after the PHE is lifted, 15 million people will be disenrolled from Medicaid.[2] Georgetown University estimates that almost 7 million children will lose Medicaid.[3] According to the report, "states where children are at the greatest risk… are Delaware, Florida, Georgia, Missouri, Nevada, and Texas." In addition, health disparities come into play as "New research finds that two-thirds of children expected to lose Medicaid coverage at the end of the public health emergency are from communities of color."[4]

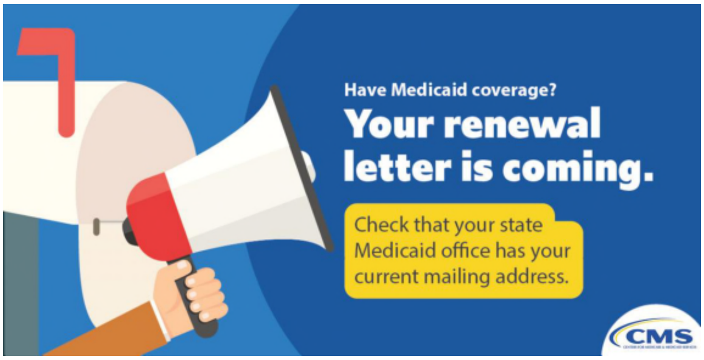
OTHER OPTIONS IF MEDICAID IS LOST

As we go to print, the PHE is expected to end mid-July, which means people can lose Medicaid coverage as early as August 1. However, it is expected to be extended again with states getting 60 days' notice prior to ending. The table below demonstrates possible timelines:

If PHE is extended on:	The PHE will end on:	Notice will be provided on or around:
July 15, 2022	October 15, 2022	August 16, 2022
October 15, 2022	January 15, 2023	November 16, 2022

Options besides Medicaid include the State Children's Health Insurance Program (CHIP), Marketplace plans, employer plans, and others.

CHIP (Children's Health Insurance Program): Depending on the state, the State Children's Health Insurance Programs (CHIP) can be combined with Medicaid or administered separately, and can be called by many names. To find the program in your state, call (877) KIDS-NOW or go to **https://www.insurekidsnow.gov/coverage/index.html**.



CHECK THE BOX: Update your contact information and check your mail. Your state will mail you a letter about your coverage, which will let you know if you need to complete a renewal form to see if you still qualify for Medicaid or CHIP.

Marketplace Plans: The federal, and in some jurisdictions, the state, Marketplace will help individuals and families locate difference types of plans. These also include links to Medicaid and CHIP if eligible. Here consumers can compare different plan benefits and costs. For those with low to moderate incomes, Marketplace plans also include federal subsidies to help make insurance more affordable. To find your Marketplace, go to https://www.healthcare.gov/

KEEP COVERED : HEALTH COVERAGE RESOURCES

InsureKidsNow.gov

CHILDREN'S HEALTH INSURANCE PROGRAMS

www.insurekidsnow.gov/coverage/index.html

HealthCare.gov

MARKETPLACE

Health plan compare

healthcare.gov

Employer Plans: Many employers offer coverage for employees and their dependents. It is important to note that under the ACA (Affordable Care Act), children can be covered under their parents' plan until age 26, or even higher in some states. In addition, children with developmental disabilities can be covered indefinitely under the federal "disabled dependent" provision. Parents can ask their employer for the necessary paperwork before their child turns 18.

The most important thing for families and advocates to remember is to keep their health coverage continuous, even if they have to switch plans. People with disabilities and their families can make sure they promptly fill out Medicaid renewal letters, appeal if they think their Medicaid is being discontinued in error, and look at other plans besides Medicaid to maintain coverage.•

References

1. https://ciswh.org/resources/phe-moe
2. https://www.urban.org/sites/default/files/publication/104785/what-will-happen-to-unprecedented-high-medicaid-enrollment-after-the-public-health-emergency_0.pdf
3. https://ccf.georgetown.edu/2022/02/17/millions-of-children-may-lose-medicaid-what-can-be-done-to-help-prevent-them-from-becoming-uninsured/
4. https://join.firstfocus.org/protect_childrens_healthcare

ABOUT THE AUTHOR:

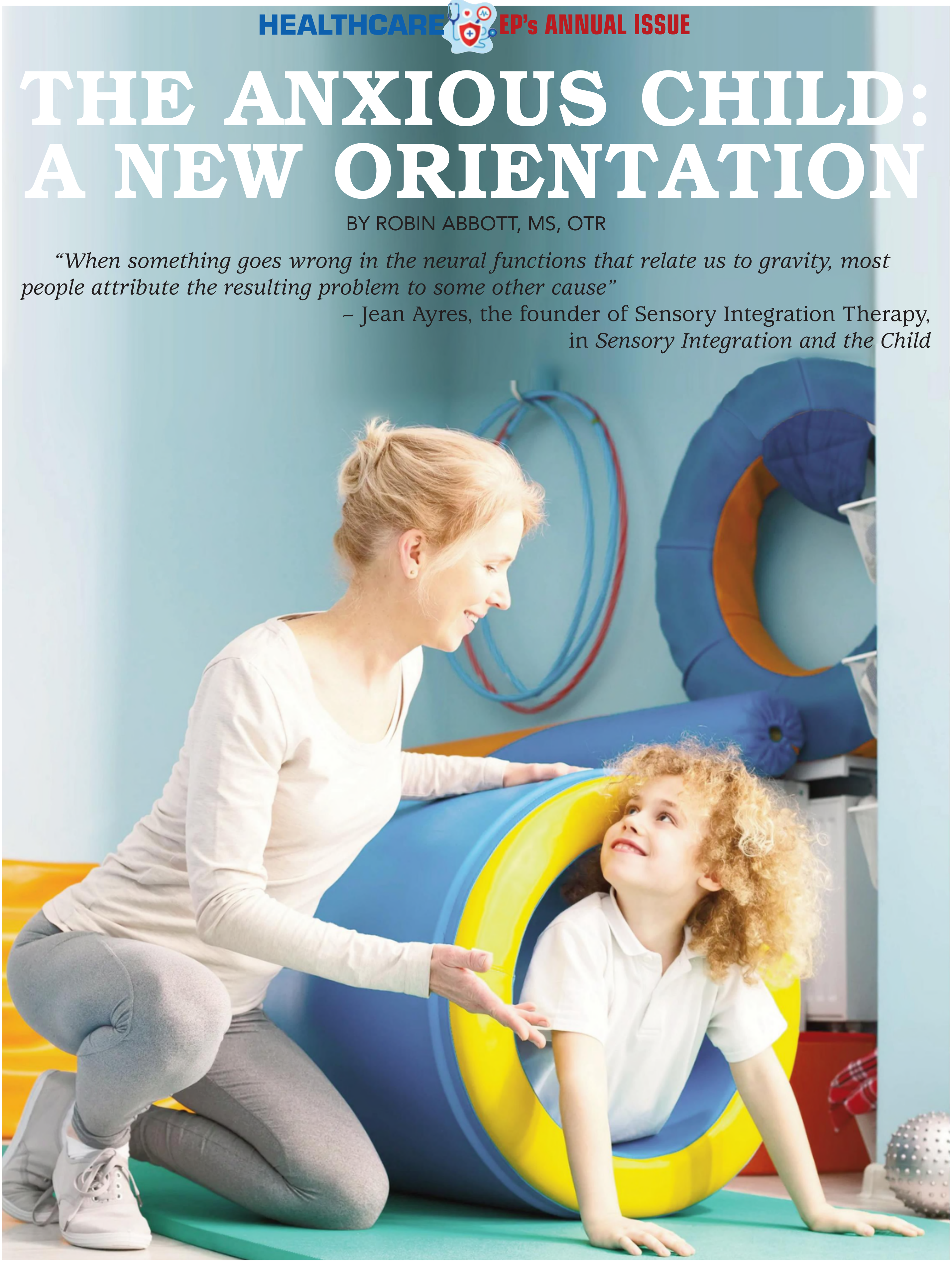
Lauren Agoratus, M.A. is the NJ Coordinator for Family Voices, NJ Regional Coordinator for the Family-to-Family Health Information Center, and Product Development Coordinator for RAISE (Resources for Advocacy, Independence, Self-Determination, and Employment). She also serves as NJ representative for 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*

IMAGES COURTESY CMS & WWW.HEALTHREFORMBEYONDTHEBASICS.ORG/WP-CONTENT/UPLOADS/2022/05/UNWINDING-FAQ-5.22.PDF

THE ANXIOUS CHILD: A NEW ORIENTATION

BY ROBIN ABBOTT, MS, OTR

> *"When something goes wrong in the neural functions that relate us to gravity, most people attribute the resulting problem to some other cause"*
>
> – Jean Ayres, the founder of Sensory Integration Therapy,
> in *Sensory Integration and the Child*



Sensory Integration Treatment founder Jean Ayres, was one of the first people to articulate the idea that some children's maladaptive behavior may be a result of a vestibular system that does not function properly. The vestibular system, housed in the inner ear, with myriad neural connections throughout the brain, is our body's way of understanding our relationship to gravity and movement. As an occupational therapist, I rely upon an understanding of the vestibular system to guide treatment, especially when that child is hampered by excessive anxiety and fear.

The vestibular system has connections to the limbic system, the emotional center of our brain that feels anxiety and fear. If incoming information is potentially threatening, then our emotional circuits get involved to prepare us for a physical response. For a child, undependable vestibular input can sometimes result in unreasonable anxiety and fear. A 2010 study of mice who had experienced genetic manipulation of their vestibular system, found that those mice experienced more anxiety and stress during space-related tests, such as mazes and being hung by the tail, than did mice without alteration to their vestibular function. In essence, tasks that were only challenging to unaltered mice, stimulated anxious behavior in those mice without dependable vestibular input.

Imagine that you move to exit the room you're in and stop directly on the threshold of the doorway. Think about the planning involved: locating the doorway (which involves being aware of your surroundings and having appropriate ocular-motor skills), estimating the steps remaining to get to the threshold (which can be done visually, based on the speed with which the doorway seems to be approaching), and knowing when you need to slow down to achieve stillness, just when you want to (which can be sensed proprioceptively – using your muscles and joints). As you stop, the muscles involved in halting your forward momentum have to coordinate with the associated muscles to keep you from using *too much* force to stop, and actually falling backward. These split-second reactions can only be processed and executed accurately by using vestibular information. In fact, it is a unique feature of the vestibular system to have such a quick response time-- the neurons that come from the vestibular centers in the brain are noticeably faster at transmitting their information than other sensorimotor neurons in the body.

For children who might not be receiving or processing vestibular information effectively, the delay in response and coordination may help explain why they use too much force for tasks, attempt to execute impossible motor plans, or have unreasonable anxieties. The vestibular system provides "a unique and complete description of head motion and orientation in three dimensions," state Day and Fitzpatrick in their 2005 summation of the function of the vestibular system. They mention five capacities for navigating the world informed by vestibular input: "Self" versus "non-self" motion (are we moving, or are things moving around us?), spatial orientation, navigation in space, voluntary movement, and ocular-motor (eye-movement) control. If we consider each of functions separately, we may perceive a link between a child's anxious behavior and the function that may be impaired. In my years in the clinic, I have encountered examples that illustrate how a child's behavior can be explained in terms of these vestibular functions. While the link between vestibular function and resulting behavior is theoretical, the resolution of these behaviors after clinical vestibular treatment, led me to the conclusion that a vestibular cause for some anxieties is worth considering.

SELF VERSUS NON-SELF MOTION

The vestibular system (made up of the vestibuli in both inner ears and the resulting neural connections with the brain and bodily muscles), in its most basic function, senses whether the body is still, or in motion. This function helps the brain unite the sensations coming from throughout our body, into one cohesive picture. Does the visual image in our eyes change as we move? Does sound rotate around or past our ears as we move? Do we feel the ground beneath our feet or our bottom, change as we move? These incoming sensations coordinate to form a picture that makes sense, because the vestibular system is playing a large role in orchestrating what our brains expect. When all this goes as expected, we feel secure and safe.

However, if body sensations are not coordinated with what the vestibular system feels, the disorientation can be disconcerting. I liken this to the common experience of pulling into a parking space at the moment the car next to you decides to pull out. Because your sensory systems do not agree (your eyes sense movement and your body senses stillness), there is a momentary panic in which you slam your foot into the brake harder. Is it possible that some children feel this moment of disquietude often, and it contributes to their overall anxiety?

> **Helping a child have a more accurate sense of their place in the world and a more coordinated way to move through it, can positively impact anxiety.**

SPATIAL ORIENTATION

This motion-sensing capability directly affects another function of the vestibular system, the ability to stay oriented in a space, and to objects around you. This provides us with perspective; both the visual perspective of objects around us, and the overall perspective of where we are within a space.

It is difficult to understand the world without the perspective provided through spatial orientation. It creates a lack of understanding of spatial relationships. My little friend Courtney suffered from great anxiety during bath time, because she was sure that her bath toys would travel down the drain with the water when the plug was pulled. No amount of showing her how they won't fit could ease her anxiety. Only when she began to have a sense of her own movement through space, could she understand that things "seem larger" when they are near, but retain their size when they "seem smaller" because they are further away.

NAVIGATION IN SPACE

The skill of spatial orientation also provides an ability to place ourselves on the "Marauder's Map" in our minds, which encompasses the physical space within a building or room. Without this

You-Are-Here sense, we can become disoriented when the visual scene before us changes, as we move through space. We might develop an anxiety related to finding our way back to a place of familiarity.

The lack of perspective is a potential explanation of unusual behavior of my friend's son, who has autism. Every time he visited a friend's house, he went straight to the freezer. Every house had one, and this might have been his way of orienting to a space that was, in all other ways, incomprehensible to him. He oriented to the freezer. As long as he knew where that was in the house, he knew where he was in relation to it.

IN A GOOD PLACE: It is always a good idea to have multiple lenses through which to observe a child's behavior, so that the root cause can be addressed in the most comfortable, and comforting way for the child.

VOLUNTARY MOVEMENT

The vestibular system helps us understand how we move through the world, but it also helps us plan to move from stillness. To initiate movement from a standstill, we must first know what direction we want to move in, then understand the corresponding muscle contractions necessary to move us in that direction. This skill can be exercised by visually interacting with the world. We see the bathroom across the hall, and we move in that direction. But, without the inherent understanding of what causes the body to move through space, a child may have difficulty staying oriented. It might be best to illustrate this through two clinical examples.

Kevin was a sweet nine-year-old who tried his best, but was failing in school, could not draw a coherent picture of himself, and was unable to tell me what street he lived on, or town he was in. While not the primary focus of treatment, his mother was pleasantly surprised that his life-long fear of bridges had improved greatly during treatment. In particular, we were able to cross a pedestrian bridge that used to cause him excessive anxiety. Before treatment, Kevin navigated in his immediate space by seeing an object, and proceeding there. In the case of seeing the edge of the bridge, he became obsessed with not heading there--he wanted to stay safe. But because he was not used to navigating via an inherent understanding of where he was and how to choose his direction, he did not feel that he could avoid the edge of the bridge.

Seven-year-old Bradley suffered from a fear that was equally difficult to understand. Some nights before bed, he would make his mother promise not to jump out the window during the night. No amount of discussion could allay his fear. Like Kevin, Bradley did not understand the physical, muscular and mental coordination that initiate moving in a particular direction. He felt things in the physical world happen randomly. Because he didn't understand how he controlled the direction of his own body, he assumed his mother lacked this control as well. How could he keep her safe? These two examples are sad, as the anxiety for these boys was impacting their happiness and that of their family. I'm happy that both of these issues were resolved after vestibular treatment.

OCULAR-MOTOR CONTROL

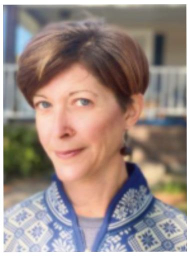
The final capacity closely linked to the vestibular system as outlined by Fitzpatrick and Day, is ocular-motor control. There are direct neural links from the vestibular system to the six muscles that control the direction of each eyeball within the eye socket. These connections help keep our vision stationary, as we move and keep our head stable as we move our eyes around our visual field, giving us better coordination with objects in the world around us.

Very often, a child with poor ocular-motor control will visually "lock on" to objects around them to stay oriented. This dependence on vision over internal, vestibularly-provided awareness, does not always present a problem itself. The problem may become obvious when a child has trouble controlling their eye movement through a space, such as when reading or searching the environment for a specific object. This lack of ability to scan can create nervousness regarding misplacing or losing treasured objects. As a result, a child may carry objects from place to place, obsessively check on objects or people, or have excessive tantrums related to leaving objects at home, when they wouldn't be appropriate to take along. The underlying fear for the child is that they will not be able to locate those things again.

A DIFFERENT WAY TO APPROACH ANXIETY

If you have an anxious child in your house, there may be a variety of reasons for their apprehension. They may have auditory processing issues, not touched on in this article. Some foreboding, stems from real fears related to lived experiences, such as abuse or neglect. Those fears may not be part of a child's memory, as the trauma may have occurred at an age before memory fully forms. Some fears are a normal part of childhood; fear of the dark, fear of dogs, fear of storms. Not every anxiety has a root in a dysfunctional vestibular system. But, helping a child have a more accurate sense of their place in the world and a more coordinated way to move through it, can positively impact anxiety. As a caregiver, it is always a good idea to have multiple lenses through which to observe a child's behavior, so that the root cause can be addressed in the most comfortable, and comforting way for the child. To that end, an occupational or physical therapist trained in vestibular treatment, and possibly in Ayres Sensory Integration Therapy, may be a good starting point. •

ABOUT THE AUTHOR:



Robin Abbott, MS, OTR is a pediatric occupational therapist and author of the book *Sound Advice: Helping Your Child with SPD, Autism and ADHD From the Inside Out*, from which this article is adapted. She can be contacted through **www.booksoundadvice.com**

EP FOR FREE!

Empowering the
Special Needs
Community
since 1971

RECEIVE *EXCEPTIONAL PARENT eMAGAZINE* AT NO COST!

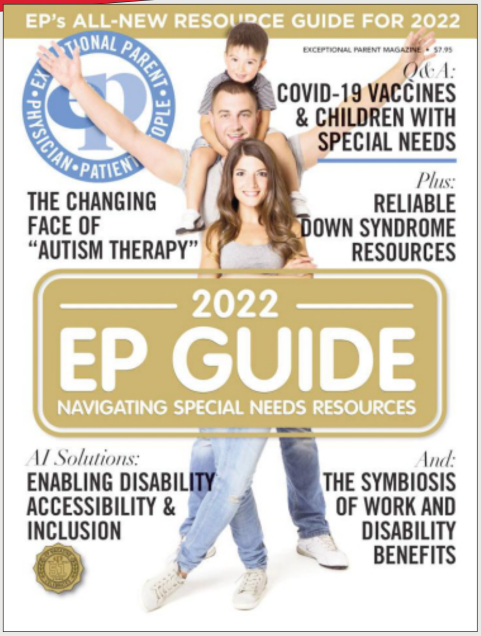
Exceptional Parent Magazine, a 51-year-old award-winning publication, provides practical advice, emotional support and the most up-to-date educational information for special needs families.

IT'S EASIER THAN EVER!

Simply visit us at
www.epmagazine.com
and click
"EP FOR FREE"
and you will receive a link
to the magazine every month.

Print subscriptions: $95 a year;
email ***epmagazinevp@gmail.com***

Subscribe Today at www.epmagazine.com



EP's ALL-NEW RESOURCE GUIDE FOR 2022

EXCEPTIONAL PARENT MAGAZINE • $7.95

Q&A: COVID-19 VACCINES & CHILDREN WITH SPECIAL NEEDS

THE CHANGING FACE OF "AUTISM THERAPY"

Plus: RELIABLE DOWN SYNDROME RESOURCES

2022 EP GUIDE

NAVIGATING SPECIAL NEEDS RESOURCES

AI Solutions: ENABLING DISABILITY ACCESSIBILITY & INCLUSION

And: THE SYMBIOSIS OF WORK AND DISABILITY BENEFITS

AN AMAZING ADVERTISING OPPORTUNITY

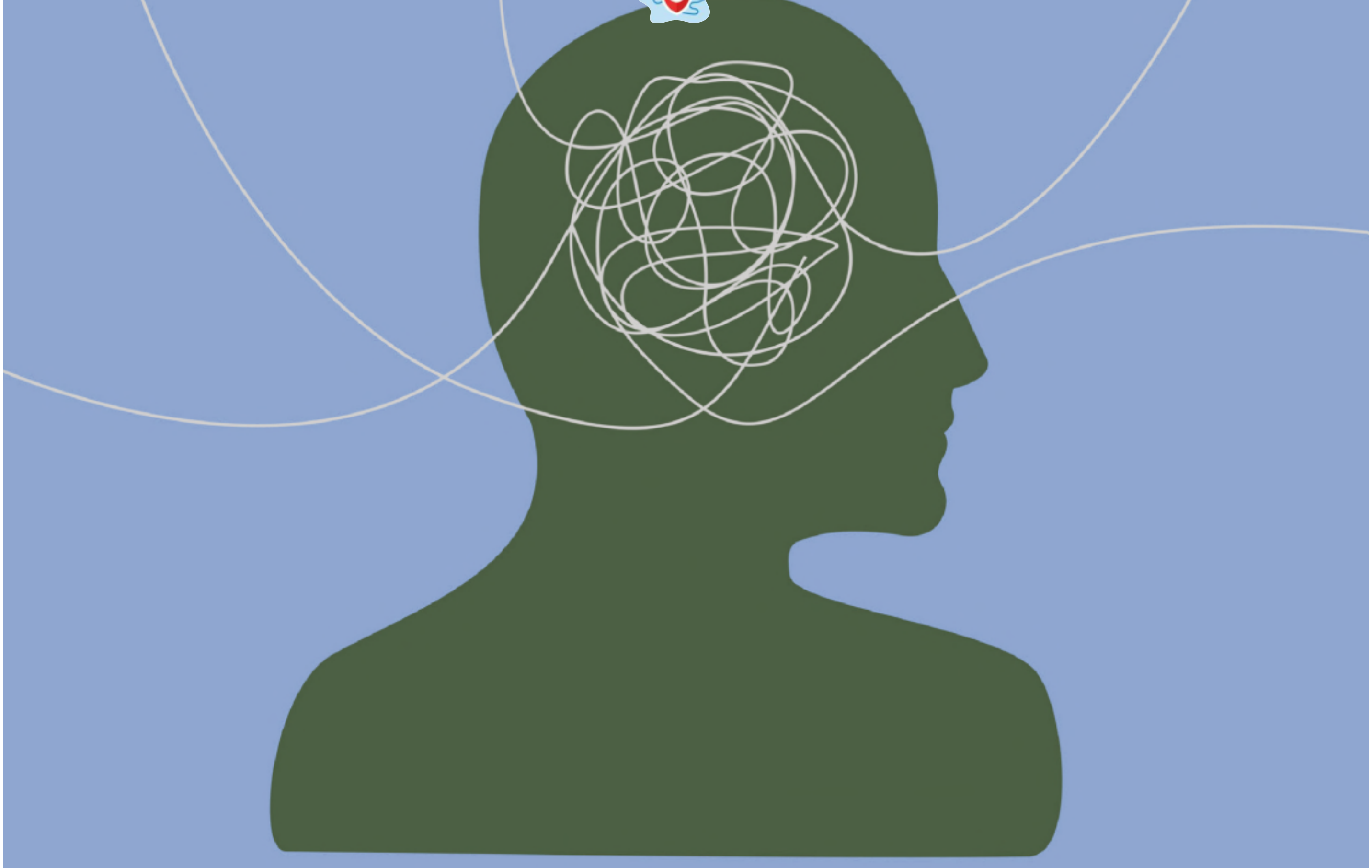
With a dedicated readership and a rapidly expanding audience, more and more advertisers are taking advantage of the unique opportunities that **Exceptional Parent** can offer. Whether it's a full or half page ad in our print and digital magazine editions, or a dynamic banner ad on our **www.epmagazine.com** website, there has never been a better value enabling your products or services to capture a large and motivated readerhip. Discounts and special offers are available for cross-platform insertions.

We are now offering many additional opportunities for lasting partnerships that can affordably and effectively communicate your brand's message.

For more advertising opportunities, email us at
fsimon@epmagazine.com

EXCEPTIONAL PARENT • PHYSICIAN • PATIENT • PEOPLE

EP MAGAZINE: THE JOURNAL FOR SPECIAL NEEDS FAMILIES AND PROFESSIONALS



TRAUMATIC BRAIN INJURY:

STATS; MYTHS; RESOURCES

BY CHRISANNE GORDON, MD

With summer being a time for outdoor activities, including the pool, sports practices, and playgrounds, it is also a time to tackle TBI and raise awareness about these injuries which forever change how people, especially children, think and process information. A slip at the pool, a fall off the swing, a "header" in soccer, all common occurrences that can lead to concussions – are erroneously classified as "mild" Traumatic Brain Injuries (mTBI).

These injuries can cause disability and lead to a protracted recovery. As a rehabilitation physician, I had treated many patients with brain injuries, but it wasn't until I experienced the effects of TBI firsthand, that I really understood this life-altering injury that affects over 4 million of patients each year in the United States alone, and over 20% of our all-voluntary military personnel. We are, in fact, experiencing a global TBI epidemic.

While the solution for suffering veterans may be more complicated than the action you should take if your child receives a concussion, they are similar at their core. Listen to your child, should they make complaints about headaches, dizziness, or overall feelings of being unwell after experiencing a fall. If you notice behavioral changes in your child, such as sleep patterns, mood or temperament, take them to the doctor for a proper concussion assessment. Remember, the earlier you act, the better!

BRAIN TRUST : DISPELLING THE BIGGEST MYTHS SURROUNDING CONCUSSIONS AND TBI

Traumatic brain injuries can cause disability and lead to a protracted recovery. When it comes to TBI and brain health, knowledge is power. Below, I have included some of the biggest myths surrounding concussions and TBI.

MYTH #1

You need to be knocked out to have a brain injury

Studies have revealed that even mild injuries such as a soccer header or hitting your head on the car door frame can result in TBI. Often, there is a dazed feeling that lasts for only a few seconds, but you do not have to be knocked out to suffer a TBI. The more severe the injury, the greater risk of blacking out. The longer you are unconscious, as a rule, the more likely that injury is severe.

MYTH #2

If you are dazed or only mildly knocked out, you can return to normal activities immediately

Multiple studies have revealed that resting the brain is imperative to healing. That includes limiting stimuli from light, noise or physical and mental activity. For example, high school athletes who suffer concussions, may not return to school immediately, due to difficulties they experience with studying.

MYTH #3

A small concussion without noticeable effects is nothing to worry about

Every head injury should be evaluated, treated, and followed, based on the diagnosis. It is proven that the number one predictor for a brain injury is having had a previous head injury, even a very mild one. Also, the effects of repetitive injuries are more than additive. In fact, “Second Impact Syndrome,” when the second concussion, is close to the first (i.e. within hours, days or weeks) can lead to a more severe injury or death.

MYTH #4

Everyone with a brain injury who fears or avoids crowds has Post Traumatic Stress Disorder (PTSD)

Avoidance of crowds and light or loud noise is a trait of PTSD but also a hallmark trait of TBI. This results from the injured brain’s ability to filter information and stimuli. If a TBI sufferer experiences high activity areas, the result is stimulus overload for the brain, creating an adrenaline release, which may lead to panic attacks and further avoidance of these activities.

MYTH #5

Everyone can self-medicate the effects of TBI with alcohol or drugs

Self-medication, especially with alcohol, is prevalent with TBI patients. The initial use may help to reduce the brain overload typically related to the injury, but over the long term can lead to significant social, financial and legal problems. A combination of brain injury and addiction is the leading cause of the suicide and homelessness epidemic currently facing our veterans.

MYTH #6

You just have a headache after injury, nothing serious; aspirin or acetaminophen will help

The persistent headache resulting from TBI occurs as a warning sign and is often related to vascular instability in the brain. Migraine-type headaches are common with TBI and should be treated differently. Aspirin can increase bleeding, as it acts as an anti-coagulant, and acetaminophen used in high dosages or used regularly over a long period of time can lead to liver problems. Any pain treatment, even over-the-counter medicating following a TBI, should be prescribed by a physician.

MYTH #7

You can’t concentrate or remember things after your injury. You must be going crazy. You are out of your mind

Difficulty remembering and concentrating are functions of the brain that may be affected by TBI. Recent advances in neuroradiology, such as Diffusion Tensor or Functional MRI can show us the areas of the brain that are injured or deficient. In the brain, even a small area of injury can affect a significant function, such as a lesion in the speech center.

MYTH #8

Your CT Scan or MRI were normal, so you must not have an injury

Current standard imaging techniques such as the MRI and CT scan do not have the capabilities to show the lesions or damage in a majority of TBI cases. Newer imaging techniques such as diffusion tensor MRI, SPECT and PET scans can better determine the extent of injury in people with TBI. Neuropsychological testing, similar to tests done with athletes, can also help to determine functional difficulties and identify the location of the brain injury.

MYTH #9

You still feel out of sorts six months after brain injury, so you won’t ever get better

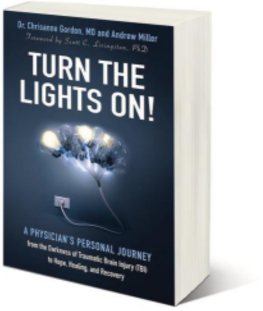
The brain can continue to recover for up to two years or longer after an injury. Brain retraining through speech therapy and mind strategies such as computer games or other applications can assist the brain healing process by prompting the brain to lay down new pathways to perform the functions lost with injury.

Note: Even mild traumatic brain injury can lead to a shift in brain function and personality. Usually, the period of loss of consciousness or decreased consciousness is often followed by a period of heightened awareness or hyperactivity, especially if you have been injured during a time when you were adrenaline charged.

While healing and recovery are possible for those affected, the diagnosis comes first. This requires an increased awareness of what TBI looks like to healthcare providers, first responders, employers, family members, friends, and community leaders. From professional football players to war heroes returning home, it is our job to support those suffering from this injury.

During my professional career as a Rehab Physician, I saw many veterans returning from conflict abroad, struggling to understand why they were suffering from headaches, depression and had trouble with critical thinking. This led to my founding of Resurrecting Lives Foundation in 2012, a 501(c)(3) whose mission is to assist veterans with TBI. Over 750,000 veterans from the Global War on Terror and Operation Iraqi Freedom suffer from TBI/PTSD. However, this is not just a young veterans' problem, as over 150,000 Vietnam veterans also suffer from TBI. Within the first year of contracting an undiagnosed TBI, 45-70% of veterans will become addicted to some substance that impacts their brain, ranging from amphetamines, to opiates and marijuana. Additionally, these patients have an 8x greater risk of dying by suicide than those without a TBI. Often, they express feelings of being a burden to their family, and due to the severe chemical depression, they are prone to suicide ideations.

In my book, *Turn the Lights On! A Physicians Personal Journey from the Darkness of Traumatic Brain Injury (TBI) to Hope, Healing and Recovery,* I share the story of my recovery from TBI, a process I did not learn by reading medical texts; a process I developed in a survival challenge to return to my old self; to regain my brain. This year long process of recovery is recounted to let the reader understand that recovery is difficult; but it is possible. The first step to recovery is discovering the truth about mild TBI, and not falling victim to the many myths surrounding this injury which we are just now defining and treating. If you or anyone you know is struggling from a sport's "concussion" or TBI, please share this information. It may be the difference between light and dark; hope and despair; life and death.



Title: **Turn the Lights On! A Physicians Personal Journey from the Darkness of Traumatic Brain Injury (TBI) to Hope, Healing and Recovery**

Author: **Chrisanne Gordon, MD**

Publisher: **Corpus Callosum Creations, Ltd**
Publication Date**: January 2018**
Paperback: **230 pages**
ISBN-13: **978-0692999561**
Available at: amazon.com and www.barnesandnoble.com

Please note that there are many resources available for TBI diagnosis and treatment. You should seek out the specialists in your area: most commonly, physical medicine specialists, sports medicine specialists, and family physicians, especially those connected with sports, as team physicians. •

ABOUT THE AUTHOR:

Dr. Chrisanne Gordon graduated summa cum laude from The Ohio State University College of Medicine after completing her undergraduate studies at Duquesne University in Pittsburgh, PA. She has experience in internal medicine, emergency room medicine, occupational medicine and rehabilitative medicine, and is board certified by the American Board of Physical Medicine and Rehabilitation. Her special interest is with Traumatic Brain Injury (TBI), since she has experienced TBI recovery, both as a physician and as a patient. In 2008, Dr. Gordon was called to action. Her one year "tour of duty" (2008-2009) included a part-time position at the Chalmers P. Wylie Veterans Administration Outpatient Clinic in Columbus, Ohio, where she performed second-level screening for the Iraq and Afghanistan veterans suspected with traumatic brain injuries. Her experiences with young heroes affected by TBI, led to the production of a documentary, Operation Resurrection, to educate the military world about the signs and symptoms of the injury, and to educate the civilian world about the difficulties with reintegration, our heroes were experiencing, as a result of their service. In 2012, Dr. Gordon founded The Resurrecting Lives Foundation which attained 501 (c) (3) status in July, 2012.

HEALING IS POSSIBLE : RESOURCES FOR TBI DIAGNOSIS AND TREATMENT

BRAIN INJURY ASSOCIATION OF AMERICA

BRAIN INJURY ASSOCIATION OF AMERICA
www.biausa.org

VA | U.S. Department of Veterans Affairs

UNITED STATES DEPARTMENT OF VETERANS AFFAIRS
www.va.gov

CNS CENTRE FOR NEURO SKILLS®

CENTRE FOR NEURO SKILLS
www.neuroskills.com

Elizabeth Dole Foundation
CARING FOR MILITARY FAMILIES

THE ELIZABETH DOLE FOUNDATION
www.elizabethdolefoundation.org

National Resource Center for TBI

NATIONAL RESOURCE CENTER FOR TRAUMATIC BRAIN INJURY
www.tbinrc.com

RESURRECTING LIVES FOUNDATION

RESURRECTING LIVES FOUNDATION
www.resurrectinglives.org

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.

Contact: Vice President of Operations
pmaloney@ljselectric.com
201-777-6625

LJS FAC/X, Inc.
430 Commerce Blvd, Unit C
Carlstadt, NJ 07072

LJS FAC/X, INC. I 430 COMMERCE BLVD, UNIT C I CARLSTADT, NJ 07072 I 201-777-6610

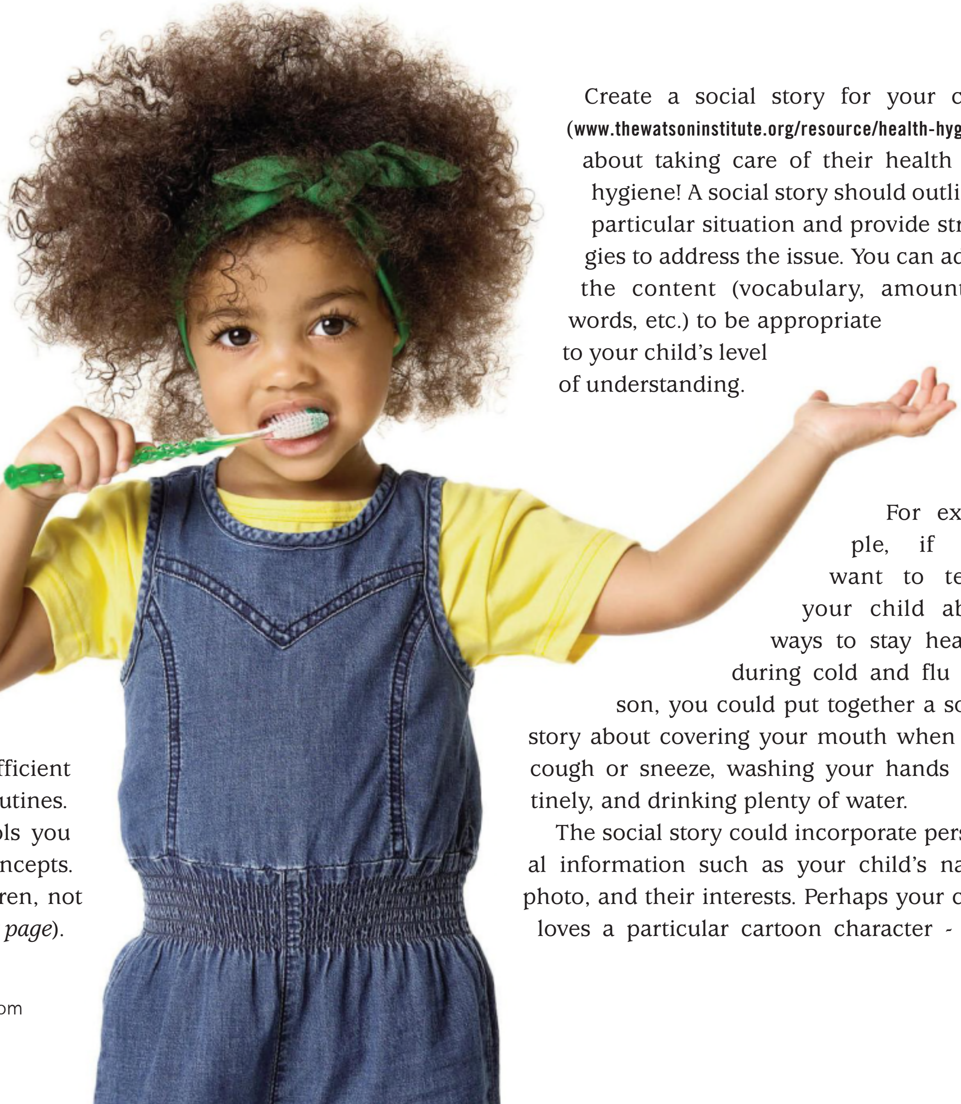
COMPETENT ■ PROFESSIONAL ■ COMPASSIONATE

LJS FAC/X

TEACHING INDEPENDENT HEALTH AND HYGIENE ROUTINES

BY ANDREA MORRIS, M.ED.

From a young age, children start to learn more about their bodies, especially as they mature and experience changes. Throughout adolescence and puberty, these changes become more noticeable.



Teaching your child how to independently care for their health and personal hygiene is a great way to help them build a positive self-image, and develop confidence in their abilities!

There are a number of factors that contribute to overall health, such as eating a balanced diet, moving and exercising your body, getting sufficient sleep, and maintaining good hygiene routines.

Similarly, there are a number of tools you can use to teach and reinforce these concepts. These tools can be helpful for all children, not just those with exceptionalities (*see next page*).

Create a social story for your child (**www.thewatsoninstitute.org/resource/health-hygiene**) about taking care of their health and hygiene! A social story should outline a particular situation and provide strategies to address the issue. You can adjust the content (vocabulary, amount of words, etc.) to be appropriate to your child's level of understanding.

For example, if you want to teach your child about ways to stay healthy during cold and flu season, you could put together a social story about covering your mouth when you cough or sneeze, washing your hands routinely, and drinking plenty of water.

The social story could incorporate personal information such as your child's name, photo, and their interests. Perhaps your child loves a particular cartoon character - you

DAILY DUTIES : CARING FOR HEALTH AND PERSONAL HYGIENE INDEPENDENTLY

Use visual supports such as a behavior chart, or a mini-schedule to encourage your child to learn how to navigate through their daily routines with greater independence.

1. A behavior chart is a simple chart or grid that can be used to track a set of behaviors or in this case, tasks. For example, you could create a hygiene chart and include tasks such as:

- ✓ *brushed teeth (morning)*
- ✓ *brushed teeth (evening)*
- ✓ *washed face*
- ✓ *put on clean clothes*

You should post the behavior chart in a prominent location, preferably in the room in which the tasks will take place, such as the bathroom in this example. Consider laminating the paper, or placing it in a plastic page protector, and using a dry erase marker so it can be reused repeatedly!

Every time your child completes one of the activities on the chart, encourage them to place a check in the appropriate box to indicate its completion. This serves as a visual reminder for them as well as a way for you to ensure they are taking care of their personal hygiene independently!

SAMPLE BEHAVIORAL CHART

TASK TO COMPLETE	MON.	TUES.	WED.	THUR.	FRI.	SAT.	SUN.
Brushed My Teeth (morning)							
Bathed/showered							
Washed My Face							
Cleaned My Ears							
Put on Clean Clothes							
Put on Deodorant							
Brushed/combed my hair							
Brushed My Teeth (before bed)							

SAMPLE MINI-SCHEDULE
Getting Ready Morning Routine

Brush Teeth	Wash Face	Put on Clean Clothes	Put on Deodorant	Brush or Comb Hair
1	2	3	4	5

2. A mini-schedule can be used to break down an activity into a series of tasks, providing step-by-step visual representations of each task, written explanations of the tasks, or a combination of the two.

It's called a mini-schedule because it should be just that - mini! It shouldn't be used to map out the entire day or even a large portion of the day's agenda. Rather, it could be used in conjunction with a behavior chart to outline each step in your child's hygiene routine, or reinforce how to prepare a healthy snack, like an apple to eat at snack time.

Mini-schedules are really versatile and can be easily customized to best suit your child's needs. Don't be afraid to get creative with it! Use pictures or graphics to represent each step. Including a favorite story character or super hero can really grab your child's attention and increase his or her "buy-in" to the system.

Bonus tip: *A great way to reinforce your child to actually use the mini-schedule and follow each step, is to add a place at the end for your child to earn a highly desired item such as a toy, book, or 10 minutes of iPad time! This lets them know that they will earn a reward for completing the task as outlined.*

For more about teaching independent health routines, including prepared social story templates on health and hygiene topics, visit www.thewatsoninstitute.org/resource/health-hygiene

could create a social story explaining how that cartoon character always covers his mouth when he has to sneeze and is sure to drink plenty of water when his allergies act up!

Adding these personal touches makes it more fun and relatable for your child! Be sure to read through the social story together at first and explain any concepts or topics that aren't clear to your child. Once they have a better understanding of these topics, you can adjust the social stories as needed.

The combination of visual resources and social stories is an effective way to teach your child about maintaining their overall health and establishing good hygiene routines. •

ABOUT THE AUTHOR:

Andrea Morris, M.Ed. has more than 30 years of experience in special education and currently works as an educational consultant for the Watson Institute. She has a Masters of Education and M/PH Certification to work with students with mental or physical disabilities from the University of Pittsburgh. In her current role, Andrea provides training and consultation to educational teams serving students with disabilities in a variety of educational settings. Her areas of expertise include: autism and related disorders, inclusive practices, positive behavior support, naturalistic and structured teaching strategies. Prior to her work at Watson, Andee was an Early Childhood Consultant for the Early Learning Institute, Developmental Specialist for LEAP Pre-school and a Head Teacher for North Area Preschool. She has authored several journal articles and is a skilled presenter.

IMAGES COURTESY ANDREA MORRIS / WATSON INSTITUTE

A GOOD LOOK: Montclair Audiology Clinical Professor Alexis Rooney examines a student's ear with an otoscope at a Newark school; The hearing screenings provide a public service and give audiology students hands-on experience.

Montclair audiology students offer hearing screenings to Pre-K and kindergarteners in community schools

HAPPY TO HEAR THAT

BY SYLVIA A. MARTINEZ

Skylah, a Pre-K student at a school run by The Leaguers, Inc. in Roselle, NJ, holds a paper cookie to her left ear. She's wearing headphones attached to one of the portable audiometers the Montclair State University students and professors have brought to the school.

Upon hearing a beep, the three-year-old gives the cookie to Quinley, the mouse from the children's book If You Give a Mouse a Cookie, as instructed by Gita Balser, a second-year Montclair audiology student.

Nearby, first-year audiology student Grace Gleba works to get a 4-year-old boy to play a similar game as she checks his hearing. "If you hear a beep, throw the bean bag in the bucket, okay?" Gleba instructs him.

Jowel holds the bean bag to his left ear. But after the beep, nothing.

"Did you hear the beep?" He nods.

"Was it this ear or this ear?" Gleba asks, pointing to the red and blue headphones he's wearing. He points to one ear, then the other. Audiology Clinic Director Faith Mogila steps in to help, challenging the boy to beat her at tossing the bean bag into the bucket. They continue working with him, ultimately determining that he can hear, he's just quite shy. Jowel moves on to an otoscopic examination with first-year audiology student Max St. Germain.

In all, on this day about 40 Roselle children had their hearing screened using the audiometer and a visual ear examination with an otoscope. In addition, they underwent an otoacoustic emission test, which involves placing a tiny device in the ear that emits sound and records an echo, measuring cochlear function. It's commonly used with babies and small children because it doesn't require a behavioral response from them.

PHOTOGRAPHS COURTESY MONTCLAIR STATE UNIVERSITY AUDIOLOGY CLINIC

CHECK IT OUT: Second-year audiology student Cindy Fernandez tests a Newark child's hearing using an audiometer; Audiology students were challenged to come up with new activities to make the assessments more entertaining and less scary for the 3- to 5-year-old children.

The four Montclair students in Roselle are among 13 audiology doctoral students dispatched to three Early Head Start and Head Start programs run by The Leaguers, the oldest incorporated African American social service agency in New Jersey. The nonprofit organization provides services to 1,700 low-income families in Essex and Union counties. The hearing screenings, part of a partnership with the New Jersey Department of Health's Early Hearing Detection and Intervention, provide a public service and give audiology students hands-on experience. Audiology students in the University's Department of Communication Sciences and Disorders also provided hearing screenings to athletes who participated in the Special Olympics New Jersey Summer Games in Ewing Township in mid-June.

On that day, screenings were also taking place in Irvington and Newark – the same day news of Mattel's release of a new Barbie with hearing aids made the rounds among the students. The activities used during the screenings are meant to make the assessments more entertaining and less scary for children. Audiology students were challenged to come up with new age-appropriate activities that could be used to condition a child from 3-5 years of age. Gleba's idea for the mouse-and-cookie activity, sparked by a trip to her mother's basement where her mom still keeps all of her childhood toys, was approved for use. In fact, it was her stuffed mouse that was used at the Roselle school. At The Leaguers school in Newark, five Montclair students used toy elephants and building blocks to engage the children.

Second-year audiology student Sean Kleczkowski conducted his first screening of young children in a preschool setting. "It's really important to screen their hearing because they may be missing learning in class and not even know it," Kleczkowski says.

While children are screened as newborns, as required by law, hearing issues can still develop. "They could have a late onset [or progressive] hearing loss," Kleczkowski says. "Incidents of hearing loss can double between birth and age 6, so it's crucial that we do these screenings."

Ivonne Jaramillo, a health and nutrition specialist with The Leaguers, said she and other specialists typically travel to schools to do hearing and vision screenings at the beginning of the school year, as required by the school, but that having an additional

FOLLOWING UP: Rosie Ovadia examines a child's eardrum; Parents provided consent for the screenings and received letters explaining their children's results. Any student who doesn't pass the screening is referred to their pediatrician and an audiologist in their area.

follow-up screening is also good. "It's important because we want early intervention," Jaramillo says. "Not being able to hear could interfere with school productivity."

Pre-K teacher Mariam Gonzales monitored the proceedings, as some of her preschoolers got tested while others awaited their turn. She was optimistic that they would pass the screening. "I haven't had any problems with them not hearing me in the classroom," she says.

Parents, who provided consent for the screenings, received letters explaining their children's results. Any student who doesn't pass the screening are referred to their pediatrician and an audiologist in their area. The parents of all the children tested also received literature explaining the importance of screening and signs of normal speech and language development.

At The Leaguers' Early Head Start and Head Start programs in downtown Newark, first-year audiology student Vanessa Coppola says she enjoyed testing the children, "It was a lot of kids and a lot of experience screening children." Some, she says, will need follow-up testing.

While second year student Gita Balser, second-year student Cindy Fernandez and third-year student Rosie Ovadia had tested young children before, more often than not these screenings are the first opportunity for Montclair audiology students to screen children, says Mogila.

At Montclair's audiology clinic, the students work mostly with adults, who are in a soundproof booth. At the Newark school, "it was interesting," says Nicole Genser, a first-year student. "We had to think about the best way to set it all out in terms of environment and noise. The kids were great."

Professor Joan Besing, director of Clinical Graduate Programs in the Department of Communication Sciences and Disorders, says going to schools sometimes affords Montclair students new experiences. "There were some students who had tubes in their ears, our students hadn't seen that before. It provides them with hands-on experience so that they become more comfortable."

There's also the added bonus of giving back while also learning. "It's really rewarding to be able to do screenings for one's community," says Fernandez. "We're applying our knowledge for the better good."•

ABOUT THE AUTHOR:

Sylvia A. Martinez is a Montclair State University Staff Writer.

3 WAYS EDUCATORS CAN HELP PARENTS CONFIDENTLY ADVOCATE IN SPECIAL EDUCATION

BY JENN ADAMS

Something that's becoming more evident is advocacy in special education. More and more parents want to be advocates for their children's needs in education. The stress on the families to advocate for their children can be overwhelming.

It's hard for families to understand all the information and phrases used. Remember, many don't have a degree in education. Let's talk more about making informed decisions when advocating for a child with a disability. These are things that teachers, administrators, and providers can do to support families and work together as a team. Ultimately, we must remember that we all want the same thing, for the child to succeed.

FIRST STEPS FOR ADVOCACY IN SPECIAL EDUCATION

First, advocacy is when someone helps you express your views and helps you stand up for your rights. An advocate takes action to create change. The advocate will tackle an issue for the betterment of the child. The advocate voices the needs of the child to drive the decision-making in a meeting or on an educational document.

Next, is communication. Hopefully, it's set up before any meetings through the use of communication logs or regular phone calls and emails. Make this the first thing you set up with the family at the beginning of the school year. Just ask the family what means of communication and time of day works best.

Before you meet with the family, make sure you send the draft of the document, prior to the meeting. This will ease tension and nerves. It helps all parties feel more prepared for what will be discussed in the meeting.

Lastly, make contact with the family a day or two prior to the meeting to see if they have questions after reviewing the documents. This gives the school a chance to find answers more easily. Then everyone can leave the meeting more confident that things are resolved. One of the worst things is when you leave a meeting with more questions than answers.

LINGO FOR ADVOCACY IN SPECIAL EDUCATIONE

There are many words and acronyms in the field of special education. It is very overwhelming to someone new. In meetings, parents' heads are spinning when the professionals at the table start using acronyms. In meetings, common acronyms are "LRE, BIP, & AAC." "LRE" stands for "least restrictive environment", "BIP" stands for "behavior intervention plan" and "AAC" stands for "Alternative Augmentative Communication."

While in meetings, ask frequently if parents understand or need further clarification. Another suggestion is to use the acronym, but immediately follow that acronym by stating what it means. I do this especially if they are acronyms that I think the parents may not have heard before.

I keep a "cheat sheet" at the table of acronyms and terms for any team member to reference during the meeting.

ADVOCACY BY KNOWING RIGHTS

Families do not necessarily feel comfortable knowing what they can do or ask in a meeting for a child with disabilities. This is an opportunity to sometimes ask questions for the parents. These questions might include things like:

- *Can you explain what that IEP goal might look like in the classroom?*
- *Where and when will you be providing that service?*
- *What areas does that assessment focus on?*
- *Why is that IEP goal-relevant for the student?*
- *What is the timeline for the completion of that assessment or evaluation?*
- *What are the next steps from here? Discuss timelines.*

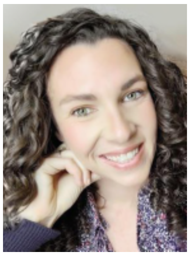
KNOWING THE PROCESSES AND PROCEDURES

Every school and district are different in the way that they do things in special education. In different states, there are different laws and policies that should dictate the way schools work with students and families in providing education.

As the teacher and IEP case manager, it is your job to support families in understanding the timelines and procedures for different parts of the process like: how an evaluation for a new service might take place, as well as the timeline for getting documents prepared, signed, and put into action. This needs to be communicated with families. It helps them understand their rights and when to ask if something isn't going as planned.

In conclusion, these few things can be done to help families advocate for their children with disabilities, in school. It can be very stressful for parents to learn about what their child needs and how to get it. As a professional, it is your job to make sure that the family and child feel comfortable with the information and the processes. •

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.

WHAT IS A CARE PLAN AND WHY SHOULD WE HAVE ONE?

BY JOSHUA FISHKIND, J.D., MBA

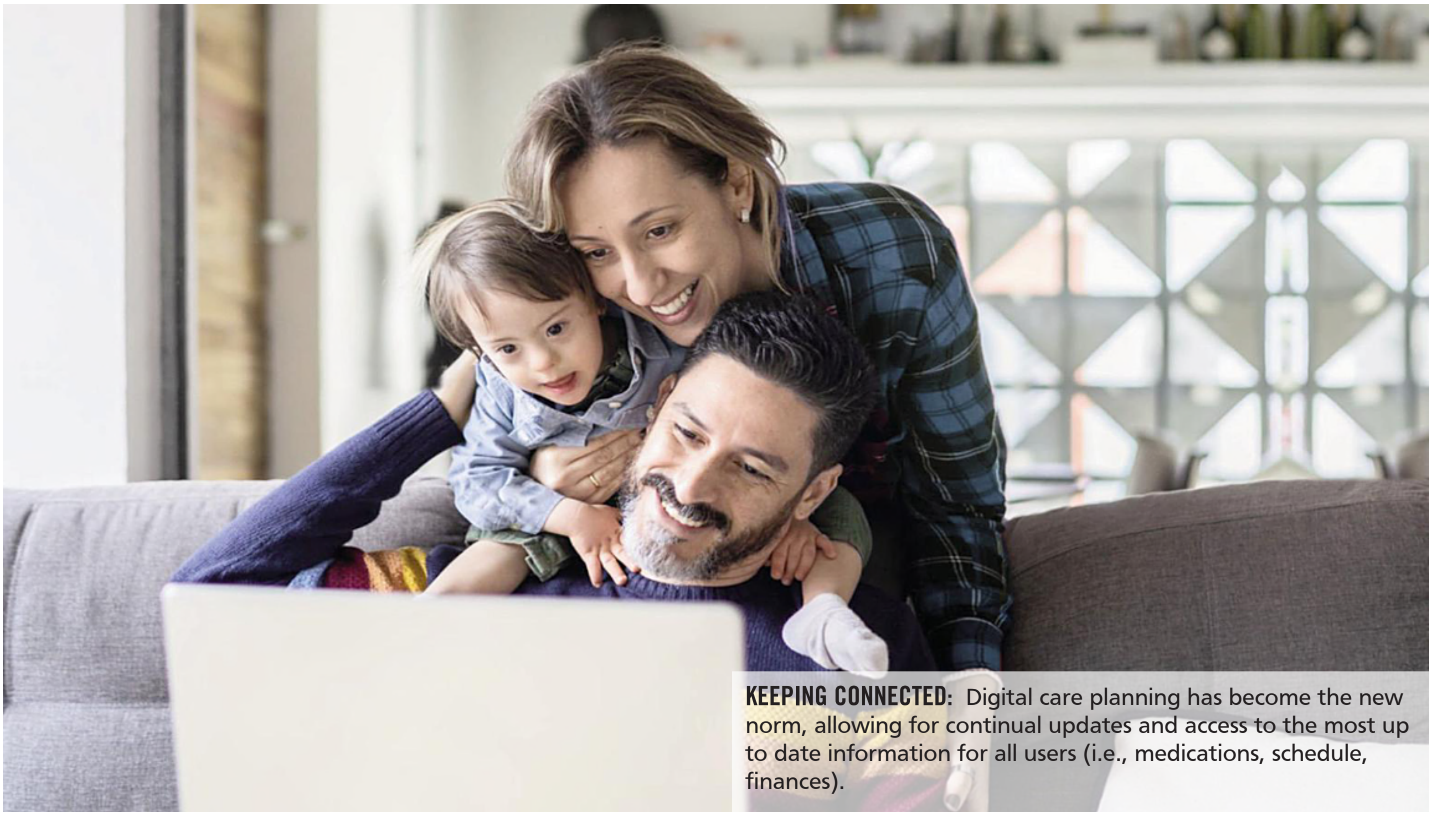
Creating an estate plan for your family involves three different kinds of planning: legal, financial, and care. Every family needs an estate plan which may include wills, living wills, powers of attorney, and sometimes trusts. For families providing support for a loved one with special needs, this often includes a Supplemental Needs Trust (SNT). Unfortunately, nowhere in the trust are your loved one's daily living needs or nuances addressed. Your SNT creates the framework for protecting government benefits and a vehicle for preserving assets for your loved one's needs.

Every family should also have a comprehensive financial plan. A good financial plan will include a review of retirement objectives, life insurance strategies, and investment management strategies. Rarely, does a financial plan include costs specific to a loved one's disability, medical expenses, therapies, or other costs that may exceed standard formulas. Moreover, government benefits, such as SSDI, Medicare, and Medicaid, are not commonly incorporated into calculations for your loved one's lifetime needs. Your financial plan will identify resources that may be used to address your loved one's needs, perhaps by funding the SNT, but doesn't speak to practical, daily concerns.

For families like ours, a care plan is the crucial third leg of the stool, the document that ties financial and legal planning together into a special needs focused action plan. Many estate planners will recommend that caregivers write a letter of intent with thoughts on their loved one's care or how funds should be used. However, letters of intent are often a simplistic set of aspirations; this is only a small portion of what a care plan should encompass.

A good care plan should be a method of sharing and coordinating information specific to the individual with special needs, such as medication instructions, emergency procedures, food preferences, social activities, and more. This document should be extremely comprehensive, from overarching topics like medical, social, legal, and financial needs, to day-to-day topics like the way your loved one likes their sandwiches cut or their preferred fidget toy. A care plan is a way to bring together the circle of support around your loved one, making sure that everyone is on the same page, from family and friends, to an interdisciplinary team of professionals. Additionally, a care plan should incorporate the individual's hopes and dreams for their own future, as well as their caregivers wishes. As life circumstances change, so too should your care plan.

There are many approaches to creating a care plan. Nurses, social workers, or care planning attorneys are one way of creating a care plan, however, families often find that they don't remember to reengage professionals for updates, or that they have stored their plan with the rest of their legal and financial documents – out of the way and forgotten.



KEEPING CONNECTED: Digital care planning has become the new norm, allowing for continual updates and access to the most up to date information for all users (i.e., medications, schedule, finances).

Recently, digital care planning has become the new norm, allowing for continual updates, as well as a number of other advantages:

1. *Bringing together all family, caregivers, trustees, and stakeholders on one platform, where they can see and share relevant information;*
2. *Easy to update as life happens and things change (for instance: medication updates, doctor changes, evolving housing circumstances, etc.);*
3. *Inclusion of a document storage and sharing system attached to the care plan, keeping all relevant information in the same place;*
4. *Access to the most up to date information for all users (i.e., medications, schedule, finances).*

This critical data can then flow back to the attorney and the financial planner, to help incorporate your family's specific circumstances into a holistic plan. The financial planner can then know your loved one's needs and plan accordingly for how much money is needed (e.g., what type of housing should be provided, what types of benefits, what kinds of care and support). Attorneys can also understand how much money will be in the trust, what are the goals, and therefore what type of trust should be created. The care plan can guide this process, in addition to guiding future caregivers and trustees who will support your loved one.

Unfortunately, we have all heard the horror stories of individuals left unattended in group homes or residential settings. Sometimes, this is not because of a lack of resources, but is instead, a lack of proper planning. When done properly, a care plan can enhance the quality of life of your loved one and bring relevant parties into the fold. It gives a voice to your wishes and incorporates your loved one into the planning process, thereby maximizing the impact of the financial plan.

SURVEY SAYS : PREPARING A CARE PLAN

Do you need a care plan for your loved one? Take this quick survey to find out if digital care planning is right for you.

- Can your loved one fully advocate for themselves? ☐ Yes ☐ No
- Does your loved one understand their own strengths and weaknesses? ☐ Yes ☐ No
- Will they seek help when they need it, absent a structured approach to do so? ☐ Yes ☐ No
- Would all medical, legal, financial, or social needs that exist be met without guidance? ☐ Yes ☐ No
- Do your professionals understand your care planning goals, such that they are integrated into a holistic plan? ☐ Yes ☐ No
- Are you confident that your wishes and intentions for your trust would be fulfilled without additional guidance? ☐ Yes ☐ No

If you answered no to any of these questions, chances are that you should have a care plan in place to protect your loved one. •

ABOUT THE AUTHOR:

Joshua Fishkind, J.D., MBA is the CEO and a co-founder of Hope Trust, a full-service care planning company dedicated to helping families plan for their loved one with special needs, provide daily care management and support, and administer special needs trusts.


Team of Special Needs Experts
Financial Advisor
Special Needs Trust
Life Care Plan

HOW DO I ENSURE MY ADULT DISABLED CHILD RECEIVES APPROPRIATE HEALTH CARE AND GOVERNMENT BENEFITS UPON REACHING THE AGE OF 18?

BY BETH C. MANES, ESQ.

Although reaching the age of 18 signifies attaining adulthood for legal purposes, few 18-year-olds are able to be completely independent. When someone with disabilities reaches the age of 18, parents must consider not just continued support, but also protection. For example, some disabilities impact a person's ability to read social cues, which leaves them vulnerable to nefarious people and financial exploitation. Fortunately, there are steps parents can take to protect their adult disabled children, while still encouraging as much independence as is appropriate.

LEGAL DOCUMENTS

If an adult child has the capacity to understand and sign documents authorizing others to act on their behalf, then parents should consider a Power of Attorney, Health Insurance Portability and Accountability Act (HIPAA) Release, and Health Care Proxy.

Durable Power of Attorney: A Power of Attorney (POA) is a written document in which one individual appoints another as an agent who has authority to act on their behalf. The word “durable” simply means it remains in effect even when the person who signed it becomes disabled. In this document, an adult child would authorize their parent(s) to act on their behalf with respect to financial and legal affairs. For example, the parent(s) would have the authority to communicate with insurance companies and government agencies who might provide services the adult child needs. A POA would only be appropriate if the adult child has the capacity to understand the document being signed.

HIPAA Release: Once someone turns 18, that individual’s parents can no longer access their health information without written consent. A HIPAA release allows parents to access their adult child’s medical records and receive medical updates. This document is also only appropriate if an adult child has the capacity to understand the document being signed.

Health Care Proxy: Another document an adult child can sign is a Health Care Proxy (HCP). In this document, an individual appoints someone to make medical decisions for them if they are unable to do so themselves. Again, an adult child cannot be asked to sign this document unless they have the capacity to understand it.

> **“There are many vehicles available to parents to protect and advocate for their children, while still encouraging them to be as independent as possible.”**

GUARDIANSHIP

If an adult child is unable to understand the above documents, then parents should consider a protective arrangement, such as a guardianship. In New Jersey, this requires certifications from doctors stating the alleged incapacitated person’s (AIP) diagnosis and prognosis. The doctor is also asked to opine as to how the disability impacts the AIP’s ability to be independent. Sometimes, only a limited guardianship is necessary. Perhaps an AIP is able to make decisions in certain domains, but not others. For example, although someone needs support with banking and healthcare, they may be independent with respect to vocational decisions.

GOVERNMENT BENEFITS

Once parents have ascertained the level of support their child needs, they should address issues of health care and government benefits. If an adult child is on their parents’ health insurance plan, the parents should inquire how long an adult disabled child can remain on the plan. It is possible that if the child is disabled, they can remain on the policy beyond age 26. Regardless, parents should consider applying for certain government benefits for their adult disabled children.

Supplemental Security Income (SSI): SSI provides minimum basic financial assistance to older adults (65+), and persons with disabilities (regardless of age), who also have very limited income and resources. Social Security has its own definition of disabled (related to anticipated length of disability, and ability to perform work).

Medicaid: Medicaid provides health insurance. If a person qualifies for SSI, they typically automatically qualify for Medicaid.

Division for Developmental Disabilities (“DDD”) Services: *(If you are not in NJ, please check your state eligibility criteria)* In NJ, DDD provides services to individuals who have reached the age of 21 and meet the eligibility criteria. DDD eligibility requires that an applicant:

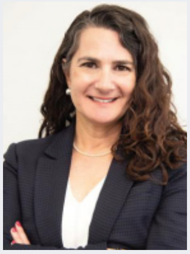
- be a New Jersey resident,
- be Medicaid eligible, and
- meet the functional criteria of having a developmental disability – in order to establish this last factor, an applicant must document a chronic physical and/or intellectual impairment that:
  - manifested before age 22,
  - is lifelong, and
  - substantially limits the individual in at least three of the following life activities:

self-care; learning; mobility; communication; self-direction; economic self- sufficiency; and the ability to live independently.

As disabled children reach adulthood, there are myriad issues to be addressed. Fortunately, there are also many vehicles available to parents to enable them to continue to protect and advocate for their children, while still encouraging them to be as independent as possible.

Consult a professional to discuss your options, and decide whether you should have your adult disabled child sign documents granting you authority to act on their behalf, or if a court ordered protective arrangement would be more appropriate.•

ABOUT THE AUTHOR:



Beth C. Manes, Esq., is a founding member of Manes & Weinberg, Special Needs Laywers of New Jersey, LLC. She is licensed to practice law in New Jersey, where she has been practicing for over 25 years. Her practice concentrates in Special Education Law, Special Needs Planning, Guardianships and Estate Planning. Beth is also active in her community, raising puppies for the Seeing Eye of Morristown, and serving as a member of her synagogue’s Accessibility and Inclusion Task Force. Beth resides in Essex County with her husband, several dogs, and whichever adult children are home at the time. Beth loves to travel; her favorite vacations are on a bicycle, in a tent, or observing animals not typically found in New Jersey. Beth started her career in corporate law but did not like the impersonal nature of the practice and decided to change direction. After a few more turns in her career path, Beth searched for the field of law where she could have the most impact and discovered a love for special needs advocacy and planning. (973)376-7733 **admin@manesweinberg.com**

Have a special needs lawyer in your corner.

MANES & WEINBERG, LLC
SPECIAL NEEDS LAWYERS

Our team of attorneys, advocates, and paralegals work tirelessly and collaboratively to provide services to special needs students and adults ranging from bullying and education advocacy to guardianship and estate planning.

We are here to make your difficult times easier.

Education Advocacy Services

Protection for Young Adult Children

Wills and Estate Planning Special Needs Trusts

New Jersey's BEST LAWYERS FOR FAMILIES

RATED BY Super Lawyers

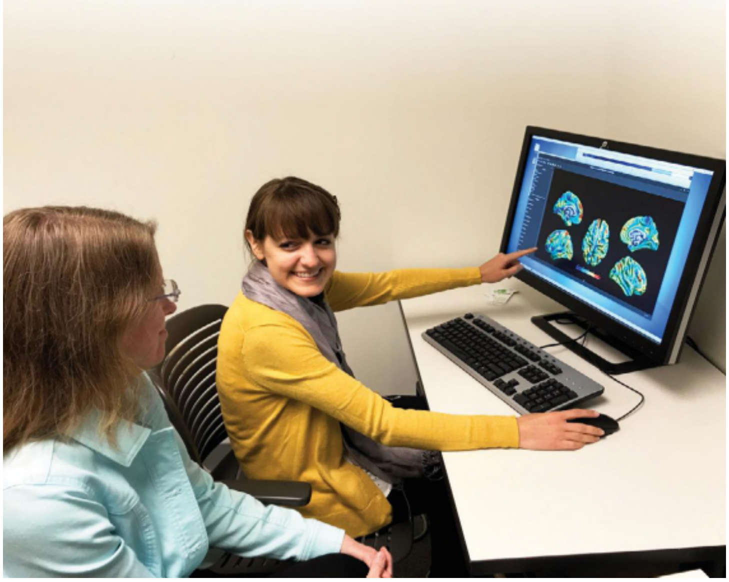
CALL OR EMAIL MANES & WEINBERG, LLC TODAY FOR A CONSULTATION:

(973) 376-7733 | admin@manesweinberg.com

BRAIN RESEARCH
IES
FOUNDATION
Since 2004

VOLUNTEERS ARE NEEDED. IF INTERESTED, EMAIL IESBRAINRESEARCH@GMAIL.COM

THE IRENE AND ERIC SIMON BRAIN RESEARCH FOUNDATION



www.iesBrainResearch.org

(973) 726-6218 • iesBrainResearch@gmail.com

FROM OUR FAMILIES… TO YOUR FAMILIES

MILITARY SECTION

U.S. MILITARY ★ BOOK EXCERPT PART III

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 fifth chapter in a series of articles about this process.

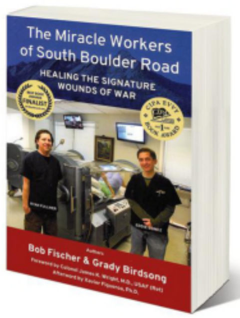
CHAPTER 5

DR. JULIE STAPLETON: IN HER OWN WORDS

Born in Detroit, Michigan, and growing up in a family of five children, Dr. Julie became interested in healthcare when her dear mother went back to school to become a nurse, motivated by the need to pay for Julie's older brother's medical school tuition. As Dr. Stapleton describes the beginning of her life's journey, "I went off to school to become an occupational therapist, but because I enjoyed and excelled in my first years of college, and combined with my mother's influence, I instead opted to pursue the practice of medicine."

Nearing the end of medical school, Dr. Julie discovered physical medicine and rehabilitation (PM&R) as a specialty. This brought her full circle back to her original interest in occupational therapy since PM&R is a specialty whose philosophy is based on providing patients the opportunity to recover from injuries and regain their maximal functional capacity. PM&R physicians are also known as physiatrists and treat a wide variety of medical conditions affecting the brain, spinal cord, nerves, bones, joints, ligaments, muscles, and tendons, focusing on the entire body in hard-to-diagnose problems.

"When I got further into rehabilitation as a specialty, I became intrigued by the opportunity to rehabilitate individuals with TBIs, especially those injured combat veterans I now interview and prescribe treatment for at the Rocky Mountain Hyperbaric clinic in Louisville, Colorado. Rehabilitation of such a devastating injury allows me, as the physician, to work closely with my patients and their families over an extended period of time, watching their initial survival from a catastrophic injury, through recovery, through the process of regaining functions, and eventually to the capacity to get back their life… that is what I find most rewarding."



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

SCREENING TIME: Dr. Julie Stapleton examining veteran suffering from TBI; When Charlie Hansen asked her about HBOT treatments, Dr. Julie told him, "I think it is safe, yet there is no concrete evidence that it works. But there is no harm in trying."

HYPERBARIC OXYGEN TREATMENT

Dr. Julie Stapleton's introduction to hyperbaric oxygen treatment came through her established medical practice in Boulder, Colorado. About ten years ago, through her patient Charlie Hansen, she became intimately involved with HBOT treatment. When Charlie asked her about HBOT treatments, Dr. Julie told him what she often told others, "I think it is safe, since it is dealing with oxygen under pressure, yet there is no concrete evidence that it works. But there is no harm in trying."

After some research on chambers, Charlie bought his chamber and installed it in the back of his Boulder business. He intended to train some of his family members and key employees to administer the treatments. However, he became quickly overwhelmed once he got the chamber, realizing he needed more help. That's when he began to look for a trained individual to operate the chamber properly, and that skilled technician turned out to be Ryan Fullmer.

HBOT is FDA not approved for TBIs or spinal cord injuries, yet the drug employed in HBOT is one of the most common in nature... oxygen.

As Ryan set up the chamber to treat Charlie, the two of them began conversing about a mutual dream of starting a hyperbaric oxygen clinic. They discussed plans to offer oxygen treatment to other patients but soon realized, per the FDA regulations, that they would need a medical doctor to screen each patient and write a prescription for the HBOT technician to operate the chamber. Quickly, they approached Dr. Julie. The beginning of the "miracle team" had begun.

As Dr. Julie recalls, "Since I was the one who wrote the prescriptions for Charlie, I also referred a couple of my other patients to them so that I could learn a little more about the treatment and witness the results firsthand." Agreeing to do so for Charlie and bringing in a few of her other patients, Dr. Julie told Ryan, "Okay, fine. I am in as medical director on one condition… it has to work! If it doesn't work, I am out of here!"

As Dr. Julie now confirms, "It has worked and has continued to be an amazingly rewarding experience."

ADMITTANCE – THE SCREENING PROCESS

Dr. Julie has become quite familiar with the technology and politics of hyperbaric oxygen treatment. She tells us that the FDA has determined HBOT to be safe and effective but has limited their approval to fifteen specific diagnoses, including decompression sickness, radiation tissue damage, diabetic wound healing, and carbon monoxide poisoning.

HBOT is not approved for TBIs or spinal cord injuries, yet amazingly, the drug employed in HBOT is one of the most common in nature... oxygen. As Dr. Julie explains it, "There is no single drug in the United States that is FDA approved to treat TBI. Every drug I use in my patient population is borrowed from another diagnosis, which is legitimate, legal, ethical, and considered safe. It is done all the time across the board in multiple specialties. I prescribe oxygen under pressure. Then I give the criteria for how much oxygen, how deep the pressure is, how frequent the treatments, and the total number of treatments that should ideally be aimed for. The only thing that the FDA controls in this situation is the oxygen." She further elaborates, "While it is safe and ethical to use drugs off-label, it is not required that insurance companies pay for things off-label, and so they most often do not."

PHOTO COURTESY GRADY BIRDSONG

Dr. Julie first screens patients for indications or conditions that might make hyperbaric unsafe. Longtime smokers, who have emphysema or potential lung cancer, or anyone who has had recent chest surgery, are considered patients who may not handle the pressure that is administered in the hyperbaric chamber. The pressure depth administered in the treatment of TBI and/or PTSD is 1.5 ATA, which is the same as 1.5 times the amount of pressure at sea level, which is roughly the equivalent of going 17 feet below sea level here in mile-high Colorado.

Dr. Julie's screening approach is simple. "My first goal is to make sure the patient doesn't have any contraindications, and my second is to provide them with education and reassurance that it is safe. My third is to start educating them on how to manage their ears in the chamber while undergoing compression. Then, finally, my goal is to answer all of their questions and again reassure them that the treatments are safe and comfortable."

TREATING VETERANS

Dr. Julie observes that the veterans who come to her are somewhat different in presentation compared to her civilian population—the traumatic events that have led to their concussive injuries (likely caused by either a blast injury or motor vehicle accident, which in turn may have been caused by the IED blast) are also very likely to be associated with significant combat experience with a possible associated secondary diagnosis of PTSD. Also, these individuals may have had multiple prior concussive events, which makes their recovery even more challenging.

In describing the phenomenon of treating both post-concussion syndrome (PCS), a minor form of TBI, and PTSD, Dr. Julie explains that "fear is a big part of the traumatic event." She takes it a step further and adds, "I believe that the fear component that these individuals are experiencing at the time of their injury directly impacts their symptoms and recovery. For example, we know that people who have had past traumatic histories are at greater risk for having more severe and prolonged consequences of a mild brain injury. It is possible these individuals are at a heightened fear response because of PTSD in the field. These veterans may be more likely to have exaggerated and/or prolonged sequelae [after effect or secondary result] of their injury. It is a true neurologic predisposition that makes them more vulnerable to these injuries."

According to Dr. Julie, a component of that PTSD can be seen "in the hyper-vigilance these individuals experience that manifests as anxiety, insomnia, and irritability—also noticeable after a brain injury. It is the association of TBI and PTSD that is very difficult to tease apart in the military patient population. It presents as a decreased capacity to manage and respond to anxiety, or to anxiety-provoking situations, compared to their pre-injury or pre-combat or pre-post-traumatic state. Significant effort is being made in both the military and civilian medical communities to help sort out and optimally treat both these coexisting conditions."

FIRST STEPS: Dr. Julie first screens patients for indications or conditions that might make HBOT treatments unsafe.

When asked if there is a connection between individuals' physical and psychological wounds, she responds, "I don't like it when people try to distinguish between neurological versus psychological, or organic versus psychological. Do they think that emotions and psychological well-being come from the heart? No, these can be manifestations of changes in the normal functioning of the brain."

EXPERIENCES

While some experts claim that TBI is a physical injury and HBOT provides the physical healing therapy for TBI, yet PTSD is a psychological injury and requires a much different therapy, she quickly responds, "Not true! They can both be organic brain injuries!" Dr. Julie believes PTSD can respond to HBOT in the chamber, and the results are optimal if supported by complementary trauma counseling during the weeks of hyperbaric therapy.

Dr. Julie honestly believes that she doesn't have all the answers for HBOT and whether it works for PTSD as well as for TBI. However, she bases her opinion of treating PTSD on the experience of having treated a civilian patient who came to her with disabling PTSD symptoms without ever receiving any physical injuries.

Her patient had witnessed a horrific motor vehicle accident, which had only narrowly missed her vehicle when she and her young children were stopped at a red light. Dr. Stapleton explains, "That woman experienced a singular moment in time, which I describe as the 'oh shit' moment, where an individual experiences the fear of death or serious injury to themselves or their loved one, and they are completely hopeless or helpless to do anything about it. That

PHOTO COURTESY GRADY BIRDSONG

THOROUGH THERAPIES: Dr. Julie in front of the second chamber; “A traumatic experience can change how the brain operates, and there is neuro-scientific evidence of that. So it is not simply psychological. It is neuro-physiological.”

moment triggered the fight or flight reaction in this patient, which then persisted, manifesting as post-traumatic stress symptomatology for well over a year. She couldn’t sleep, was hyper-vigilant, depressed, extremely anxious, couldn’t handle stress, couldn’t focus her attention, couldn’t problem solve or make decisions… classic textbook symptoms of PTSD. Finally, I prescribed forty sessions of HBOT, and her symptoms resolved.”

As justification, Dr. Julie reminds us, “This story is an example of the definition of what is required to have PTSD and how it changes one’s psyche. A traumatic experience can change how the brain operates, and there is neuro-scientific evidence of that. So it is not simply psychological. It is neuro-physiological.”

Veterans dealing with the dual complexity of PTSD and TBI receive both kinds of treatment at the Rocky Mountain Hyperbaric Institute.

She makes another important distinction about the coexistence of PTSD and concussion. PTSD doesn’t occur in other events, such as sporting events where the individual has chosen to participate in a risky activity, is aware of, and assumes that risk. These individuals may well sustain concussions and are vulnerable to multiple concussive injuries, for example, the types of head injuries that are now being recognized in the NFL, but without the coexisting condition of PTSD. “You make that choice, and you know you are going to be in a violent, potentially risky sport. You do not experience that overwhelming fear and are not at risk of triggering the fight or flight reaction. That outcome is different than somebody who gets in a car accident or, worse yet, is the victim of an assault or sustains an injury under combat conditions.”

THE HEALING TIMELINE

Dr. Julie points out that when a patient is in the chamber for the prescribed treatments, an obvious point often comes when their energy, memory, and cognitive faculties start to come back, and a new sense of wellness comes into play. At that critical point, the veteran may experience a tremendous psychological boost or a big emotional letdown. It is different for each person. “And so it does help to have a counselor on the team, like Pepe Ramirez, a combat veteran who has been there. These vets, if they do not have good coping skills or good communication skills, and if alcohol and drugs are a factor, may go back down a path of regression. Without the right kind of support system when they leave our clinic, it will look like HBOT didn’t help the PTSD.”

Dr. Julie also continues to learn from experience and her patients. She further emphasizes, “You have to look at the patient’s prior history. How did they function pre-injury? What challenges did they endure? Do they have good coping skills? Do they have good family support?” She contends that if these skills are not there to begin with, then it makes the rehabilitation process all that much harder for the patient who is dealing with the dual complexity of PTSD and TBI. At the Rocky Mountain Hyperbaric Institute, veterans benefit from integrating both kinds of treatment.

Dr. Julie further stresses that HBOT doesn’t work for everybody with TBI and/or PTSD, and forty hours in a chamber is not the magic number of treatments for everyone. It may be just the minimal starting point. Experiences with severely injured veterans who suffer from TBI and PTSD confirm this.

PHOTO COURTESY GRADY BIRDSONG

PAST, PRESENT, AND FUTURE

When asked why hyperbaric oxygen treatment is not an accepted practice in the medical community, Dr. Julie thoughtfully replies, "Because nobody knows about it yet… they look at old literature, which does not show the success and strides we have made more recently, or become understandably confused and discouraged by the research carried out by the Department of Defense. However, due to the pioneering work of Dr. Richard Neubauer and Dr. Paul Harch, there have been numerous articles, books, and well-designed studies that have demonstrated the benefit of HBOT in the treatment of mild TBIs.

Dr. Harch has been educating and documenting these benefits for several decades. Despite that, the benefits of hyperbaric therapy are often considered anecdotal, which implies favorable human interest stories suggesting good outcomes rather than solid scientific research. It has been extremely challenging to perform controlled studies in HBOT like you can with medication. It is hard to design a placebo since it is hard to fake a hyperbaric oxygen treatment. Despite that challenge, progress is being made, and evidence is mounting that HBOT is a safe and effective addition to a comprehensive multi-disciplinary treatment approach."

WHAT KEEPS DR. JULIE STAPLETON IN THE HBOT ARENA?

"Hyperbaric therapy treats the problem rather than just putting on a Band-Aid. In my treatment of patients with TBI, I first treat sleep and pain, and then I compensate for cognitive and emotional issues, mostly through medication, education, and therapy. But hyperbaric oxygen treatment does heal the brain! Long ago, I used to say that acupuncture likely works but has no good evidence-based science to back it up. Now I am an acupuncturist, and I do not doubt that it works. I also do not doubt that hyperbaric therapy will soon be readily recognized as a mainstream treatment option, as acupuncture has become."

Dr. Julie is still very much in the game because of all the success she has witnessed. She revels in the stories about veterans who tell their buddies that they should come to the clinic and try it out. One of the first questions she asks a new veteran who is checking in is, "How did you hear about us?" Their response is often, "Through a friend… another veteran you helped!"

WHAT THE VETERANS THINK ABOUT DR. JULIE AND HBOT

What is most apparent about Dr. Julie's practice is reflected in the comments of the many veterans she has treated at the clinic (and the civilian clientele). She is held in very high regard, and that respect is reflected in their comments about her.

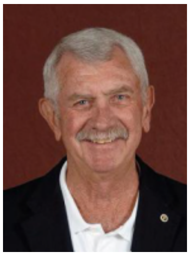
One veteran responded, "Dr. Julie. She really cares for us. You can tell by the way she talks to you and the nice way she gets your medical information that she really likes us. She puts us at ease when we first meet her, and her smile and demeanor give you a sense of confidence that she will really help heal us and make our lives so much better." •

ABOUT DR. JULIE STAPLETON

Dr. Julie Stapleton of Boulder, Colorado, joined the Rocky Mountain Hyperbaric team in 2007. She commits time and energy from her established physiatry practice to function as the medical director for the Rocky Mountain Hyperbaric Institute. Dr. Stapleton graduated from the University of Michigan Medical School in 1985 and has been in practice for thirty-one years. She completed a residency at the University of Michigan Health System in Ann Arbor, Michigan. As a clinical professor at the University of Michigan, she administered the TBI Day Treatment Program as its medical director. She currently practices at Julie A. Stapleton, M.D., and is affiliated with Avista Adventist Hospital, Boulder Community Foothills, and Boulder Community Hospital. Dr. Stapleton is board certified in Physical Medicine and Rehabilitation.

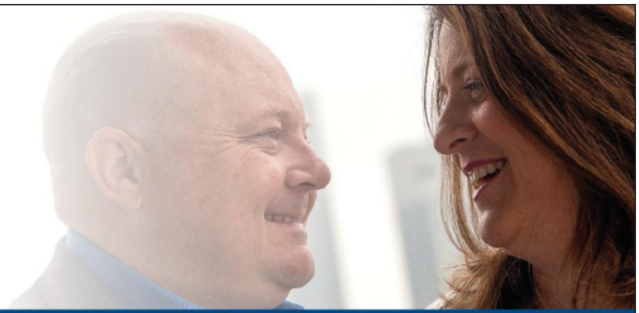
ABOUT THE AUTHORS

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.

VA Family member



As a service member's spouse, child, or parent, you share in that service member's service and sacrifice. So after your loved one leaves the service, you may qualify for certain VA benefits. And if your family member died or was seriously injured in the line of duty or as a result of a service-related injury or disease, you may receive additional assistance.

Did You Know...

- You may qualify for monthly payments that are tax-free and not counted as income.
- You may be entitled to comprehensive health care benefits and affordable dental coverage through the VA dental insurance program.
- You may be eligible for education and training assistance to earn a degree or professional certificate, become an apprentice, or learn on the job.

VA Serves Veterans

In gratitude for their honorable service to our nation, VA provides benefits to help Veterans take care of their family; buy, retain, or modify a home; earn a degree; start a career; stay healthy; and do so much more in their life after the military.

VA also recognizes the family members who support Veterans and service members. Explore these VA benefits that may be available to spouses, dependents, and survivors:

- **Monthly payments.** Under the Dependency and Indemnity Compensation program, VA provides income to certain surviving loved ones of deceased Veterans and service members. Annual payments average about $15,500 to spouses and $7,000 to children. Spouses or children of service members who died while on duty or survivors of Veterans who died from their service-connected disabilities may qualify. Parents may also benefit.
- **Health coverage.** Under the Civilian Health and Medical Program of VA, the medical expenses of spouses and children of Veterans may be covered in whole or in part. To qualify, the Veteran must either be rated permanently and totally disabled due to service or have died while rated as such or as a result of service or a service-connected disability.
- **Education, pension, home loan, and other benefits.** You or your children may have earned education benefits to pay for college or training. Survivors of Veterans who are of limited means may qualify for VA pensions. As a surviving spouse, you might qualify for a VA home loan. In addition, you or your children may receive burial benefits and many other services.

Find Out How You Can Benefit

Explore VA benefits for spouses, dependents, and survivors, including eligibility rules and how to apply, at **VA.gov/family-member-benefits**.

/VeteransAffairs
@DeptVetAffairs

EXPLORE VA BENEFITS AT
VA.gov

Choose VA

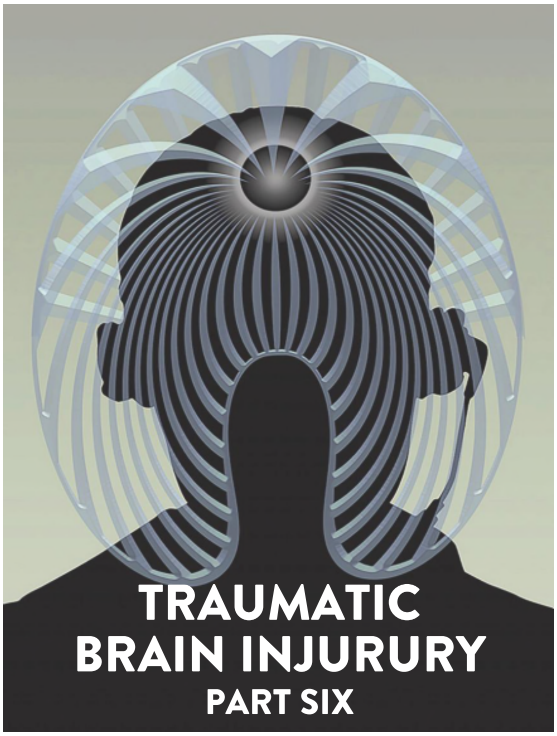
U.S. MILITARY ★ PTSD SERIES PART VI

Origins of Anxiety: from Infancy to War

BY RALPH CANCRO, PHD AND LORRAINE SILVETZ, MSW

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 (TBI), post-traumatic stress disorder (PTSD), and related health issues. In this month's article, researcher Dr. Ralph DePalo explores the role that hope and spirituality can play in a servicemember's life by reviewing the literature which chronicles the findings of noted professionals working in the areas of hope and spirituality and the connection that these have to recovery. The article also examines hopelessness and its connection to depression. Understanding the psychological workings of the process of being hopeful or hopeless can help servicemembers cope with a newly acquired condition or disability. For family members, understanding hopefulness and hopelessness can shed light on what a loved one is going through so that more effective support can be offered.

The history of mankind is replete with trauma. It has long been known that traumatic events can produce serious emotional reactions. Whenever troops are deployed, psychological casualties will result. With the advent of post-traumatic stress disorder (PTSD) as a distinct psychiatric diagnosis, victims of severely stressful events are regarded as suffering from a specific mental disorder, originating from a specific traumatic event.



The DSM-IV (1994) clarified Criterion A of PTSD: "The person experienced, witnessed, or was confronted with an event(s) that involved actual or threatened death or serious injury." Recurrent and intrusive distressing recollections and dreams of the event (including images, thoughts or perceptions, and dissociative flashback episodes, illusions, hallucinations, and other instances of acting or feeling as if the traumatic event were recurring) characterize Criterion B.

The Nature of Anxiety

Anxiety has played a major role in the development and history of man. Anxiety is a major symptom of posttraumatic stress disorder (PTSD). To understand the origin and nature of anxiety, we must return to a person's childhood to get the full picture.

Powerful Influence in Maturation

Anxiety is prominent from the standpoint of individual character formation and personality development. Infantile behavior and childhood standards are substantially developed and modified so as to conform according to the wishes of significant adults.

This modification is accomplished largely through the desire for approval, acceptance, and love, the absence of which gives rise to anxiety. Anxiety can be destructive or constructive, or both.

Principle of Universality

Anxiety is experienced universally; everyone seeks to avoid anxiety. As a result of unconscious efforts at its avoidance, mental mechanisms come to be employed and psychological defenses are evolved.

Symptom formation may result. The symptoms, which develop in emotional illness, can be considered the result of defensive efforts versus anxiety.

Anxiety: Normal or Pathological

Anxiety arises in response to danger or threat. The source of this danger or threat is largely unclear. Anxiety can comprise an alarm-like reaction, appearing when there is a threat to the person and becoming abnormal only in terms of its intensity, the cue which evokes it, and the form that it takes.

Anxiety Defined

Anxiety is the apprehensive tension or uneasiness that stems from the subjective anticipation of imminent or impending danger in which the source is not always known or recognized.

Thus, the reaction that is experienced is out of proportion to any known stimulus or clearly recognized threat or danger. Its overall net effect for the individual concerned can be constructive or destructive.

In contradistinction, fear is the emotional response to a consciously recognized and usually external threat or danger.

Anxiety and fear are accompanied by similar physiologic changes. These changes are an important part of the individual's total response to crisis, and include all those preparations intended to help prepare the person for any physical or other kinds of activity that may seem necessary to cope with that threat. Anxiety may also be defined as fear in the absence of an apparently adequate cause, sometimes referred to as free-floating anxiety.

Emotional Conflict

There is a relation to anxiety and its role in the initiation of emotional symptoms. A clash exists between two emotional forces: instinctual drives versus prohibiting personal and social standards. The result of the above is conflict.

Conflict is defined as the clashing of two opposing interests. Emotional conflict takes place between the instinctual drives (id) of the personality and the demands of the conscience (superego) or society. The ego serves as the mediator but is also the battleground. Emotional conflict may be conscious or unconscious; the latter has the greater psychopathological import.

Conflict/Anxiety/Repression/ Symptoms

Customs and restrictions of society block or frustrate fulfillment of instinctual drives. The most important and basic intrapsychic conflicts from the standpoint of psychopathology occur or relate to the sexual and aggressive types of drives. These drives may be categorized as those concerned with the preservation

YOU ARE NOT ALONE : A INTERVIEW WITH AN ANONYMOUS MARINE

Editor's Note: This narrative was penned by a concerned former United States Marine Corps Non-Commissioned Officer. Lorraine Silvetz, the co-author of this feature article, had the opportunity to talk with him extensively as the article was researched and written.

When I was five years old, my family was in a terrible car ccident. We were hit by a drunk driver. My mother was killed instantly and my brother left in a permanent coma. I remember thinking we were being hit by an ice truck since there was a lot of shattered glass. When the car stopped, my father said, "Are you okay?" and pulled me out of the wrecked car. When I saw my mother, her neck was pulled back more than humanly possible, and she had a big gash across her forehead. My father kept shaking her saying, "Lee, wake up. Are you okay?" That was the last time I ever saw my mother. I have no recollection of what happened to my brother, which haunts me to this day. In the emergency room, a nurse came to me and put me on her lap saying, "Your Mommy went to heaven." At first, I couldn't comprehend what she meant, and then when I understood, I started to cry. Soon after, my father came out and walked over to me and said, "Real men don't cry."

The years passed, my father eventually remarried, and my brother continues to remain in a coma. After high school, I decided to join the United States Marine Corps.

Upon entering the Marine Corps, I became immersed in training, my duty, and my schooling in an effort to improve myself and become a good Marine. I was constantly volunteering to go on any assignment that entailed risk. My first assignment was extracting land mines in certain areas, since I was trained as a combat engineer. In my first exposure to combat, I witnessed a Marine get blown up, which gave away our position, subsequently drawing attention from enemy forces who opened fire. My brain felt like it was rattled from the explosion,

but eventually, I got up, carried the wounded Marine to safety," "and began firing back at the enemy in a murderous rage, killing several of them.

After returning to my base camp, I volunteered for another assignment. I had thought we were supposed to be building refugee camps, but we ended up receiving enemy fire from guerrilla forces. This resulted in more loss of life. At the end of my tour of duty, I returned to the United States to serve in Headquarters Marine Corps, Quantico.

After a time, I began to have nightmares, waking up with incredible feelings of anxiety, shortness of breath, and heart palpitations. I started experiencing these feelings during the day, along with vivid memories of the traumatic events I'd experienced overseas. I am a devout Catholic, and I began having feelings of deep remorse for the people killed in combat. This caused overwhelming anxiety for me. I had brought up some of the details of this experience to my ex-wife, and she said, "You are a Marine, and you are supposed to be stronger than that." I felt very alone and embarrassed to express my feelings.

(cont.)

YOU ARE NOT ALONE : A INTERVIEW WITH AN ANONYMOUS MARINE (cont.)

I was honorably discharged from the Marine Corps, but the overwhelming feelings of anxiety remained. I experienced it quite intensely at my first civilian job, due to a very stressful work environment. I was working with equipment worth millions of dollars. The stress caused me to have angry outbursts with my peers and superiors. My boss, a Vietnam veteran, also had anxiety and was prescribed Valium. He noticed my anxiety and offered me one of his Valiums. The first time that I took one I felt no anxiety or mental anguish whatsoever. I was completely relieved, so I would keep asking my boss for Valium, which he was willing to give me. I finally went to the doctor and got a prescription.

I still continued to have some anxiety as well as nightmares, but I always knew I could turn to the medication for relief. Knowing alcohol and medication could give me relief, I started using them more and more. I finally received medical help through a good friend of mine who introduced me to a psychiatric treatment team at a prestigious hospital. Since then, my anxiety level has lowered a great deal, although in situations such as large crowds, traffic—basically any situation that is not in my control—I still experience intense anxiety. Occasionally, I take more meds than are prescribed and feel the need to take the edge off but not to completely numb myself as I had before treatment. I don't know when or if my anxious feelings will ever completely go away, but I continue to go to therapy twice a week and receive medication modification to continue making progress.

I know I am not alone with respect to the problems I face. I know there are many others who have experienced much worse situations than I did. The purpose of telling my story is to alert others to not give in to overmedicating themselves and other negative behavior, such as the use of alcohol in combination with medications. One of the best ways of dealing with this is to talk about your feelings with people you trust. I recommend that you find a therapist to help you open up. Don't be discouraged if you don't find the right therapist or psychiatrist right away. Keep looking around until you find the one who makes you feel safe enough to expose all the pain you are carrying. Even with this help, you may still suffer from some anxiety, but always keep in mind that there are others who experience similar anxiety. Everyone has a cross to bear. It may not be as bad as yours, but they don't manufacture anxiety medications just for us. Posttraumatic stress disorder (PTSD) is a widespread problem. There are those experiencing PTSD who are victims of sexual and child abuse, domestic violence, natural disasters, terrorism—basically, anyone who experienced a situation of life-threatening danger. Any of these experiences can emotionally scar you. Remember, you are not alone in your struggle with this diagnosis, and there are people who want to help. Remember also that PTSD is not something to be ashamed of.

A final caveat: The improper use of illicit or prescription drugs will temporarily alleviate symptoms but will cause you more complications down the road. Don't be afraid to tell your psychiatrist if the medicine is not working. Make sure that it is right for you. Combine medication with therapeutic work. The combination is what has helped me the most. You must express your deep-rooted feelings to get rid of what ails you. Pent-up emotion, anger, anxiety, and pain is equivalent to a pressure cooker. All these feelings will eventually overwhelm you and will lead to inappropriate blow-ups towards family and friends, especially those who care about your well-being the most.

Don't give up finding the person you can confide in. You will struggle, but we all endured struggle, whether in boot camp training, or combat, and we have always been in stressful situations. This is a battle, too, and you can't give in to temporary fixes. Remember that we've honored our country, so don't disgrace your honor by destroying yourself with drugs or alcohol. I have tons of medals hanging on my walls, tons of certificates, letters of commendation, and I'm not going to disgrace all that with drugs and booze. There are men that came before us that have made these medals possible to receive, and we don't want to disgrace their valor and bravery as well as our own.

of the race and those relating to self-preservation.

Sexual thoughts and strivings and those with a hostile, aggressive, or acquisitive coloring are not only likely to be stronger drives, but also are more likely in turn to be met by stronger opposition from personal or social standards when there is conflict.

It is the repressed (unconscious) or partially repressed conflicts which are most important in symptom formation. The repression takes place as an attempted resolution of the conflict. When lifting of the repression is threatened, anxiety is subjectively experienced.

This is one reason interpretations must be carefully timed; otherwise it can swamp the personality with anxiety.

Emotional Conflict Defined

An emotional conflict occurs when clashes take place between one's moral, social, and personal standards on the one hand, and one's egocentric and instinctual strivings on the other.

Anxiety arises from conflict. Anxiety leads to repression. The repressed data leads to symptom formation. The infant possesses a keen ability to sense intuitively the presence of all kinds of emotional feelings, especially including anxiety, indifference, resentment, and hatred.

Instincts and Acculturation

The so-called Id drives (instinctual drives) are universal in the infant.

As the capacity of a child to achieve the objects of his basic instinctual needs increases so does his learning of control, modification, and sublimation. The capacity and the control develop together. Therefore, the increase of one kind of capacity (i.e., for securing gratification) is simultaneously accompanied by an increase in the other kind of capacity (i.e., for inhibitory power and control).

A child's success in "learning" these controls is one of the most important areas of child development. Our ability to help him or her organize these controls is one of our most important contributions as parents. This is called "learning" or "acquisition" and involves processes such as interpretation, adaptation, identification, conditioning, sublimation, and others.

The underlying presence of intrapsychic conflict with the resulting tension, attempted defenses, and sought-after resolution and its disguised outward expression is to be recognized today as the central dynamic concept in the origin of the neurotic and the functional psychotic's emotional illness.

Attempted Defenses Against Anxiety: Emotional Conflict/Anxiety/Internal Defenses

Internal defenses are called mental mechanisms, mental dynamisms, ego defenses, and defense mechanisms. These mental mechanisms represent attempts to reach solutions and compromises in response to serious conflicting drives.

Sources of Anxiety

During infancy and childhood, certain important prototypes or patterns for later responses may be established.

Precedents which are so established are often repressed or partly repressed. These precedents, however, may later determine the emotional response of an individual in a similar given situation.

Infancy and early childhood anxiety arise as a consequence of:

- **Helplessness:** The basic helplessness and dependence of the infant and young child gives rise to considerable anxiety. Infancy and childhood are long for the human organism. The development of resources to cope with the external world is a long, difficult, and gradual process.

- **Separation Or the Threat of Separation:** In normal personality development, security develops as dependency decreases. Separation no longer results in anxiety. Such an ideal sequence does not always transpire.
- **Deprivation and Loss:** Sudden environmental change is always a threat to the infant. The parental attitude can be a most vital and important agent or reassurance in these situations. Emotionally traumatic meaning can be one example of important infantile deprivation.
- **Frustration/Anger/Hostile, Aggressive Impulses/Conflict to Anxiety:** Anxiety is present because of threatened loss of control and in view of the threat of retaliation.
- **Emotional Contagion of Anxiety:** An emotional kind of contagion of anxiety takes place intuitively and through identification, largely from parents. The infant possesses a keen ability to sense intuitively the presence of all kinds of emotional feelings, especially including anxiety, indifference, resentment, and hatred.
- **Disapproval or Fear of Disapproval from Significant Adults**
- **Common Threats From the External Environment:** These would include accidents; changes in temperature and position; surgical procedures; parental disharmony; and excessive emotional stimuli.
- **Common Internal, Environmental Threats:** These would include hunger, thirst, illness and other physiological needs, actual physical punishment or threat of physical punishment, or abuse. While some of the above do not seem to be physical in nature, they represent, at least in part, a potential physical threat to the infant's equilibrium from the external environment.

Specific events that are emotionally traumatic during childhood—i.e., the death of a parent, sibling, or close playmate; frights; certain accidents; sexual assault, etc.—may lead to acute anxiety reaction or may contribute to various types of psychopathology.

- **Conditioned Responses:** Exposure to painful experience on a sufficiently frequent basis may cause the individual to experience anxiety later in life when some of the sensory cues of the earlier experience are present.
- **Superego Conflict:** Superego develops largely in response to the real or assured attitudes of significant persons in early life. By the acceptance and internalization as well as by the rejection (and sometimes with the reaction of the opposite; i.e., reaction formation) of the standards of these significant persons, the conscience gradually takes form. The role served by external censors is now assumed by internal censors. To the extent that this internal censor is successful as a replacement for previous approval or disapproval from external sources, the importance for approval from out-

side sources decreases. With development of the superego, conflict becomes increasingly possible; i.e., conflict between superego and id.

- **Threats to Self-Preservation:** Environmental threat may lead to anxiety. The threat may be physical or psychological. Anxiety in this connection may be referred to as situational (e.g.: illness, accidents, war, natural catastrophes, terrorism, riots).

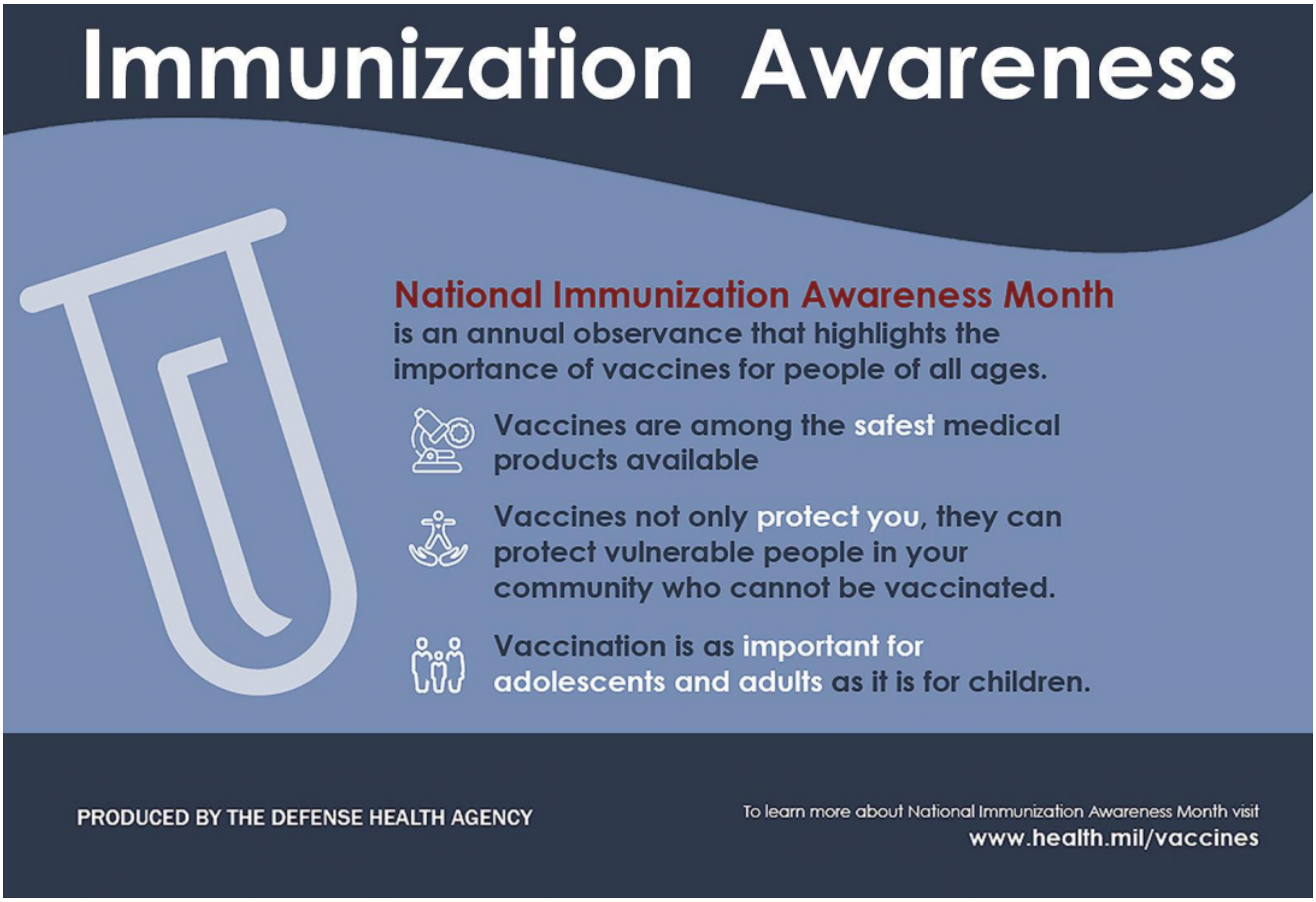
PTSD is a multifaceted disorder, involving not only post-traumatic stress but difficulty in other areas of functioning. The goal of treatment is the gradual lessening and modification of stimuli through various antianxiety exercises. When the person begins to cope adequately with the stresses of everyday life, treatment is considered to be successful. PTSD is a significant aftermath of war. Government and military leaders must calculate the cost of war in terms of psychological as well as physical casualties.

By raising awareness of the symptoms of PTSD, more veterans and their loved ones may be able to recognize if they are suffering from this debilitating disorder and pursue the treatment for recovery that will lead to a more meaningful life. •"

ABOUT THE AUTHORS:

Dr. Ralph Cancro received his PhD in Clinical Psychology from Columbia University in New York City. He has practiced in this area of psychology for 53 years. At the Burke Rehabilitation Hospital in White Plains, NY, he served as Director of Psychological Services for 23 years and as Co- Director of Mental Health Services for a similar period of time. While at the Burke Rehabilitation Hospital, in addition to clinical and supervisory responsibilities, he initiated and participated in research projects, lectured in seminars, and conducted workshops at colleges and universities in the tri-state area. Following his tenure at the Burke Rehabilitation Hospital, he was an attending psychologist at St. Agnes Hospital and Medical Center in White Plains, NY..

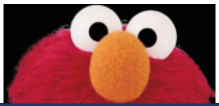
Lorraine Silvetz received her BFA from N.Y.U. Film School and her Master's from N.Y.U. School of Social Work in 2005. She is a psychotherapist, active in philanthropy, having founded Global Stress Initiative (GSI) under the International Committee Against Mental Illness (ICAMI), a mental health foundation directed by her Uncle, Robert Cancro, MD in 2010. ICAMI-GSI's goal is to provide non-invasive treatment for survivors of trauma. GSI utilizes individualized transcranial magnetic stimulation (iTMS) for the treatment of service members, domestic violence and human trafficking survivors impacted by PTSD.



MILITARY ONESOURCE

MILITARY ONESOURCE

is available to help with your concerns regarding military life.



WE OFFER

Sesame Street's *Talk, Listen, Connect* resources help military families and their young children cope with deployments, changes and grief. Visit Military OneSource to learn more.

Sesame Workshop
http://www.sesameworkshop.org

Sesame Street for Military Families
http://www.sesamestreetformilitaryfamilies.org

WE'RE HERE FOR YOU

No question is too small and no issue too big for Military OneSource.

Real help is available anytime, anywhere, at no cost to you:

- Speak to a specialty consultant about education, special needs, and health and wellness questions.
- Receive confidential non-medical counseling services on relationships, anger management, parenting and coping skills.
- Navigate your PCS checklist and plan for your financial readiness with expert help.
- Access resources and valuable information including articles, podcasts and videos to build your knowledge on safe sleeping environments, childhood milestones and healthy boundaries.
- Explore child care options, connect with your local school liaison and discover parenting tools for every age.

WE SERVE

Active-duty service members, National Guard and reserves, recently separated service members, military families and survivors

SESAME STREET 123

Connect with Military OneSource

Learn all of the ways Military OneSource can support you. Call **800-342-9647** or visit us at **www.MilitaryOneSource.mil** to find OCONUS calling options or to connect online.
We're ready to assist by phone and online, around the clock.

PUZZLES & CAMO SHELLY HUHTANEN

Comfort in What We Know

Broden is probably more like us than we sometimes realize. There will always be a wave coming to shore to rush up onto our feet, and then it will leave us and head back out to sea.

In the midst of our annual beach trip, I am again reminded of how Broden is so much more than autism. He is a 16-year-old teenager who looks forward to a break from the day-to-day grind, just like everyone else. A few days before we were scheduled to leave on our beach trip, I broke the news to him so he would be ready for what was ahead. In recent months, our family has been more cognizant of telling Broden what is going to happen, so he is aware of any plans our family has in the days ahead. For example, last week at the dinner table he looked over to me and asked, “Wednesday?” I responded, “Yes, Broden. It’s Wednesday today and tomorrow will be Thursday.” He smiled and continued to eat his dinner. As far as time is concerned, there is comfort in what we know and what will be, just as it is for Broden.

I’ve realized that as Mondays slide into Tuesdays, spring transitions into summer, and so forth. With summer, Broden knows that our beach trip is on the horizon. This time, Mark and I made sure to talk about our plans with him so that he was prepared for the trip. When the days drew closer to beach time, Broden began to ask if it was time to go. Friday morning, I leaned in to him as he woke up for clinic, “Tomorrow we’re going to the beach.” Broden smiled, slowly rolled over and softly said, “beach.” That morning at clinic, Broden jumped out of the car towards the building to start his day. His behavior analyst smiled, “Broden knows it’s beach time, doesn’t he?” I smiled and nodded.

The morning of our trip, I gave Broden the schedule of what was going to happen, “We’re not that far from leaving for the beach. After we do some grocery shopping, we’ll come back and pack up the car. We’re not going to leave until after lunch.” After lunch, I could tell Broden was growing impatient. As he saw his bag being packed, he knew it was getting to be that time. I said, “Pick out the blankets you want to sleep with at night, and put them in your bag.” He grabbed a few of his favorites and shoved them in the bag he packs every summer.

As we shuttled the bags down to the car, Broden leaned into my face and said sternly, “Beach!” Then he jumped in the car and looked at me as if he couldn’t wait any longer. “I know honey, we are all ready to get out of here. Just give us a few more minutes,” as I shoved a few more

SOUND WAVES: Mark leaned over to me and asked, “It’s the rhythm, isn’t it? Broden loves music and I think there is some sort of rhythm to the ocean. Maybe that is why we come here every year.”

PHOTO COURTESY SHELLY HUHTANEN

things towards the back of the car.

After several checks to make sure we didn't miss any suitcases or grocery bags, everyone piled into the car to head east. Mark and I sighed a moment of relief, leaving the worries of work and other stressors behind us. Hayden leaned back with his air pods in his ears, listening to his favorite music. I looked over at Broden to see a big smile on his face as he bounced up and down in his seat. It was time. I looked behind us and my parents were following us in Mark's truck with our two dogs, Bo and Jack. Everyone was together, we had everything we needed, and we were headed to our annual beach paradise.

Along the ride, the top 400 rock songs on the Sirius XM 70's channel were playing. As the list grew closer to number one, popular bands were playing like Styx, Boston, and AC/DC. Broden knew them all, and I could hear him singing with us as our favorites started to play. Again, Broden was just like us. He was gravitating to what he knew. As we reminisce of the past, of when we had heard these all-time favorites before, I'd like to think that Broden does the same. He may think about the times in the past he has heard Boston's "More Than a Feeling" play in the car on his way to clinic in the morning, or on an outing with the family for a car ride. I can't count how many times I have turned up the radio when AC/DC plays, so he can enjoy it. There's comfort in what we know and there's something special about remembering what we love.

> "I can't count how many times I have turned up the radio when AC/DC plays, so Broden can enjoy it. There's comfort in what we know and there's something special about remembering what we love."

At the beach, Mark looked over at Broden, as he was sitting in the water as the waves rushed over him. Broden would grab handfuls of sand and watch the sand leave his hands, as the water left the beach and headed back out to the sea. Mark leaned over to me and asked, "It's the rhythm, isn't it? Broden loves music and I think there is some sort of rhythm to the ocean. Maybe that is why we come here every year." I agreed and then said, "Broden is probably more like us than we sometimes realize. There is comfort in what we know. We know the beach will always be here every year waiting for us. There will always be a wave coming to shore to rush up onto our feet, and then it will leave us and head back out to sea." Broden takes comfort in that. We all do.•

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.

PRODUCTS AND SERVICES

ADAPTIVE & INCLUSIVE FITNESS

SPECIAL STRONG

E: daniel@specialstrong.com
W: www.specialstrong.com

Adaptive & inclusive fitness for mental, physical and cognitive challenges. Franchise opportunities are available.

ADAPTIVE/SPECIAL NEEDS BEDS

KAYSERBETTEN-US

P: 800-574-7880
E: ruthann@kayserbettenus.com
W: www.kayserbettenus.com

Tall Rail and Home Care beds with unique designs to meet safety and medical needs.

ALTERNATIVE SEATING

CHILL-OUT CHAIR

https://chill-outchair.com

Chill-Out Chairs provide tailored comfort & positioning in all environments – Home, school, or therapy settings. Available in two unique models, Rock'er or Roll'er, the Chill-Out Chair features a patented deep "V" foam design that provides maximum comfort and support to people of all ages and abilities.

AUTISM RESEARCH

SPARK

www.sparkforautism.com

Today we simply don't know enough about autism. SPARK—a groundbreaking autism research study—aims to make important progress possible. SPARK's mission is simple: we want to advance research and our understanding of autism to help improve lives.

CLEANING/SANITIZING SOLUTIONS

BANTEC SANITIZING

www.bantec.store

Easy to use disinfecting products and safe, environmentally friendly hygiene strategies that are efficient and cost effective.

P-GUARD URINE DEFLECTOR

www.sweethomeventures.com

A bathroom accessory that keeps urine contained inside the toilet bowl. Save cleaning time and protect against the spread of germs. Easily installs on bottom of toilet seat. Remove, dispose of and replace as needed. Made in the USA.

FINANCIAL PLANNING/ ESTATE PLANNING/ INSURANCE

MASS MUTUAL SPECIALCARE

www.massmutual.com/specialcare

Financial planning products and services by a company that cares.

THE AMERICAN COLLEGE OF FINANCIAL SERVICES

www.theamericancollege.edu

A private college focused on professional training for financial practitioners

HOME ADAPTATION/DESIGN

LJS ELECTRIC

www.ljselectric.com

Home automation products and devices professionally installed.

NON-PROFIT

IRENE AND ERIC SIMON BRAIN RESEARCH FOUNDATION

www.iesbrainresearch.org

Helping to further research and find answers to addiction, pain and other brain diseases and disorders.

IT CAN BE HARD TO GET HIS ATTENTION.

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

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

www.underagedrinking.samhsa.gov

SAMHSA
Substance Abuse and Mental Health
Services Administration