PLUS: UNITED STATES MILITARY SECTION

EXCEPTIONAL PARENT
MAGAZINE
NOVEMBER 2022
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FOR FAMILIES WITH SPECIAL NEEDS:

ESTATE PLANNING

INSIDE:

FUNCTIONAL MONEY SKILLS at ANY AGE

ALSO:

NAVIGATING IEPs

PLUS • PART I OF A SERIES:

SPAN's NATIONAL GUIDE to CHILDREN'S MENTAL HEALTH

FINANCIAL PLANNING ISSUE:

Yes, You Do Need to Plan

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NOVEMBER 2022 VOLUME 52 ISSUE 11

FINANCIAL PLANNING

FEATURES

ON OUR COVER

Recent polls have shown that up to 80% of parents of children with special needs share the same biggest concern: “What will happen to my child when I am gone?” EP’s Annual Financial Issue can provide some answers, as our most experienced contributors offer solutions for comprehensive estate and care plans that include how to plan for daily living needs, medications, schedules, housing goals, and supplemental needs trusts. In our features section, we explore diagnostic overshadowing, IEP best practices and electrical stimulation therapy. *Coverage begins on page 15.*

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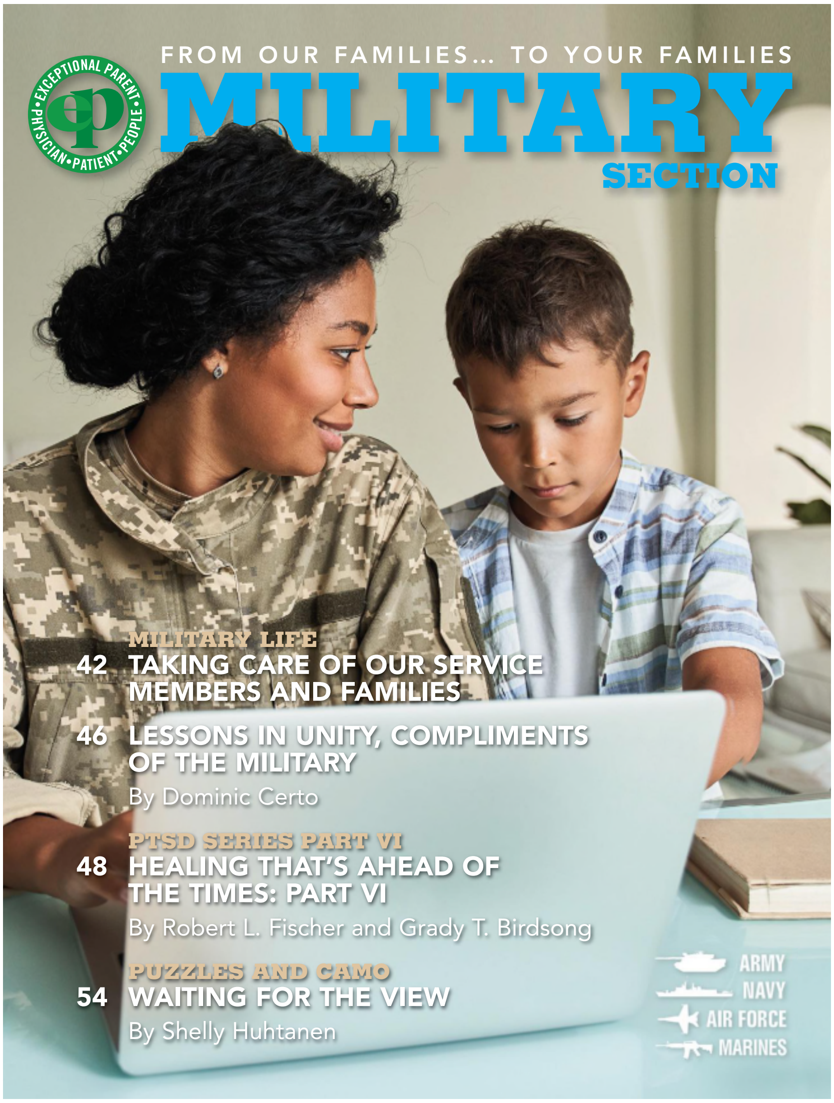

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Time to Give Thanks

Gratitude can help us refocus on what we have instead of what we lack.

Now that November has arrived, and we approach Thanksgiving and the holiday season, hopefully we can reflect on all that we have to be thankful for, and people who are supportive of and special to us. Gratitude can help us refocus on what we have, instead of what we lack.

Over the course of my time as Editor In Chief of *EP Magazine,* I am thankful to have met and interviewed so many amazing people who, despite facing daunting challenges of their own, do everything possible to advocate and give back to their communities. I am also grateful for our advertisers and corporate partners who have stepped up and made it possible to continue to offer "EP for Free."

I would also like to express my gratitude to all of the writers and contributors who devote their time and expertise to make the content of this magazine so extraordinary. This month, regular contributors Joshua Fishkind, J.D., MBA and Beth C. Manes, Esq. anchor our Annual Financial Planning Issue with detailed articles on estate and care planning. Special education teacher and author Stephanie DeLussey rounds out the section with a great piece on practical money skills.

November features include an article on the persistent problem of diagnostic overshadowing, and another on the best practices for navigating IEPs. Also, The SPAN Parent Advocacy Network presents the first article in a series of six that highlight updates to its National Children's Mental Health Family Guide.

> "I am thankful to have met and interviewed so many amazing people who, despite facing daunting challenges of their own, advocate and give back to their communities."

Finally, I'd like to thank EP's readers – we truly appreciate our dedicated audience for their support and participation. Our readers are the reason we work so hard on each and every issue of EP, and our goal is to be very responsive to them. If there are topics that you feel we should cover, or issues that we should explore, please share them with me at epmagazinevp@gmail.com.

We encourage you to share this latest issue with family, friends, coworkers, and associates. It's easy for anyone to subscribe, just visit www.epmagazine.com and click Subscribe. While you're at it, please share our Instagram feed at instagram.com/epmzine and be sure to like us on Facebook at facebook.com/exceptionalparentmag . Thank you!

Faye Simon

Editor In Chief

THE EDITOR IN CHIEF'S DESK

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

Information and Support for the Special Needs Community

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WHAT'S HAPPENING

FED PLEDGES $177M TO PHASE OUT SUBMINIMUM WAGE FOR PEOPLE WITH DISABILITIES IN 14 STATES

An estimated 100,000 people with disabilities are paid less than $7.25 an hour. Federal officials are sending $177 million to states to shift people with disabilities from minimum-wage work to competitive integrated employment.

AN HONEST WAGE?: Employers can obtain special certificates from the DOL that allow them to pay workers with disabilities less than the federal minimum wage of $7.25 an hour.

The funding will go to 14 state providers of vocational rehabilitation over the next five years as part of the so-called demonstration project Subminimum Wage to Competitive Integrated Employment.

Secretary of Education Miguel Cardona cited the Rehabilitation Services Administration, which distributes the funds, “These grants will support ongoing nationwide innovative efforts to provide educational opportunities for youth and adults with disabilities so they can secure better-paying jobs, build economic security, and lead more fulfilling, independent lives,”

Projects funded by the effort aim to reduce the use of minimum wages and increase access to competitive integrated employment. The pilot program was originally proposed in a government spending package for fiscal year 2021.

U.S. Senator Bob Casey (D-PA) led the fight to include funding for the pilot program in the FY21 federal spending bill. The Pennsylvania Office of Vocational Rehabilitation will receive $13 million to begin phasing out subminimum wage jobs for Pennsylvanians with disabilities.

“Many people with disabilities are being paid below the minimum wage without the possibility of gaining new skills or moving to a job that pays a higher wage. This is incompatible with the promise of our Nation: to provide every American with the opportunity to earn fair wages and achieve financial independence,” said Senator Casey. “This funding will begin to phase out subminimum wage employment in 14 states while protecting the jobs of people with disabilities, but in order to truly end this discriminatory practice, Congress needs to pass my legislation to stop this problem at its root.”With the grants, state vocational rehabilitation agencies will focus on connecting people with disabilities with novel approaches to green jobs and opportunities in key labor industries, the transportation industry and the arts, where they work with their non-disabled peers for comparable wages, the Department of Education said said.

The projects will involve collaboration between state and local providers, public and private employers and attorneys, officials said.

Currently, under a 1930s law, employers can obtain special certificates from the Department of Labor that allow them to pay workers with disabilities less than the federal minimum wage of $7.25 an hour. However, the practice known as the minimum wage is falling out of favor as several states and cities phase it out and some federal lawmakers seek to do so statewide.

“Far too many people with disabilities would like to work but live in poverty because they have not had an opportunity to find a career in competitive integrated employment,” said Rep. Bobby Scott,(D-VA), chair of the House Committee on Education and work and has introduced legislation to abolish minimum wages. “This historic investment in support of innovative activities to increase competitive integrated employment will help ensure that people with disabilities not only have meaningful opportunities to work, but to thrive in their communities.”

According to the Department of Labor, an estimated 100,000 people in the United States are paid subminimum wage. A 2020 U.S. Commission on Civil Rights report found that between 2017 and 2018, the average wage of a person with a disability working under such certificates was only $3.34 per hour – less than half of the federal minimum wage.

Grants from the new program will go to vocational rehabilitation facilities in California, Connecticut, Florida, Georgia, Illinois, Indiana, Iowa, Minnesota, New York, North Carolina, Ohio, Pennsylvania, Texas and Virginia.

For more information on this program, please visit www.casey.senate.gov/news/releases

WHAT'S HAPPENING

CHILDREN'S SPECIALIZED HOSPITAL LAUNCHES NEW RESOURCE HUB TO ADVANCE SAFETY EDUCATION

Children's Specialized Hospital, part of the Children's Health Network at RWJBarnabas Health, today announced the launch of the Living Safely Online Center for Safety, a new website designed to advance safety education and injury prevention for people with disabilities.

As the latest initiative of the hospital's Living Safely with Disabilities and Special Health Needs program, the website ((rwjbh.org/cshlivingsafely) serves as a one-stop accessible hub of safety tools and resources, guidance documents, public service announcements, and discussion templates to support community safety conversations between disabled residents, community caregivers, and local emergency response teams.

Funded in part by a $250,000 grant from the Division of Disability Services, New Jersey's Department of Human Services, Living Safely with Disabilities and Special Health Needs is a partnership among disability advocates, organizations, agencies, and caregivers focused on improving equity, accessibility, and functionality of safety education and injury prevention.

"More than sixty million adults in the United States have some type of disability, but public safety resources usually aren't designed with disabled individuals in mind – and emergency responders typically aren't trained in recognizing and addressing the safety needs of disabled people," said Jill Harris, AVP of the Research Center and Coordinator of the Autism Program at Children's Specialized. "As a result, people with disabilities often aren't prepared in safety situations and are more prone to injury. Ultimately, our goal is to change that narrative and lay the groundwork for a national safety coalition that prioritizes people with disabilities."

> ***"Emergency responders typically aren't trained in recognizing and addressing the safety needs of disabled people. Our goal is to change that narrative and lay the groundwork for a national safety coalition that prioritizes people with disabilities."***

Resources and tools available through the Living Safely Online Center for Safety were developed following a disability safety survey and a nationwide brainstorming summit, both of which engaged key audiences to identify challenges and opportunities for growth within safety education. As a result of those findings, the new website includes educational material on topics such as law enforcement interactions, fire safety, wandering and elopement, and interpersonal violence. These safety resources are available in multiple formats and outlets to address different learning styles, sensory issues, cognitive abilities, and accessibility needs.

SAFE SIDE: Extensive resources are available for emergency responders, law enforcement, and others involved in safety, including guidance and tools that support inclusive safety practices at **rwjbh.org/cshlivingsafely**

"Any successful population health initiative requires deep and ongoing engagement with the individuals and communities that we work in conjunction with," said Adrienne Robertiello, Special Health Care Educator at Children's Specialized. "Throughout this process, we have collaborated closely with a network of disabled self-advocates, organizations, agencies, emergency responders, academics, researchers, justice activists, and other safety stakeholders – all of whom are united in their commitment to bring forth more inclusive safety policy, practice, education, and outcomes."

Extensive resources are available for emergency responders, law enforcement, caregivers, educators, researchers, technology developers, and others involved in safety, including guidance and tools that support inclusive safety practices. Access these resources and learn more about Living Safely at **rwjbh.org/cshlivingsafely**.

ABOUT CHILDREN'S SPECIALIZED HOSPITAL

Children's Specialized Hospital, part of the Children's Health Network at RWJBarnabas Health, is the nation's leading provider of inpatient and outpatient care for children and young adults from birth to 21 years of age facing special healthcare challenges – from chronic illnesses and complex physical disabilities like brain and spinal cord injuries, to a full scope of developmental, behavioral, and mental health concerns. At 15 different New Jersey locations, our pediatric specialists partner with families to make our many innovative therapies and medical treatments more personalized and effective so each child can reach their full potential. Visit **www.rwjbh.org/childrens-specialized-hospital**

WHAT'S HAPPENING

MATTEL INTRODUCES INCLUSIVE NEW BARBIE DOLL LINE FOCUSING ON DISABILITY REPRESENTATION

Barbie's parent company Mattel announces upcoming additions to Barbie's Fashion Doll line will focus on disability representation and diversity inclusion, featuring a Barbie with a behind-the-ear hearing aid, a Barbie with a prosthetic leg, and a Ken doll with vitiligo.

The line will also integrate other aspects of inclusion, such as various body types and hair textures. In fact, a company statement described the upcoming line as its "most diverse and inclusive doll line."

SMALL WORLD: Barbie Fashionistas line features the diversity kids see in the world around them.

Lisa McKnight, EVP, Global Head of Barbie and Dolls Portfolio at Mattel, says "Our Barbie Fashionistas line features a range of skin tones, body types and disabilities to reflect the diversity kids see in the world around them. Knowing that kids' early childhood experiences help shape how they perceive the world, we are dedicated to reflecting a multi-dimensional view of beauty and fashion in our dolls."

Initial consumer response appears to be overwhelmingly positive. One social media respondent, for example, said: "As someone who grew up with Barbie being her favorite toy, collects Barbie as an adult, and has worn a hearing aid since the age of five – Thank You! This brought tears to my eyes."

This isn't the first time Barbie's parent company, Mattel, engaged the disability community with an inclusive product. In 2020, Mattel introduced a Barbie wheelchair user. This may be the first time, however, that the toymaker worked with medical professionals to ensure accurate representation. Dr. Jen Richardson, an audiology expert and hearing loss advocate, consulted on the inclusive design.

"I'm honored to have worked with Barbie to create an accurate reflection of a doll with behind-the-ear hearing aids. As an educational audiologist with over 18 years of experience working in hearing loss advocacy, it's inspiring to see those who experience hearing loss reflected in a doll," Richardson said. "I'm beyond thrilled for my young patients to see and play with a doll who looks like them."

WHAT'S HAPPENING

WHEN YOUR DISABILITY GETS YOU SENT HOME FROM SCHOOL: STUDENTS WITH DISABILITIES ARE OFTEN MET WITH OFF-THE-BOOKS SUSPENSIONS

BY MEREDITH KOLODNER AND ANNIE MA

The phone call from her son's school was alarming. The assistant principal told her to come to the school immediately.

But when Lisa Manwell arrived at Pioneer Middle School in Plymouth, Michigan, her son wasn't sick or injured. He was sitting calmly in the principal's office.

John, who has ADHD and finds it soothing to fidget during class, had been removed from the classroom after he refused to stop using a pair of safety scissors to cut his cuticles.

When she asked why he couldn't stay for the rest of the day, Manwell said the school told her they would call child protective services if she didn't take him home.

The call was just one of a dozen that Manwell received last fall telling her John couldn't stay in school because of behaviors she says stemmed from his disability. Many schools have promised to cut down on suspensions, since kids can't learn as well when they aren't in class. But none of these pickups were ever recorded as suspensions, despite the missed class time.

REAL DEAL: Lisa Manwell was summoned repeatedly in the middle of the day to pick up her son John when he attended Pioneer Middle School last fall.

PHOTO COURTESY PAUL SANCYA /ASSOCIATED PRESS

The practice is known as informal removal, defined by the U.S. Department of Education as an action taken by school staff in response to a child's behavior that excludes the child for part or all of the school day – or even indefinitely.

Excessive use of informal removals amounts to a form of off-the-books discipline – a de facto denial of education that evades accountability, advocates and legal experts say. It has special implications for kids with disabilities: Informally removing these students circumvents federal law that protects them from being disciplined or barred from class for behaviors related to their disability.

Since the pandemic began, parents of kids with disabilities say the practice is on the rise, denying their kids their legal right to an education.

"This is a repeat issue that we see in enforcement across the country, over years," said Catherine E. Lhamon, assistant secretary for the department's Office for Civil Rights. "And that means that the practice has taken hold in a way that is dangerous for students and needs to be addressed."

In July, the department issued guidance on discriminatory practices in discipline for students with disabilities. Lhamon said the guidance included informal removals because of how often they appeared in the office's investigations of complaints against school districts. Informal removals can happen through frequent parent pickups, shortened school days or hours spent in "time-out" rooms.

The Associated Press and The Hechinger Report interviewed 20 families in 10 states who described being called repeatedly and at all hours of the school day to pick up their children. In some cases, parents were called less than an hour into the school day. Others said they had to leave work to get their child so frequently they lost their jobs. Many felt they had no choice but to change schools, or even districts.

Because the removals aren't recorded, there's no way to quantify how often they happen. But the National Disability Rights Network says it has seen an increase during the pandemic.

Teacher shortages mean there are fewer staffers available to do evaluations and provide services for students with disabilities, creating "more of an incentive or more of a push for getting kids with behavioral needs out," said Dan Stewart, the organization's managing attorney for education and employment.

Students of color with a disability appear to be disproportionately affected based on anecdotal reports to the network from disability rights advocates around the country.

Children are not supposed to be removed from classrooms for extended periods of time without recording the action as a suspension, although it happened to John Jinks a dozen times last year. Credit: Paul Sancya for The Associated Press

"It's pervasive," said Ginny Fogg, an attorney at Disability Rights North Carolina, "And the reason for that is that most parents don't know their rights, and the consequence for the school system is not enough to make them not do it.

"The remedy isn't, 'You just can't go to school,'" she added. "The law was enacted 50 years ago to prevent this very outcome — that students with disabilities aren't allowed to go to school and participate in an education."

Manwell said the calls from her son's school felt relentless.

“They would be calling my personal phone, my work phone. They were calling my husband, who works nights,” said Manwell, a resource planner at Ford Motor Company. “It was impossible. I couldn’t function. I never knew when they were going to call or what was going to happen.”

An official from the Plymouth-Canton Community Schools district in Michigan where John goes to school said he couldn’t comment on specific student issues, citing federal student privacy law.

> ***“The remedy isn’t, ‘You just can’t go to school.’ The law was enacted 50 years ago to prevent this very outcome – that students with disabilities aren’t allowed to go to school and participate in an education.”***

Federal law protects students with disabilities from being repeatedly disciplined or removed from school for behaviors related to their disability. If they are suspended for more than 10 days, families are entitled to a meeting with the school to determine whether the behaviors are a result of the child’s disability. If so, then the school must offer adjustments instead of suspension. For example, if a child’s disability makes it difficult for them to focus in a loud classroom with dozens of other children, the parent has the right to request a quieter classroom or one with fewer children.

The Education Department’s July guidance made clear that children who are informally removed have the same rights, such as reviews of whether the student’s behavior was a result of their disability, as those who have been officially suspended.

Tricia Ellinger says she would have requested a hearing to make sure her 10-year-old daughter Cassie was getting appropriate services and support, had she known that her frequent removals from the classroom amounted to suspensions.

One day last spring, she received three phone calls in rapid succession, telling her to immediately pick up Cassie from Kenneth J. Carberry Elementary School in Emmett, Idaho. When she arrived, her daughter was sitting quietly in the school’s resource room eating a snack. She says a school staff member told her that Cassie was refusing to do her work and needed to go home.

“When I got her in the car, I asked her, ‘Cass, what happened? Did you tear up your notebook, did you throw your pencil?’” Ellinger recalled. “She said, ‘No, it was just hard. Math is hard.’”

The call was one of about 20 Ellinger says she got last year from the school, which is designed specifically to educate students with disabilities. She says her daughter was also taken out of class repeatedly and kept in a room by herself. None of the removals were recorded as suspensions.

Emmett School District Superintendent Craig Woods said he couldn’t comment, citing federal student privacy law.

Families often do not know what grounds they have to lodge a complaint, Lhamon said. Sometimes they aren’t aware their child should not have been suspended in the first place.

“That is so concerning when schools are excluding students for reasons that are unlawful,” she said. “We want our kids to be in class, learning with other students, fully participant and respected as learners. We do not want our school communities to be sending a message that there’s some category of kids who can’t be there.”

Manwell said most of the calls she got last year from her son’s school were a result of bullying. On the fourth day of school John got shoved in the locker room, and she got a call to pick him up. Another time, he went to the bathroom and another student threatened to beat him up.

Because of his disability, John was supposed to be granted access to a quiet room so he could recover from difficult incidents. But often, she said, either there wasn’t a room or when he didn’t want to return to class, she’d get a call to come pick him up.

“It was just the stress of never knowing what I was sending my kid into each day. I was worrying the whole time he was gone,” said Manwell. “I could see the damage.”

“He was withdrawing. He started talking about hurting himself,” she said, her voice breaking.

In January, she made the decision to switch John to homebound instruction, sending him to a tutoring center every day for a couple of hours and rearranging her work schedule. It made her life more predictable, she said, and John began to act like his old self.

She said she’d like to send him back to school but doesn’t trust what will happen.

“You want to protect your kids, right?” she said. “I just can’t send him to a school where he won’t be safe.”•

This story **www.hechingerreport.org/when-your-disability-gets-you-sent-home-from-school** *was produced by The Hechinger Report, a nonprofit, independent news organization focused on inequality and innovation in education.*

WHAT'S NEW FALL INTO PLACE

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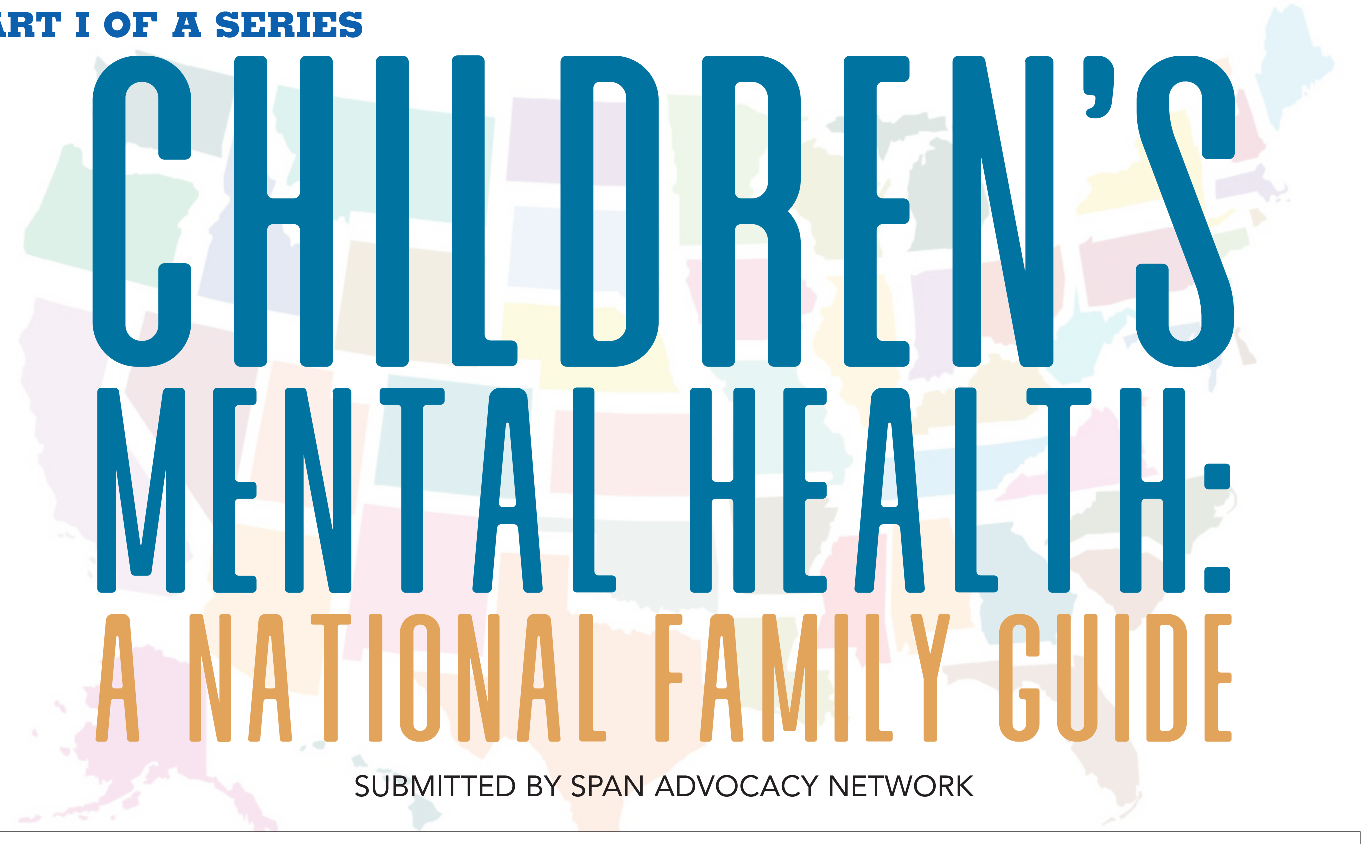

CHILDREN'S MENTAL HEALTH: A NATIONAL FAMILY GUIDE

SUBMITTED BY SPAN ADVOCACY NETWORK

> ***Editors Note:*** *The SPAN Parent Advocacy Network has recently updated its* ***National Children's Mental Health Family Guide*** *and have provided it to EP Magazine for publication in a multi-part series. SPAN is here to support you in making the important decisions needed to ensure that your child with mental health challenges receives the services and supports needed for the best life possible. Connect with SPAN at 800-654-7726, online at* www.spanadvocacy.org*, on Facebook at* @parentadvocacynetwork*, and on Twitter at* @SPANadvocacy

INTRODUCTION

We are families of children with special health care needs, including mental health needs. We are not here to tell you what to do with your child, because you are the expert on your child. We are here to support you in making the important decisions needed to ensure that your child with mental health challenges receives the services and supports needed for the best life possible.

Children's mental health, just like physical health, should follow the "medical home" model. A "medical home" is not a place, but an approach to care that ensures that care is:

- *Accessible*
- *Family-centered*
- *Continuous*
- *Comprehensive*
- *Coordinated*
- *Compassionate*
- *Culturally-competent*

Learn more about the Medical Home Model at www.pcpcc.org/about/medical-home

ABOUT THE SPAN PARENT ADVOCACY NETWORK

Our Mission is to empower and support families and inform and involve professionals interested in the healthy development and education of children and youth. Our focus is on the whole child and family, including education, health and mental health, human services, child care and early childhood development, and child welfare/prevention.

Our Foremost Commitment is to children and families with the greatest need due to disability or special health/mental health needs; poverty; discrimination based on race, gender or gender identification, language, immigrant or homeless status; involvement in the foster care, child welfare, or juvenile justice systems; geographic location; or other special circumstances.

Our Vision is that all families will have the resources and support they need to ensure that their children become fully participating and contributing members of our communities and society.

Our Motto is Empowered Parents: Educated, Engaged, Effective! We hope that we can help you along your journey.

DID YOU KNOW?

- 4 million children have mental health issues
- 1 in 5 children ages 9 and up have an identified mental illness
- 50% of lifetime cases begin by age 14
- Only 20% of children are able to access needed mental health care
- 50% of kids with mental illness drop out of school before graduating
- 70% of children in juvenile justice system have mental health issues
- Research shows that early identification and treatment result in best outcomes[1] •

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[1] https://nami.org/mhstats

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COVER STORY

FINANCIAL PLANNING

Yes, You Do Need to Plan

FIRST OF A THREE-PART SERIES

BY JOSHUA FISHKIND, J.D., MBA

Recent polls have shown that up to 80% of parents of children with special needs share the same biggest concern: "What will happen to my child when I am gone?" So much is wrapped up in that thought: where will they live, who is going to understand their unique needs, how will their expenses be paid, and of course, where will they turn for support?

Even without special needs, the loss of a parent is an extraordinarily difficult life event. While every special need, and every individual, has their own nuances, members of our community have a more acute challenge: up to 80% of individuals with special needs are living in their childhood homes, and have never experienced daily life without the support of their parents. Losing mom and dad isn't just the loss of a loved one, it's the loss of their core financial, social, and emotional infrastructure. Moreover, many of the supports we rely on may not be available to our children, and they need even more support than we do.

While there is no substitute for a parent's love or care, with proper planning, stress and worry can be reduced, many of the concerns that keep parents up at night can be addressed, crises can be avoided, and the transition to life after mom and dad can be made easier.

> **"With proper planning, the transition to life after mom and dad can be made easier."**

So why do only 1 in 3 families have a will? Even fewer have done any financial planning, and if you ask most parents about comprehensive care planning, overwhelmingly you'll see expressions ranging from blank stares, to guilt, to exasperation.

We get it! Keeping our heads above water with everything going on in life is hard enough. Managing the medical, caregiving, educational, and social needs of your child is already exhausting; plus you still have all the responsibilities of a non-special needs parent: work, spouse, other children, helping your parents, and more.

For most of us, it is impossible to get to everything on the to do list, so we prioritize, and putting off long-term planning "until things settle down" has no immediate consequence, so it is the action item that gets put on the back burner. Besides:

- *Only wealthy people need wills and special needs trusts. I don't have enough money that this applies to my family.*
- *My child has government benefits that will continue when I am gone, so I don't need to plan.*
- *My other children will handle everything when I pass, so there is no need for me to do anything.*
- *I've done some planning, it'll be fine. The will I downloaded online is sufficient for my needs.*
- *All financial planners and lawyers do is figure out the money. I don't have any money; I am worried about care. Planning won't help MY issues.*
- *Planning is difficult and time consuming and I have too much going on, and not enough time as it is. I am not dying any time soon. I'll get to it – eventually.*

If this sounds like you (and statistically speaking it probably does), every one one of these responses is based on misinformation, or a fallacy that has become ingrained in our community. We have to fix this, because it leaves our loved ones vulnerable, and may lead to unintended, sometimes tragic outcomes.

LOOKING DOWN THE ROAD: While there is no substitute for a parent's love or care, with proper planning many of the concerns that keep parents up at night can be addressed.

YES, YOU DO NEED TO PLAN : THREE SCENARIOS

Below are three scenarios: same modest assets and the same family dynamic. The only difference is the planning.

Scenario: Barbara, 55, is the mother and primary caregiver of her son, Matthew, 28, who lives with her. Matthew has autism and other comorbid conditions including epilepsy and gastrointestinal issues. Barbara owns a modest home, has a small IRA and social security, and together with her son's part-time income and SSI, is able to make ends meet. Barbara spends her days driving Matthew to and from his job and various therapies, preparing meals, helping with daily hygiene, and managing medications. Matthew is partially verbal, receives Medicaid benefits, and, when not working, has learned to take the bus to an adult day program.

Barbara feels alone, stressed, and has missed her last two doctors' appointments. As a results of her untreated hypertension, she suffers a fatal heart attack.

OUTCOME 1:
NO PLAN

Despite Matthew's future being Barbara's biggest concern, she doesn't know how to create a plan, or where to start. Like 2/3 of Americans, no estate or care planning has been done to protect Matthew's future. Upon Barbara's demise, Matthew inherits $25,000 which he cannot manage or properly utilize. Not only can he not live safely on his own, but he cannot afford the home without his mother's contribution. His inheritance makes him ineligible for Medicaid benefits, which terminate 30 days after his mother's passing. The home he has always lived in needs to be sold to settle the estate.

He is soon to be homeless, uninsured, no longer has transportation to his job, and cannot participate in his day programs or therapy because of his lost benefits. Without his mother to monitor his medications, he has a seizure and is taken to the emergency room where a social worker is brought in to evaluate his circumstances. Since Matthew is uninsured, he receives a $25,000 hospital bill, wiping out his inheritance. If someone helps him find his social security card and birth certificate and assists in completing the applications, he can now reapply for benefits. Hopefully, he can find a safe living situation for the next six months while his applications are reviewed.

OUTCOME 2:
INCOMPLETE/POOR PLANNING

Barbara creates a trust with her local attorney. In this trust, Barbara names her nephew, David, as Matthew's trustee. When Barbara passes, David learns of his appointment as trustee and scrambles to try to find appropriate housing for Matthew. However, David finds that there is a waiting list at many homes. He decides that Matthew can live with him while they wait for a housing option to open up. Barbara's IRA, which hadn't been updated in years, named her husband (deceased) then her children as beneficiaries.

IRAs (and other qualified plans) are not governed by wills, but by the beneficiary designations. The incomplete planning means that while Barbara's home and other assets were included in the trust, the IRA is still distributed to Matthew. David will need to go to court, with the hope of setting up a 1st party special needs trust to hold the IRA assets. There are now 2 trusts with different regulations to manage – and the meaningful legal expenses of setting up a trust and going to court.

David has a hard time understanding government benefits regulations and managing the two trusts. With the best of intentions, he makes a distribution that triggers a loss of benefits. Matthew is told that he should consider suing David, but he doesn't know if he should, nor does he have any desire to sue his cousin, who was only trying to help – leaving him with little recourse. David, in addition to his continued housing search, is now looking for a benefits expert to help him appeal the Medicaid decision and reapply for benefits.

OUTCOME 3:
PROPER PLANNING

Barbara and Matthew create a comprehensive estate and care plan that includes all of Matthew's daily living needs, medications, schedules, housing goals, and a supplemental needs trust. Working with their care coordinator, appropriate supports are determined, and a plan for Matthew's life after Barbara's passing is put in place. With the added supports, and improved mental and physical health, Barbara doesn't miss her doctors' appointments.

When Barbara eventually passes, $25,000 and the balance of her IRA are deposited into a supplemental needs trust for Matthew's benefit. Barbara's financial advisor put a small 20-year term life insurance policy in place. At 55 years old, she paid $100/month and got $500,000 in benefit, which funded Matthew's special needs trust. All of Matthew's benefits remain in place, since the trust does not count as a Medicaid asset. Matthew moves into the group home that he and his mother previously selected, and the trust provides furnishings. Since Barbara had a care plan that she had been continuously maintaining, the group home receives a comprehensive medical history, medications list, and list of all programs and therapies that are part of Matthew's life. Matthew emails his trustee from time to time when he needs something – a new tv, an XBOX, or tickets to a baseball game. Most of Matthew's needs are provided for by the group home and his government benefits, which are protected by his expert corporate trustee. Additional therapies and activities are paid for by his trust. David, as trust protector, visits his cousin once a month and makes sure that all is well, but doesn't have any daily responsibility or fiduciary liability. The trust is paying for David and Matthew to go to Disney World together next month, a dream that Barbara included in Matthew's care plan.

Matthew misses his mother, but is safe and secure and has new-found friends and robust support services in the residence he and his mother selected.

YES, YOU DO NEED TO PLAN:

- Even for families with modest assets, comprehensive, integrated financial, care, and legal planning are critical. In most states, the threshold for triggering a loss of Medicaid benefits is only $2,000. Most families will leave that or more behind.
- Without proper planning, the benefits you anticipate your loved one receiving may not be there. Losing benefits at the same time as losing a parent is an avoidable crisis – if YOU plan.
- Assuming your other children, or another family member can handle everything, rarely works out the way families think. Ask yourself: How well do they understand your child's needs? What about their family and work obligations? Do they understand trusts and government benefits regulations? Are they prepared for a lifelong commitment? Are they an age appropriate appointment that will align with your child's lifetime?

> ***"Without proper planning, the benefits you anticipate your loved one receiving may not be there."***

- Half a plan is not much better than no planning at all. Special need planning requires a team approach, and interdisciplinary expertise.
- Financial, legal, and care planning are interwoven. Protecting benefits and creating a trust and financial plan that accomplish your goals will lead to better care. Work with advisors to determine the right role for government, family, and professionals to meet your child's needs, and make your goals achievable.
- No one knows when their time will be up – don't leave your loved one's future up to chance. Lack of planning will never lead to a better outcome than a well thought out plan.

Charlie Munger once said, "All I want to know is where I'm going to die, so I'll never go there." Absent knowing the when, or the where, the best we can do is be prepared, have a plan, and make sure that we have done all that we can to protect our loved

YES, YOU DO NEED TO PLAN : SO, WHERE SHOULD YOU START?

1 DON'T DELAY AND DON'T BE OVERWHELMED.

Believe it or not, creating a comprehensive plan is not nearly as difficult, or expensive as you think. When working with the right professionals, all your legal, financial, and care planning can be done in as few as 10, but more commonly 20 hours, spread out to meet your schedule. Depending on where you are located, total cost could be under $5,000 for everything – including your supplemental needs trust and a review of your existing benefits, which may actually increase your household's monthly cash flow.

2 MEET WITH AN ATTORNEY WHO HAS AN EXPERTISE IN SPECIAL NEEDS PLANNING.

This is not your brother-in-law the real estate attorney! Look for an attorney who is a member of the Special Needs Alliance, Academy of Special Needs Planners, or has the CELA designation. Ask them about their special needs planning experience. Topics to include in your discussion:

a. Wills
b. Living Wills
c. Powers of Attorney
d. Supplemental Needs Trusts
e. Successor Guardians (if applicable)
f. Appropriate roles for family, friends and professional trustees
g. Integration with spouse's or ex-spouse's planning
h. Stand-alone trusts and potential for gifts from other family members

3 MEET WITH A FINANCIAL ADVISOR WITH EXPERTISE IN SPECIAL NEEDS PLANNING.

All financial advisors are not created equal. Look for an advisor with the ChSNC designation from the American College, or members of the Academy of Special Needs Planners. Ask about how they approach special needs planning, and how it is different from their ordinary retirement planning. Topics for your discussion:

a. How much money would be needed to maintain my child's current lifestyle? What is the budget for your child and how will it evolve over time?
b. Review all qualified plans and existing life insurance. Do beneficiary designations align with your trust?
c. Are there tools or products that can be used to meet your goals?
d. Do you have the right government benefits in place, or should you be receiving more support?
e. Are there strategies to save more, such as funding an ABLE account, that will help protect your child?

one's future. Without such planning, we leave our loved ones vulnerable, and create an undue burden for the friends or family who are left to pick up the pieces.

If you use a digital care planning platform, log in and make an update. Proactive families frequently do this as often as monthly. Even better, if digital, everyone in your circle of support can access the update instantly, so the whole team will be operating off the same playbook. This can save time and money when reviewing your plans with your lawyers and financial advisors.

Every family that has a loved one with special needs should have a plan in place – it's not a matter of rich or poor. Our children and loved ones who rely on us during our lifetime, are relying on us to think about the entirety of their lifetime. You'll rest easier knowing your child is protected, and you may even find that there are more resources or benefits available to ease your financial concerns, or coordination services that can lighten your workload. A great place to start is with the Academy of Special Needs Planners (**https://specialneedsanswers.com**), Special Needs Alliance (**www.specialneedsalliance.org**) attorneys with the CELA designation, or Hope Trust (**www.hopetrust.com**).

> *"You'll rest easier knowing your child is protected, and you may even find that there are more benefits available."*

Get started – it's not hard, not that expensive, and yes, YOU do need a plan! •

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.

4 ENGAGE A CARE PLANNER WITH CARE COORDINATION SERVICES AND GOVERNMENT BENEFITS EXPERTISE.

A good care plan will review all the medical, legal, social, and financial needs of your loved one, and will be the guiding force for your plan. Understanding the care needs and budget will help determine your financial planning goals, and what type of trust should be created. It will also identify who in your circle of support should be a part of your plan, and in what capacity. Topics to include in your discussion:

a. *Review of government benefits – is your loved one entitled to more?*
b. *Appropriate long-term housing options*
c. *Employment and daily activities that enrich your child's life*
d. *Medications, daily schedules and the tips and tricks that make life "work"*
e. *Gathering and digitizing key documents such as IEPs, benefits awards letters, estate and financial planning documents, diagnostic results, etc.*
f. *Case coordination services – are there things that you can delegate to an expert?*

5 HAVE THE HARD DISCUSSIONS.

Death and taxes are inevitable, and ignoring the topics doesn't make them go away, it just leaves you unprepared. Talk to your family, your advisors, and your loved one about what will happen in the future. What are your goals, and are they shared with your loved one and your circle of support? Don't assume that family will just pick up where you left off – ask them! Often family members say what they think you want to hear; dig deeper. Very often it turns out that family members don't understand what is being asked, how much work you're doing, and what being a guardian, caregiver, or trustee would mean in practice, or how it would impact their daily life. It is better to figure this out now, while you can plan, than to make an assumption that proves false when you're gone. Also, really consider everything you do, and if it is reasonable to ask someone else to assume that role.

6 BRING EVERYONE TOGETHER – ANNUALLY.

Congratulations, you've put together a comprehensive plan with your legal, financial, and care professionals! Now is the easy part – maintaining it. Please do not leave your documents on the top shelf of your closet to collect dust. Life is dynamic, and we all hope to live a long time. A care plan that gives all the details about school lunch requirements for your 12-year-old isn't going to be helpful for your 37-year-old, when you pass in 25 years!

Bring your team together at least once per year. Update all your plans. Talk about benefits, housing, changes in goals, employment, diagnoses, medications, and more.

ESTATE PLANNING FOR FAMILIES WITH SPECIAL NEEDS

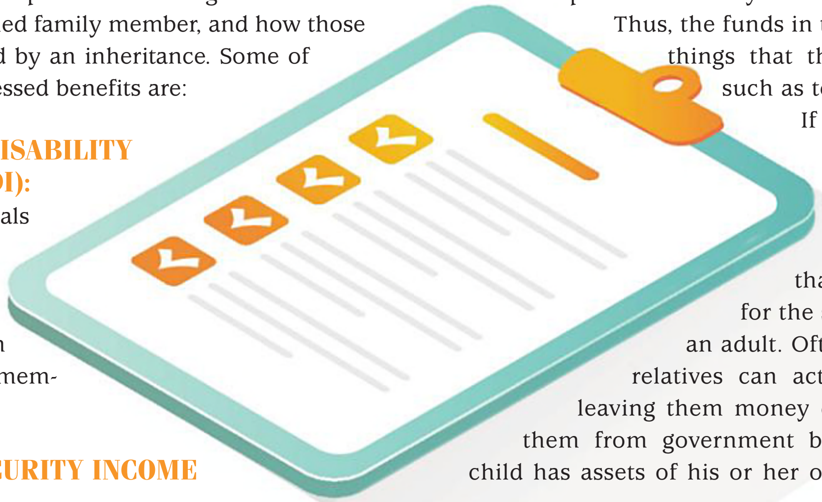
BY BETH C. MANES, ESQ.

Estate Planning is the process of "putting your affairs in order." This means not just signing a Last Will and Testament, which advises how your assets should be distributed upon your death, but also designating people to make decisions for you while you are still alive, but unable to make them for yourself.

GETTING A PLAN IN PLACE: If a family is planning for a child with special needs, whether an adult or a minor, it is imperative to be cognizant of the benefits available to the disabled family member, and how those benefits will be impacted by an inheritance.

Estate planning also involves not just passing your assets to the next generation, but your values as well. Whether it be through charitable gifts, expressing your wishes for end of life decisions, or special planning to protect disabled family members, a carefully drafted estate plan will ensure that your wishes are fulfilled.

If a family is planning for a child with special needs, whether an adult or a minor, it is imperative to be cognizant of the benefits available to the disabled family member, and how those benefits will be impacted by an inheritance. Some of the most commonly accessed benefits are:



SOCIAL SECURITY DISABILITY INSURANCE (SSDI):

SSDI supports individuals who are disabled and have a qualifying work history, either through their own employment or a family member (spouse/parent).

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 (relates to anticipated length of disability, and ability to perform work).

> **"It is essential that this type of estate planning is done by a special needs lawyer who understands the challenges faced by families with special needs children, and can help ensure that you are doing everything you can to protect your assets and pass them down to the next generation, minimizing confusion and red tape."**

MEDICAID:

Medicaid provides health insurance. If you qualify for SSI, you typically automatically qualify for Medicaid.

DIVISION FOR DEVELOPMENTAL DISABILITIES ("DDD") SERVICES:

DDD provides services to individuals who have reached the age of 21, and meet the eligibility criteria, which require 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 that he or she has 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.

SSI, Medicaid, and DDD Services are all "means tested," and require that an applicant fall below the income and asset thresholds set by the federal government. Those thresholds must be maintained while receiving benefits, as well; even a small bequest left directly to a disabled person can disqualify them from benefits they are already receiving. In order to protect a disabled person's inheritance, family members may direct that person's bequest (whether specific or residual) into a special needs trust ("SNT"). A SNT is a trust is drafted to direct that the funds in the trust be used to supplement, not supplant, any funds or services the person with special needs may receive from government programs. Thus, the funds in the SNT can be used to pay for things that their benefits do not provide, such as technology and travel.

If you wish for your estate plan to provide for someone with special needs, be sure to speak with a knowledgeable attorney to protect that family member's eligibility for the services he or she will need as an adult. Often, well-meaning parents and relatives can actually hurt their children by leaving them money directly, thereby disqualifying them from government benefits and services. If your child has assets of his or her own, there are ways to protect them too. It is essential that this type of estate planning is done by a special needs lawyer who understands the challenges faced by families with special needs children, and can help ensure that you are doing everything you can to protect your assets and pass them down to the next generation, minimizing confusion and red tape. •

If you have questions about your current estate plan, or would like assistance drafting a new one, please contact Manes & Weinberg, LLC, to discuss your family's needs and options. (973) 376-7733
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ABOUT THE AUTHOR:

Beth C. Manes, Esq., is a founding member of Manes & Weinberg, Special Needs Lawyers 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.

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FINANCIAL PLANNING

WRITING IEP GOALS FOR FUNCTIONAL MONEY SKILLS AT ANY AGE

BY STEPHANIE DELUSSEY

IEP. Three little letters that pack a lot of punch for families of school-aged children with disabilities, who qualify and attend public schools. IEP. Individualized Education Program.

In a small nutshell, an IEP is designed for each child with a disability to help them learn alongside their same-aged peers with appropriate accommodations, modifications, and adaptations. Although those words (appropriate accommodations, modifications, and adaptations) are very important, we aren't going to be talking about those words today. There is one other huge piece of every IEP that really can help a child with their "further education, employment, and independent living" – and that's IEP goals.

IEP goals are written to help a student achieve and master new skills. But IEP goals do not and should not be only academic in nature.

This month we will be talking about IEP goals that align with money. Money skills are important, and your child's peers begin learning what money is and how to count, add and subtract money early in elementary school. But using money and your child's money IEP goals, should be so much more than knowing what money is and how to count coins.

So, what money skills can a child's IEP goals practice and build on that aren't "Jaxon will identify coins" or "Zoie will count coins up to $1"? Let's take a look at four skills every student needs to know for independence.

1. PLANNING + BUDGETING

It's one thing to make and have money, and it's another thing to plan out your bills and budget the money in your bank account. Skills that fall under planning and budgeting:

- *Do I have enough money to pay for (insert want, need, or service)?*
- *How much money will I have left?*
- *How much money will it cost to pay for (insert want, need, or service)?*
- *Can I find this (item) somewhere cheaper?*
- *Do I really need this item, or can I buy a similar item for less money?*

Planning and budgeting also fit well into having a conversation about wants and needs.

2. PAYING FOR A SERVICE

Part of budgeting is making sure you have enough money to pay for something you want or need. There comes a time, though, when you are paying for a service and you have to calculate a tip into the total price. Students also need to learn that a service provider's tip most often depends on the quality of service provided.

It's also important to learn about different situations where a service provider may not ask for a tip, but it is best practice to give the service provider a tip (example: a bellman at certain hotels who takes your luggage to your room, or service providers on a vacation excursion, like a fishing boat captain).

3. SAVING MONEY

Saving money is a great skill for all students to have. More importantly, it's a skill students need to understand and implement, so they don't go into debt.

Saving money is also a part of planning ahead and budgeting. Emergencies happen, and if a person doesn't have money saved, it can cause a lot of stress and anxiety. To plan ahead, a student might save a certain dollar amount each paycheck or each month, or they may have a system for calculating how much to save each month. As the parent, you can help your child decide which option works best for them, and then work with your child to implement the system each month.

In addition to saving money for emergencies, students should learn how to save money to purchase things. When students are young, they may want to save money for a specific toy or game. When students are older, it may be saving money for a car, apartment, or new phone or laptop. As the parent, you can help facilitate these events with or without your child's IEP team.

4. BALANCING YOUR BANK ACCOUNT

Being able to balance your bank account, or checkbook, as many of us know, is a skill vitally important to planning and budgeting. Sure, it can fall under that category - but it is so important, it deserves its own category.

Being able to balance your bank account by adding in deposits and calculating withdrawals, needs students to know the math basics: addition and subtraction. A student also needs to understand how to check and double check the work to make sure the results calculated are actually accurate.

Functional money skills help students live more independently and ultimately help them succeed. Everything in our everyday life costs money, and you can have your child – no matter how young or old – practice these money skills with you… and your child's IEP team.

If this has made you want to call up your child's caseload manager to make an IEP goal change or two, share this month's article with them! In next month's article, you will learn more about writing functional IEP goals for more student independence. •

ABOUT THE AUTHOR:

Stephanie is a dual-certified special education teacher, Master IEP Coach®, children's book author, and teacher mentor. She has a passion for creating engaging, adapted resources for teachers and students with disabilities, and is self-proclaimed #datanerd. She understands that not everyone will love IEPs as much as she does, but it is her hope that with the appropriate training and resources, teachers will not only advocate harder for student services and supports, but also bridge the gap between teachers and families to foster a true IEP Team. She also provides professional development for teachers. You can connect with her at **www.mrsdscorner.com** and **www.theintentionaliep.com**. Stephanie is also a huge mental health advocate, sharing her experiences and struggles to let others know that you can survive the dark seasons and thrive in life and teaching with a mental illness.

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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.

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DIAGNOSTIC OVERSHADOWING

The responsibility lies with health professional schools, medical societies, and licensing and regulatory bodies to ensure skills are taught to students so the estimated 10 to 16 million people in the US with IDD can count on them to eliminate unnecessary suffering from unmet healthcare needs.

BY CRAIG ESCUDE, MD, FAAFP, FAADM

Mitchell was taken to the ER because his supporter noted that he was becoming noticeably agitated, was refusing to eat and had begun biting his arm intermittently. His supporter, who knew him well, recalled how he had done this a few times in the past, and most of the time, he was eventually found to have some underlying condition that caused him discomfort. Unfortunately, on some of those previous occasions, it took several clinician visits to get to the right diagnosis.

Because Mitchell does not use words to communicate, it can be quite challenging for clinicians to determine what might be going on. Once, his supporter recalled, he had a dental abscess that caused the same behavior, and it wasn't until after going to the ER and having multiple tests done, seeing a primary care physician and a psychiatrist due to his self-abusive behavior, and being started on two different behavioral medications, that an astute nurse who had experience in the IDD field insisted on a dental exam. Once his dental abscess was treated properly, he returned to his usual, pleasant self, and his behavior medications were discontinued.

THE WAY FORWARD: Medical schools should be required to provide training relating to providing healthcare to people with IDD.

When a person's symptoms or behavior are attributed to their disability without looking for treatable underlying medical causes, it is called "diagnostic overshadowing" which was the recent focus of a Joint Commission Sentinel Event Alert (**www.jointcommission.org/-/media/tjc/documents/resources/patient-safety-topics/sentinel-event/sea-65-diagnostic-overshadowing-6-16-22-final.pdf**) released in June of 2022. In it, they state that "diagnostic overshadowing contributes to health disparities and is of particular concern in groups experiencing health disparities, such as individuals with disabilities." In addition, "individuals with disabilities are at greater risk of diagnostic overshadowing" and "the potential of diagnostic overshadowing presents added risk to individuals with disabilities." I could not agree more with those statements. The Alert goes on to state that "Speed, stress, and lack of training contribute to diagnostic overshadowing." I believe that of these three, the latter, "lack of training," is the factor that we can do the most about.

Medical schools and other health professional schools should be required to provide training to students specifically relating to providing healthcare to people with intellectual and developmental disabilities (IDD). In order to address diagnostic overshadowing, it is essential to educate clinicians about common presentations of treatable medical illness in people with IDD, medication management, and The Fatal Five (**https://replacingrisk.com/idd-staff-training/the-fatal-five-fundamentals**), which are the top causes of preventable morbidity and mortality in people with IDD. The Fatal Five includes aspiration, constipation, dehydration, seizures, and sepsis, with the addition of gastroesophageal reflux. In addition, education on physical and nutritional supports (**https://replacingrisk.com/idd-staff-training/physical-and-nutritional-health-supports**) which relates to physical and nutritional measures to facilitate safety in eating and bowel elimination, co-occurring mental illness, vitamin D deficiency, differences in dementia presentations, and other clinical topics are vital to improving health and wellness for people with IDD.

You may notice that the topics I listed go beyond what one might call "disability competency" and involve specific medical conditions. While learning about making healthcare facilities more physically accessible, creating calm environments for people with sensory differences, and learning how to best communicate with people with disabilities and their supporters are extremely important, there are actual, specific clinical evaluation and diagnostic skills and concepts that healthcare professionals should be taught. The responsibility lies with health professional schools, medical societies, and licensing and regulatory bodies, to ensure these skills are taught to students as well as clinicians already in practice, so the estimated 10 to 16 million people in the US with IDD can count on them to reduce health inequities, avoid preventable illness and death, and eliminate unnecessary suffering from unmet healthcare needs.

Let's get back to Mitchell. At the emergency room, Mitchell and his supporter met Sarah, a nurse who received her degree from a school that taught IDD healthcare principles. Sarah spoke with Mitchell directly, in plain language, and asked Mitchell to sit down and demonstrated, one at a time, how she was going to check his blood pressure and other vitals, then escorted Mitchell to a quiet room and notified the physician that Mitchell had an intellectual disability and was ready to be seen. Mitchell then saw Dr. Smith, who had recently completed an online training course provided through his state's developmental disabilities agency. In that course, Dr. Smith learned about diagnostic overshadowing and the many different ways that people with IDD might express pain and discomfort, and the tendency for overuse of psychotropic medications to control behavior. Dr. Smith spoke to both Mitchell and his supporter and asked a number of questions relating to common causes of pain in people with IDD. Dr. Smith learned that Mitchell seemed to become more aggressive around mealtimes and refused to eat. He was also waking up at night yelling for no apparent reason, while curling up into a fetal position. Dr. Smith then evaluated Mitchell for gastrointestinal issues. He found that Mitchell had severe constipation which is one of the most common preventable causes of illness in people with IDD. Dr. Smith provided prompt treatment, and upon discharge, Dr. Smith recommended additional fiber and fluids, and to follow up with his regular doctor if the symptoms were not better within 24-48 hours.

Mitchell went back to his home, and the next day, he was back to his usual self. Both Mitchell and his supporter were so pleased that the healthcare staff treated them respectfully, listened to Mitchell's story, and had specific training about the healthcare needs of people with IDD. When health professional schools implement this vital training, better health and lower rates of unnecessary suffering for people with IDD will surely follow. •

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.

NAVIGATING INDIVIDUAL EDUCATION PLANS

BY RAJA MARHABA

School is open and children have begun their journey for the 2022-2023 school year. Many parents requested assessment plans prior to school ending in June 2022 and were told when their children return to school, they will resume.

One might ask what is an assessment plan? Assessment plans are what starts the Individual Education Plan (IEP) process. When a parent, guardian or teacher refer a child to get assessed, an Assessment Plan is provided to the parents within 15 days of the request. Parents have 15 days to review the Assessment Plan, sign and return it to the school. It is highly recommended that the request for an Assessment Plan be in writing, so that there are timelines to hold the school accountable. Once the parent

submits an executed Assessment Plan to the school, the school has 45 days to administer all the tests noted in the Assessment Plan, and hold an Individual Education Plan meeting.

A typical assessment plan tests in the areas of cognitive, social, emotional, behavioral and academic domains. If there are other concerns the school psychologist sees and/or the parent has, the psychologist can include other tests such as: speech and language, occupational therapy, assistive technology, etc. For an initial IEP, Assessment Plans are mandatory prior to making any eligibility decisions. The team consists of several school personnel, which at times can be between 10-20 individuals in the room, depending on the complexity of the child. This can be very intimidating for some parents, since they have many concerns about their children.

During the 45-day timeline, the school psychologists, special education teacher, occupational therapist, speech and language therapist, and any other assessor, will be calling the parent for more detailed information on the child. This allows the assessors to gather data and commence their testing on the child. Once the testing is completed, each assessor will provide the parent with a report of their findings. Included in this report will be the summary of findings and test data results, in numerical format. Assessors do not always provide these reports timely to the parents. At times they are provided the same day as the IEP, leaving the parents with no time to review and prepare with questions for the IEP team. I always recommend parents request in writing, and preferably on the assessment plan itself, the following verbiage **"please provide copies of all reports in this assessment plan to me five days prior to the IEP meeting, so that I can review, and materially participate in my child's IEP."**

Once the assessment reports are available, parents should read them and write down any questions and/or concerns they may have, and bring the questions with them to the IEP meeting. Look for accuracy in the information written in the report. School personnel are human and do make mistakes. The goal is to obtain information that reflects the child. Once all the reports are completed, the school will provide the parent with a few option dates to hold the IEP meeting. Schools should not impose restrictions on IEP dates. They should be flexible and afford the parents options, so they can attend the IEP meeting.

> The IEP team meeting is supposed to be collaborative between school personnel and the parents. The only way to make sure it is collaborative, is to be prepared with documentation and proof of all concerns the parent has for the child.

If a parent has an advocate, friend or someone who has knowledge of the child, and wants them to attend the IEP meeting, they can write their names and title on the **Invitation to the IEP.** A parent has the right to record the IEP meeting if the parent chooses to do so. The parent will need to write on the Invitation to the IEP **"I intend to record the IEP meeting and this is my 24 hour prior written notice."** The parent may then sign and submit this document to the school. It is typical for IEP verbiage to state something like **"if I, the parent, cannot attend my child's IEP, the school may proceed without me."** Please pay attention to detail and do not check such boxes, because the school will commence the IEP, decide eligibility, goals and objectives, accommodations, etc. on behalf of the parents. **This is not a proper way to proceed.** The IEP invite usually has a few options and boxes for the parent to check regarding attendance. **Be aware of this.**

The proper box to check will be one that states **"I intend to be there; however, if I am unable to attend, please contact me to reschedule."**

Once the Invitation to the IEP is signed and submitted, the fun starts. Prior to the IEP meeting it is imperative that parents have all the proper documentation to take with them, in order to better advocate for the child.

The documentation will consist of the following:

- *All new assessment reports (especially ones noted in the Assessment Plan)*
- *Two years of report cards*
- *Two years of IEPs (if it is not the initial)*
- *Two years of any and all assessments (private or public)*
- *Any new assessments and/or information the parent wants to share with the school*
- *Two years of Statewide standardized testing*
- *Emails and notes from teacher that may be pertinent to the child*

Parents should have a note pad to write down questions and information that is important to the parent during the meeting. Parents may want to have a list of questions prepared prior to the meeting. At times during the meeting, parents may forget important questions and concerns they have because all the assessors will be presenting, and other questions may arise. It will be easier if the above documents are tabulated into a three-ring binder and organized. This will facilitate access to documents as the meeting commences. It is a good idea to highlight statements in the above documents that the parent has concerns with.

Many times, the IEP team may state something that the parent will not agree with. Being organized will help the parent to refer to the reports and/or documents to prove a point. The IEP team meeting is supposed to be collaborative between school personnel and the parents. The only way to make sure it is collaborative, is to be prepared with documentation and proof of all concerns the parent has for the child. The IEP team will not provide a service if they do not have documentation showing that a service is needed. This does not mean that every document the parent brings with them will be considered by the IEP team. A successful IEP team depends on the school personnel training/knowledge base, and the parent, to have a meeting of the minds. IEP meetings are an opportunity to facilitate and negotiate for dire needed services.

The IEP meetings commence with the administrator making a verbal policy statement, and having all parties introduce themselves. There usually is an agenda that states who gets to present first, with timelines. Pay attention to what the assessors are saying and write down any deficits and/or challenges they state. When it is time to ask questions, you will need to refer back to those items. Those items will be very important with the Present Levels of Performance (PLOP) section in the IEP. The PLOP section is where areas of strengths and needs are stated. The information in the area of need is how goals and objectives are created. The administrator

TIME AND SPACE: Parents should take the IEP document home and not look at it for a couple of days. This way, they can have an emotional break, as these IEP meetings may be overwhelming for the parent.

will ask the assessors who contributed to the area of need in the PLOP section to provide goals and objectives. The goals and objectives may be comprehensive or not. It is important for parents to truly understand how the goal set in the IEP will benefit the child. If goals and objectives appear to be vague, ask the administrator to include more details, so that it is clear what the child will be working on for improvement in that area. Some questions a parent may want to ask are (1) How will the goal help remediate the need in PLOP, (2) How will the goal be measured, and (3) How often will the teacher communicate to the parent about progress or lack of progress with the goal.

Parents should not just agree to everything that is being stated in the IEP. It is important to ask clarifying questions, and truly understand how the goals will help the child progress in the school environment. These goals and objectives will become the scaffolding for building on improving the areas of need for the child.

> Parents should not just agree to everything that is being stated in the IEP. It is important to ask clarifying questions, and truly understand how the goals will help the child progress in the school environment.

Once the goals and objectives are created, the administrator will go over the accommodations. Usually, a child may need accommodations that will help in accessing grade level curriculum, such as: a calculator, extra text books at home and school, a note taker, sitting in the front of the classroom, extra time on test taking, extra time to submit assignments, quiet room for test taking, assistive technology, etc. If the child requires a behavioral plan, the administrator will review the plan, and ask the IEP team if changes are warranted, based on the report results and parent/teacher concerns. If there is a medical plan, the administrator should review the medical plan and attach it to the IEP, so that all the teachers are aware of the medical diagnosis, emergency contacts and procedures (based on the severity of the diagnosis). The administrator will ask the team what they think the **"eligibility"** of the child should be. Sometimes the parents may not agree with the eligibility that the IEP team suggests. The most important thing to know is, it really does not matter what the eligibility is, since the child will have the right to services and placement because of the area of need.

The **"eligibility"** helps by providing the readers (teachers/school staff) with information on what is the child's main challenge, such as: speech and language impairments, other health impaired (ADD/ADHD or medical diagnosis), autism, down syndrome, specific learning disability, developmental delay, etc. It is good to push for the eligibility that is the closest to the child's main struggle in the school environment. For example, if the child has deficits in the following areas: dyslexia, reading comprehension, phonemic awareness, reading fluency, decoding, etc. I would suggest specific learning disability for an eligibility. If the child's main struggle is speech, then I would recommend speech and language impairments. **Remember the eligibility does not impede the child from obtaining all required services,**

goals, objectives and placements that are derived from the assessments, report cards, standardized testing, teacher as well as, parent comments and concerns.

Once all the above are completed, the administrator will then state the Offer of a Free and Appropriate Public Education (FAPE). FAPE will be noted towards the end of the IEP document itself. The administrator will state or have the assessors state how many minutes, hours per week and/or per month the child will receive, in any area that requires additional support. If a child has significant language deficits, then that may require one on one speech and group therapy weekly. It is not always simple to obtain a one on one service, since that requires the school to provide a qualified individual to provide therapy, which comes with a cost. Most schools have something called "collaborative model" support where the qualified individual may go to the classroom, observe the student and provide the teacher with tools and strategies to help the child, but not truly provide one on one service. The collaborative model may not always be the best support for students with significant deficits. **That is why it is extremely important for the parent to have all the proper documentation with them, organized and ready to provide evidence to the IEP team, to back up the reasons why a one on one may be appropriate.**

Please note: it is not mandatory for a parent to sign the IEP immediately. When the IEP team asks the parent to sign the IEP, the parent should state that they want to take the IEP document home to review for accuracy, prior to signing it. The administrator is typing in all the data and it is best to review the data at home.

Parents should take the IEP document home and not look at it for a couple of days. This way, they can have an emotional break, as these IEP meetings may be overwhelming for the parent. After a couple of days, the parent should revisit the IEP document, review it and bring any discrepancies to the administrator taking the notes during the IEP.

If the parent is not in agreement with any part of the IEP, the parent may agree to the implementation of the IEP with the exception of the parts the parent is not in agreement with. When this happens, the school may request the parent to check the box that states "Informal Dispute Resolution" IDR. IDR is a way for the school and the parent to meet and go over the areas the parent is not in agreement with. The hope is to avoid a full-blown due process, and achieve resolve during IDR, where it is in the best interest of the child. **A word of caution here, IDR is a "legal procedure"** and the outcome is binding. It is best to have a seasoned advocate and/or attorney to review the IDR prior to signing it.

The IEP is a legal document and is what allows the parents to initiate a due process against the school for violations of FAPE. •

ABOUT THE AUTHOR:

Raja B. Marhaba is a mother of 2 sons who needed special education services, and is a special education advocate. She is the recipient of The Diane Lipton Award for Outstanding Advocacy. She was recognized for her work in helping students and families who strive for guidance, supporting them in navigating the right path for their special needs children. 2021 Raja Marhaba was included in, The San Fernando Valley Business Journal sixth annual Valley 200, a special standalone book featuring short profiles of the most influential leaders in the Valley area. Given her stature, and involvement in the valley from Martec Construction to The Jonathan Foundation, and her involvement with Val*Pac (San Fernando Valley Business Political Action Committee) she was honored amongst the elite in her community. She is the recipient for the 2019 L'Oréal Paris Women of Worth Awards and published in the Daily News for her accomplishments with The Jonathan Foundation.

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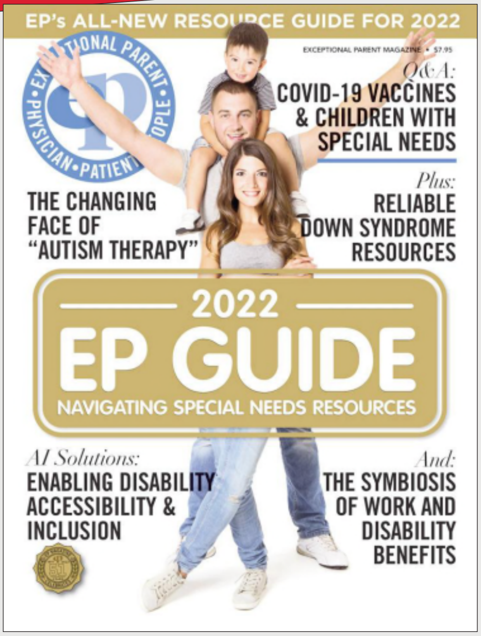

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ELECTRICAL STIMULATION AS A PHYSICAL THERAPY TREATMENT MODALITY FOR CHILDREN

Information for Parents of Children with Developmental Diagnoses including Cerebral Palsy, Down Syndrome, Hypotonia, Toe Walking, and Developmental Delay

BY JOVIAL LEWIS, PT, MPT, PCS AND YOCHEVED BENSINGER-BRODY, PT, PHD, PCS

Years of scientific research has shown that the best way for children with developmental diagnoses to achieve and maintain optimal health across all body systems (musculoskeletal, neuromuscular, cardiopulmonary) is to help them engage in age-appropriate play and functional tasks. Pediatric physical therapists work with families to help their children reach their maximum potential in these areas.

One well documented therapeutic modality to achieve these goals is electrical stimulation.[1,2] This article will describe this modality and explain how it can be useful for the pediatric population.

WHAT IS THERAPEUTIC ELECTRICAL STIMULATION?

Electrical stimulation (ES) is the application of electrical impulses with sufficient intensity to elicit a muscle contraction during an exercise program. It can be applied either percutaneously (needles placed through the tissue) or transcutaneously (electrodes placed on top of the skin). This article will only address the transcutaneous application of electrotherapy. Electrodes of different shapes and sizes are applied to the muscles, which are then connected to wires and a control unit. Specific parameters are used for children to keep it comfortable for them. Electrical Stimulation has many applications, but this article will discuss the practical applications of only neuromuscular electrical stimulation (NMES) and functional electrical stimulation (FES).

WHAT IS NMES AND FES?

When NMES is used, the unit is set to cycle to elicit muscle contraction, and then relaxation for a set period of time, as determined by the therapist. For this intervention, the child can be in any position, resting or moving. When FES is used, the unit only turns on to elicit muscle contraction when it is triggered by the therapist with a remote control, while the child is performing a functional task (like walking). This intervention is used to train a muscle to activate at a specific time during the functional task.

PART OF THE PROTOCOL: The best way for children with developmental diagnoses to achieve and maintain optimal health across all body systems is to help them engage in age-appropriate play and functional tasks. Electrical stimulation is a treatment modality that has well documented support as an intervention that produces good functional results when used in conjunction with functional task training, and when carried over in a home program.

HOW HAS THIS THERAPY BEEN MODIFIED FOR THE PEDIATRIC POPULATION?

Traditionally, clinicians have used adult protocols with their pediatric patients. These protocols do not take the developing system into account, and are often poorly tolerated by the child, leading to poor compliance. The approach described in this article is based on decades of work by various clinicians and researchers, and has been recently modified and taught by Dr. Susan Hastings, a renowned pediatric physical therapist. The differences in this approach relate to which muscles are targeted and the parameters that are used.

IS ELECTRICAL STIMULATION SAFE FOR CHILDREN?

ES is safe for most children and can be started as early as when a diagnosis is received. Age should not limit the use of e-stim, and in fact, there have been studies conducted using ES for children younger than 24 months.[3–5] There is a significant amount of research supporting this modality's efficacy and safety for children while using adult tested parameters, although there are reports of discomfort/pain. The parameters described in this paper are lower and specific for the pediatric system eliminating pain and discomfort as the side effect. Possible side effects may include discomfort from the stimulation, however pediatric parameters are well tolerated. Discomfort from removing electrodes is similar to removing a Band-Aid. If the modality is used by an untrained practitioner or untrained parent there is risk of skin burn or fatigue to the muscle. However, a trained practitioner will understand precautions, contraindications and appropriate application. There are a number of contraindications/precautions beyond the scope of the article, but this is true for all therapeutic modalities. A trained practitioner should only opt to use this modality when it is appropriate for the patient. Medical clearance should be obtained for children with complex medical diagnoses, including: seizure disorders, shunts, or cardiac issues. ES can also help children who have received BOTOX and orthopedic procedures.

WHO CAN PROVIDE THIS INTERVENTION FOR MY CHILD?

Use of NMES and FES is within the scope of practice for physical therapists and no additional certification is needed. We do recommend that clinicians take continuing education courses to learn about pediatric settings. Occupational therapists are required to take a specified number of continuing education credits to train in the use of electrical stimulation prior to being allowed to use this modality.

WHAT IS THE COST OF THIS INTERVENTION? IS IT COVERED BY INSURANCE?

If a family is purchasing an e-stim unit for a home exercise program, the cost is between $350 and $425 and is typically not covered by insurance. The cost of therapeutic services using this modality will vary and insurance coverage will depend if the clinician is an in-network or out of network provider. Clinicians will use their units and use patient specific electrodes.

HOW DOES ELECTRICAL STIMULATION WORK?

Therapeutic electrical stimulation to a skeletal muscle can initiate an artificial physiological response by stimulating the nerves and influencing the connections to the brain and spinal cord. When this intervention is applied over time, it can improve motor function by reducing hypertonicity (high muscle tone), increasing muscle strength and muscle bulk, and improving gait (quality of walking). Principles of motor learning are used when using the FES, as described in this article. Motor learning is how the nervous system reorganizes itself to improve motor function through repeated practice of a functional task, leading to improved motor skill performance. The repetitive therapeutic electrical muscle stimulation facilitates motor learning when provided at the same time as the functional task that is being practiced.[3,6]

WHAT DOES THE RESEARCH SAY ABOUT ELECTRICAL STIMULATION?

The benefits of NMES and FES have been well documented in the literature across multiple patient populations, across the lifespan.[6] Recent studies have shown that ES promotes neural recovery in individuals with an impaired nervous system, something which was thought not possible.[7] It also facilitates neuroplasticity (brain to form new connections) due to the frequent input.[8] Multiple published studies have enumerated the various benefits of ES for children. It improves muscle bulk and strength, reduces muscle tone (hypertonicity), improves passive and active range of motion, and it improves walking speed and foot and ankle mechanics during walking.[2,3,7,9–12] Many studies found that ES can lead to significant positive changes in walking in children with cerebral palsy.[11] The use of ES has evolved from stimulating a pair of muscles to multiple muscles groups, with FES units during walking.[13] Numerous studies have noted an improvement in upper extremity function in children with cerebral palsy, due to improved muscle length, reduction in tone and improved muscle strength.[2,9,14,15] A study found that children who received FES during walking together with traditional treatment, underwent an average of 4.5 fewer surgical procedures than children who just received traditional therapy.[16]

> **"A study found that children who received functional electrical stimulation during walking together with traditional treatment, underwent an average of 4.5 fewer surgical procedures than children who just received traditional therapy."**

HOW CAN ELECTRICAL STIMULATION HELP MY CHILD?

Here are some clinical examples describing how this therapeutic modality may help your child.

Hypotonia (low muscle tone): Hypotonia can be of central (Down's syndrome) or peripheral origin (spinal muscular atrophy).[17] This article does not discuss ES application for hypotonia in progressive, degenerative conditions like spinal muscular atrophy. Children with hypotonia typically present with poor posture, like a slouched back, a protruding tummy, and flat feet, and they present with decreased general strength, and activity tolerance. [18] For these children, NMES can be used on the back and core muscles to help them assume and maintain an upright posture.[19, 20] NMES or FES can also be used by placing electrodes on the child's feet to help strengthen the small muscles in the foot, for improving walking and balance skills.

Hypertonicity (high muscle tone): ES is very important for hypertonic muscles, because it can help the muscles 'reset' and decrease their tone, learn how to turn on and off, and develop true strength for functional movement. There are multiple applications for this in cerebral palsy, based on your child's gross motor function classification system (GMFCS) level of function. There are five levels within this classification system based on the motor skills attained by the child. Level 5 is the lowest functioning, where the child is bed or wheelchair bound and needs assistance for all activities. Level 1 is the highest functioning, and children in this level can walk, run, jump and go up and down stairs independently.

Levels 4-5: ES can be provided to reduce the hypertonicity in the muscles to help families perform hygiene tasks (like a diaper change, or bathing), to improve posture (in wheelchairs, standers, and gait trainers) and to assist with breathing (if it is used on the core muscles).[19,20]

Level 1-3: ES can be used to help a child develop the subskills which improve quality of movement for transitioning between positions from the floor to bed/chair/stand, for a controlled standing position, and to develop coordinated and energy efficient walking. To achieve these goals, a therapist may choose to apply e-stim to certain muscles of the legs, feet, and/or the torso. ES can also be used to help children gain the strength and control for higher level motor skills, like: fast walking, running and jumping.

Idiopathic Toe Walking: Children who walk on their toes benefit from e-stim to help them place their feet flat on the ground, realign their posture, and improve postural awareness for safe and energy efficient walking, as developed and taught by Dr. Hastings.[21]

HOW OFTEN SHOULD ELECTRICAL STIMULATION BE USED?

What is the dosage? Based on clinical experience, ES protocols are most successful when used 4-5 times a week (clinic and home program combined). Families are encouraged to use e-stim as part of a home exercise program, in between therapy sessions. The specific dosage and the number of muscles targeted will vary and be determined by the therapist, based on the child's level of function and the goal being worked on.

WHEN CAN I EXPECT TO NOTICE CHANGES IN MY CHILD'S MOTOR FUNCTION?

Changes in performance vary depending on the goals set for the child, as per their level of function. Changes like reduction in tone, improved posture, and improved components of balance can be seen within weeks. However, it takes up to 6 months of practice for a child to learn a new functional movement pattern and for that pattern to become permanent (indicates motor learning has taken place) as shown by multiple researchers. Factors like growth spurts and illness can impact change, as well. Additionally, carryover of the therapeutic benefits throughout the day at home and at school is important, and recommendations for compressive garments and foot orthoses are often made to assist with this. Overall, it is important to stay consistent with the treatment protocol and plan set by the therapist.

WHAT MACHINES CAN BE FOR THERAPY WITH ELECTRICAL STIMULATION?

It is good to use an electrical therapy unit that allows the therapist and family to select from a wide range of parameters for the individually designed treatment protocol. There are units that have remotes (hand held trigger) for the FES protocols. Safety features, such as an automatic lock to prevent the child from making adjustments and to stop if any components were to get loose, are a great benefit too. It should be small and portable for training of walking or other mobility skills. The devices used are FDA approved and are categorized as class II medical devices.

SUMMARY

While multiple treatment strategies for pediatric patients have been developed, the general consensus is that no one strategy alone works the best. When selecting a treatment protocol, one should bear in mind the long-term benefits that can be attained, like a safe and steady walk, prevention of pain and deformities, and importantly, the ease with which a home program can be done. E-stim is a treatment modality that has well documented support as an intervention that produces good functional results when used in conjunction with functional task training, and when carried over in a home program. •

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Yocheved Bensinger-Brody PT, PhD, PCS is a board certified pediatric physical therapist. She is an Assistant Professor in Touro College's Doctor of Physical Therapy program in NYC, and she is the clinician owner of a pediatric practice in northern NJ, Boutique Pediatric PT. Yocheved graduated with a BS in Physical Therapy from Florida International University, an MA in Movement Sciences from Teachers College, Columbia University, and a PhD in Psychology from the Graduate Center at CUNY. Yocheved started integrating E-stim into her pediatric practice a few years ago and has found it to be a game changer!

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How a Montclair State University program is creating opportunities for inclusion in a college atmosphere.

INCREASING ACCESS TO COLLEGE

BY ANDREW MEES

Seeking to increase inclusivity and diversity of students with disabilities in higher education, Montclair State University launched the Increasing Access to College (IAC) project in 2015 to offer comprehensive, structured support within a large, public research university environment.

The project is designed to create new pathways for people who are co-enrolled in a high school transition program, and who are not likely to attend college through traditional avenues.

Students participating in the IAC are fully integrated into campus life with peer support, and engage in auditing courses across campus, as well as participate in social and recreational aspects of college life.

The program also benefits traditionally enrolled students in Montclair's College of Education and Human Services, and students in other colleges who are involved in community-engaged course experiences with Montclair's Center for Community Engagement. Students preparing to be educators and who engage in public service, also have the opportunity to be part of the program, increasing their capacity to bring the ethics of inclusion into their future careers and lives.

"The IAC project grew out of wanting Montclair State University students studying to be teachers, to have inclusive educational experiences," said program co-founder and Professor of Teaching and Learning Susan Baglieri. "When we could not find as many inclusive schools as we wanted, we decided to create an inclusive experience on campus. We are proud of what we have been able to build in partnership with the students, leaders, and professionals from the many schools and programs, that have helped to build this road by traveling it."

HOW IT WORKS

The IAC partners with New Jersey school districts, to provide the chance to participate in courses, and engage in social opportunities and campus recreational activities, in a peer companionship model. The program is offered only in collaboration with transition programming, provided by local school districts.

Students 18-22 years old, both with and without disabilities can apply to be IAC Fellows, ensuring true inclusivity within the program's experiential learning opportunities.

SERVING THE PUBLIC GOOD

The project has allowed Montclair to share the model with the academic community, and serve as a resource for local school districts prioritizing inclusion.

Baglieri and co-founder Jessica Bacon, an associate professor of teaching and learning, have published research in the Journal of Disability Studies in Education and the Review of Disability Studies: An International Journal, and Bacon recently led a group of education students to Finland, where she shared the model with Finnish educators.

"The development of the IAC has been exciting and ongoing work. We have learned a great deal from other colleges and universities across the United States, that have been building inclusive postsecondary education opportunities for decades," said Bacon. "Building the IAC at Montclair State University has allowed us to collaborate with offices, departments, and people across the entire campus.

This has provided us with unique entry points to promote inclusivity across higher education systems. As we continue to document our successes through presentations and publications, while learning from other campuses, we see the building of inclusive postsecondary opportunities as an exciting movement in the United States. Program outcomes demonstrate beneficial impacts for the futures of students with intellectual disabilities who attend college, and we are excited that Montclair has embraced the opportunity to be a part of creating a more inclusive society."

ABOUT THE AUTHOR:

Andrew Mees is Media Relations Director for Montclair State University.

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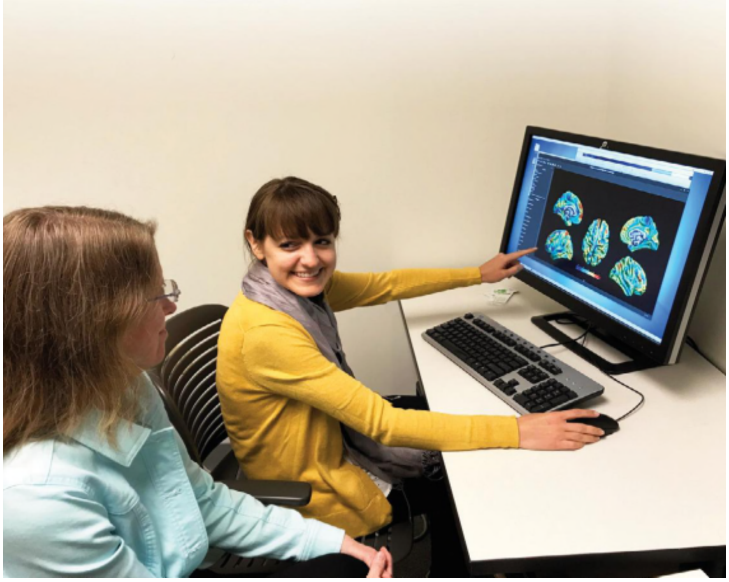

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MILITARY SECTION

MILITARY LIFE

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MILITARY LIFE

TAKING CARE OF OUR SERVICE MEMBERS AND FAMILIES

The well-being and readiness of our service members is a top priority for the Defense Department. In September 2022, Secretary of Defense Lloyd J. Austin III announced an action plan for additional support.

Changes will make military moves easier, expand opportunities for spouse employment, strengthen support for military families and ensure basic needs are met.

Read the "Taking Care of Our Service Members and Families" memo from Secretary of Defense Lloyd J. Austin III at **https://www.defense.gov/News/Releases/Release/Article/3167769/dod-announces-immediate-and-long-term-actions-to-help-strengthen-the-economic-s/**

FOUR PRIORITIES TO BENEFIT MILITARY FAMILIES, PART 1 : SECURING BASIC NEEDS

Our military families must be secure in their ability to afford the basics. In addition to the 4.6% pay increase for service members included in the president's 2023 budget, the Defense Department will:

AUTOMATICALLY INCREASE BASIC ALLOWANCE FOR HOUSING IN 28 MILITARY HOUSING AREAS

WHAT IS IT? We're temporarily increasing BAH rates for service members assigned to military housing areas where average rental housing costs have increased more than 20% over 2022 BAH rates.

WHO IS ELIGIBLE? Service members assigned to the following military housing areas qualify for the increased BAH:

Vandenberg Air Force Base California; Twenty Nine Palms Marine Corps Base California; San Diego, California; Dover Air Force Base / Rehoboth, Delaware; Patrick Air Force Base Florida; Miami / Fort Lauderdale, Florida; Orlando, Florida; West Palm Beach, Florida; Volusia County, Florida; Ft. Myers Beach, Florida; Kings Bay / Brunswick, Georgia; Maui County, Hawaii; Chicago, Illinois; Boston, Massachusetts; Cape Cod-Plymouth, Massachusetts; Martha's Vineyard, Massachusetts; Brunswick, Maine; Coastal Maine; Fort Leonard Wood, Missouri; Helena, Montana; Wilmington, North Carolina; Northern New Jersey; Newport, Rhode Island; Providence, Rhode Island; Beaufort / Parris Island, South Carolina; Knoxville, Tennessee; Houston, Texas; Quantico / Woodbridge, Virginia.

HOW TO ACCESS: If you're in an eligible housing area, you will automatically receive a higher BAH payment in your Oct. 15, 2022 paycheck. If you move to an eligible area any time from October-December, you will receive the increase.

Download the Basic Allowance for Housing Fact Sheet at **https://download.militaryonesource.mil/12038/MOS/Factsheets/basicallowancehousing-factsheet.pdf**

FULLY FUND COMMISSARIES FOR FURTHER SAVINGS

WHAT IS IT? We're allocating more funds to subsidize commissary prices so military families save at least 25% on their purchases.

WHO IS ELIGIBLE? All uniformed service members including reserve component and Coast Guard members are eligible.

HOW TO ACCESS: Shoppers will see commissary prices drop 3-5% over the next month.

Download the Commissary Fact Sheet at **https://download.militaryonesource.mil/12038/MOS/Factsheets/commissary-factsheet.pdf**

PAY A BASIC NEEDS ALLOWANCE

WHAT IS IT? We'll offer a monthly allowance for active-duty service members with dependents whose gross household income falls below 130% of federal poverty guidelines. By law, payment of the allowance begins in January 2023.

WHO IS ELIGIBLE? Active-duty service members with dependents who have completed initial entry training and whose gross household income falls below 130% of federal poverty guidelines for their location.

HOW TO ACCESS: Service members will have to apply using documents that confirm the income of members of their households, such as a tax return, a W2 or a leave and earnings statement. Military departments and service branches are required to proactively screen service members for eligibility and notify them of their potential eligibility.

Download the Basic Needs Allowance Fact Sheet at **https://download.militaryonesource.mil/12038/MOS/Factsheets/basic-needs-allowance-factsheet.pdf**

TARGETING PRIORITIES: Secretary of Defense Lloyd J. Austin III announced immediate and long-term actions to help strengthen the economic security and stability of service members and their families.

FOUR PRIORITIES TO BENEFIT MILITARY FAMILIES, PART 2 : MAKING MOVES EASIER

Service members and families are required to move frequently, and these moves often come with costs that strain budgets. We are easing the moving process by:

INCREASING MAXIMUM TEMPORARY LODGING EXPENSE ALLOWANCE

WHAT IS IT? We're making three changes: 1. We will partially reimburse a service member for temporary lodging and meal expenses while in temporary lodging, in CONUS, during a PCS, based on the local per diem rate and the number of dependents. 2. We will increase the automatic payment of TLE from 10 days to 14 days during moves within CONUS. 3. We will permanently permit TLE extensions for a location experiencing a housing shortage regardless of the reason for up to 60 days.

WHO IS ELIGIBLE? All uniformed service members including Coast Guardsmen and the commissioned corps of the National Oceanic and Atmospheric Administration and Public Health Service are eligible.

HOW TO ACCESS: To receive an extension of up to 60 days, the location must be approved by the Per Diem, Travel and Transportation Allowance Committee. Service members may request an advance or may file for reimbursement with the servicing PCS finance office based on service policies and procedures.

Download the Dislocation Allowance and Temporary Lodging Expense Fact Sheet at **https://download.militaryonesource.mil/12038/MOS/Factsheets/dislocationallowance-factsheet.pdf**

INCREASING DISLOCATION ALLOWANCE

WHAT IS IT? We are increasing the flat amount we pay eligible service members to partially reimburse them for moving expenses incurred during a PCS.

WHO IS ELIGIBLE? This action will increase DLA for E-1 to E-6 service members.

HOW TO ACCESS: On Oct. 1, 2022, DLA rates will be increased. Service members will be paid no later than one month prior to their move date.

Download the Dislocation Allowance Fact Sheet at **https://download.militaryonesource.mil/12038/MOS/Factsheets/dislocationallowance-factsheet.pdf**

ENHANCING MILITARY ONESOURCE DIGITAL SERVICES

WHAT IS IT? We are creating online tools, guides and FAQ sections to make moving simpler for military families.

WHO IS ELIGIBLE? All uniformed service members including National Guard and reserve, Coast Guard and their families, and veterans up to 365 days after separation can use these resources.

HOW TO ACCESS: Connect with intel through the PCS & Military Moves page (**www.militaryonesource.mil/moving-housing/moving/pcs-and-military-moves**), Plan My Move (**https://planmymove.militaryonesource.mil**), Military OneSource social media channels and eNewsletters (**www.militaryonesource.mil/epublications**).

Download the Military OneSource Moving Your Personal Property Webpage Fact Sheet at **https://download.militaryonesource.mil/12038/MOS/Factsheets/moving-factsheet.pdf**

PHOTO COURTESY CHAD J. MCNEELEY/DOD

FOUR PRIORITIES TO BENEFIT MILITARY FAMILIES, PART 3 : STRENGTHENING OUR SUPPORT FOR FAMILIES

We're expanding support for families and making it easier to find affordable, quality child care options by:

INVESTING IN CHILD DEVELOPMENT PROGRAM FACILITIES

WHAT IS IT? We are investing in CDP facilities and infrastructure to increase capacity.

WHO IS ELIGIBLE? All active-duty service members including National Guard and reserve on active duty, DOD civilian employees and other authorized users are eligible.

HOW TO ACCESS: You can request child care through **MilitaryChildCare.com**

STANDARDIZING A MINIMUM 50% FEE DISCOUNT FOR THE FIRST CHILD OF CDP DIRECT-CARE WORKERS

WHAT IS IT? We're offering CDP direct-care workers a fee discount for their own kids as a way to bolster worker recruitment and retention. This will help to maximize existing child care capacity, reduce waiting lists for care and support spouse employment.

WHO IS ELIGIBLE? The discount applies to the first child of all direct care staff of CDPs.

HOW TO ACCESS: Eligible CDP personnel can access the benefit through their CDP.

IMPROVING ACCESS TO CHILD CARE PROGRAMS AND RESOURCES

WHAT IS IT? We are improving access to child care programs including Military Child Care in Your Neighborhood-PLUS and the In-Home Child Care Pilot.

WHO IS ELIGIBLE?

Military Child Care in Your Neighborhood-PLUS is available to active-duty service members including National Guard and reserve on active duty and DOD civilian employees in participating locations.The In-Home Child Care Pilot is currently available in Hawaii; National Capital Region; Norfolk, Virginia; San Antonio, Texas; and San Diego, California, and will be expanding to Colorado Springs, Colorado; Seattle/Tacoma, Washington; Jacksonville/Mayport and Fort Walton Beach, Florida; Fayetteville, North Carolina; and Las Vegas, Nevada. Eligible military families include single or dual active-duty members; active-duty members with a full-time working spouse; and active-duty members with a spouse enrolled in a postsecondary institution on a full-time basis.

HOW TO ACCESS: Authorized users can request child care through **MilitaryChildCare.com**

Download the Child Care Fact Sheet at **https://download.militaryonesource.mil/12038/MOS/Factsheets/child-care-factsheet.pdf**

FOUR PRIORITIES TO BENEFIT MILITARY FAMILIES, PART 4 : EXPANDING SPOUSAL EMPLOYMENT

Military spouses are the strong foundation for our service members and military families. We are expanding employment opportunities by:

ACCELERATING DEVELOPMENT OF OCCUPATIONAL LICENSURE COMPACTS

WHAT IS IT? Compacts allow military spouses to work in a member state without having to fulfill further licensing requirements. Nine licensure compacts currently exist and are being approved by states for specific professions.

WHO IS ELIGIBLE? All military spouses including active-duty, National Guard and reserve spouses are eligible.

Download the Spouse Employment Fact Sheet at **https://download.militaryonesource.mil/12038/MOS/Factsheets/spouse-employment-factsheet.pdf**

INCREASING DIRECT HIRING AND REMOTE/TELEWORK OPTIONS

WHAT IS IT? By promoting available civilian hiring authorities and workplace flexibilities that support our military spouses, DOD can better provide critical mission talent while bolstering the financial stability of military families. Utilizing workplace flexibilities such as telework and remote work further expands recruitment and retention opportunities for military spouses.

WHO IS ELIGIBLE? All military spouses are eligible for this opportunity.

HOW TO ACCESS: Military spouses can search for job openings at **USAjobs.gov**, as well as remain aware of opportunities within DOD at **dodciviliancareers.com**.

Download the Spouse Employment Fact Sheet at **https://download.militaryonesource.mil/12038/MOS/Factsheets/spouse-employment-factsheet.pdf**

LAUNCHING A NEW CAREER ACCELERATOR PILOT INITIATIVE

WHAT IS IT? Starting in January 2023, a new pilot program will provide military spouses with paid private-sector fellowships in a variety of industry sectors.

WHO IS ELIGIBLE? Currently serving military spouses including active duty, National Guard and reserve are eligible.

Download the Spouse Employment Fact Sheet at **https://download.militaryonesource.mil/12038/MOS/Factsheets/spouse-employment-factsheet.pdf**

INCREASING PARTNERS IN THE MILITARY SPOUSE EMPLOYMENT PARTNERSHIP

WHAT IS IT? MSEP brings together employers committed to recruiting, hiring, promoting and retaining military spouses. MSEP launched in 2011 with 45 partners. We currently have 540 employer partners and will continue growing the partnership to expand opportunities for military spouses.

WHO IS ELIGIBLE? All current military spouses (active duty, National Guard and reserve) including those who are up to 365 days post separation/retirement are eligible.

Download the Spouse Employment Fact Sheet at **https://download.militaryonesource.mil/12038/MOS/Factsheets/spouse-employment-factsheet.pdf**

NATIONAL VETERANS AND MILITARY FAMILIES MONTH

Special Events and Offers for Military Families

Each November, the military community observes National Veterans and Military Families Month to celebrate how special military families are and recognize all the ways they support their service members. **Join us for virtual events all month long:**

11/5: Sleep Strategies for Stress
11/10: Family Fact-Finding: Explore Ancestry.com
11/17: Storytime with Bella (ages 3-6)
11/19: Family Picture Day
11/19: Storytime with Ryan (ages 7-10)
11/19: MilSpouse Secrets
11/20: Easy and Nutritious Meals for Your MilFam

Additional Information & Resources

https://militaryonesource.mil/military-family-appreciation

YOU'RE★EVERYTHING

Appreciation kit for military families

The Department of Defense and Military OneSource are recognizing military families and transitioning veterans with Military Family Appreciation Kits. Kits are available to military service members and their immediate family members as well as to veterans within 365 days of their post-separation date.

Virtual events all month long

At Military OneSource, we're hosting special events to celebrate military families – spouses, partners, parents, co-parents, children, extended family members and even friends. Tune into our virtual events on Facebook throughout November, and spread the word about these special online broadcasts to the families in your community. https://www.facebook.com/military.1source

Helpful resources and fun tips

In November and all year long, we'll highlight resources and services for military families on Military OneSource and Spouse Education and Career Opportunities social channels. Follow along and share posts you think will be fun or helpful for families in your community.

Support whenever it's needed

This month and all year long, Military OneSource consultants are available 24/7 to connect service members and their spouses to info, answers and support – everything from confidential counseling to specialty consultations on child care, relationships, spouse employment, relocation and more. See all the ways we can support military families at https://militaryonesource.mil/military-family-appreciation.

MILITARY ONESOURCE

LESSONS IN UNITY, COMPLIMENTS OF THE MILITARY

BY DOMINIC CERTO

There is no question we've become a nation divided in personal ideologies, but these ideologies have taken on a new form of division and hate. Never has the country and its people, so passionately drawn lines to create a clear demonstrative separation in their principles, beliefs, and convictions, except during the civil war.

But it wasn't always like this. My age will give me away as remembering a climate in this country of compromise, debate, and respect for different opinions. In fact, there was a way to see both sides, adjust to compensate for mistakes or differences, and provide a reasonable outcome. There wasn't so much of "my way or the highway," nor was there this obsession to shut out discourse. Somehow, we became a nation of team players. My team must win, no matter what the cost. And if my team is losing, I will double down to the end to fight for their right to win. And fight they do.

PHOTOS COURTESY OF DOMINIC CERTO

A BOND OF COMMON GOOD: *(Opposite page)* The author on patrol at Landing Zone Baldy in the Que Son Valley; *(Above left)* Certo while stationed at Hill 270, 12 km west of the airfield at Chu Lai; *(Above right)* Certo receives medals in front of his regiment.

But running a country, or a government and its citizens should not be a do or die team sport. It is an intellectual, moral, and historical lesson in responsibility, that needs to achieve and maintain the freedom, safety, and an improved life of its people. This only comes with the understanding that different opinions or facts are worth considering and debating, for a mutual benefit. Add to that the respect, not contempt, of the other side.

I feel the military is the best example of unity and coming together. In 1969, while serving with the Marines in Vietnam, our platoon was on patrols in the Que Son Valley. I developed malaria; I was also injured from our platoon operation of taking back a hill near our landing zone base. Our operations were long and sometimes lasted for weeks on end. The climate was unforgiving, humid, and miserably hot with temperatures well over 100 degrees. Humping gear for miles, while staying alert for an ambush, always made our lives more unbearable. We were in an area of heavy fire and constant ambushes, so it was difficult to get supplies and support. Water was priceless as the heat and lack of support only allowed us scarce water from the murky rice paddies that we treated with purifying pills. The malaria, and my injuries, along with the climate took its toll, and as I dealt with the spinning vertigo of my condition, I finally collapsed. My platoon took notice, and the corpsman said my temperature was 105 and growing. He had to call in a medivac, but we weren't sure they would come because of the danger of our position. Everything was a fog to me, but one thing I vividly remember and will never forget is the Marines in my platoon pouring their precious water over me. There was no guarantee of any more water for the next few miles or days, but they all poured their water over me to try and bring down my fever. I begged them to stop knowing what precious water they were giving away might not be replaced, but they wouldn't stop. These men were Black, White, Hispanic, and Asian, but there were no lines drawn, there were no debates or discussions, there was only a common good with an unselfish act for something more important than their own immediate needs. I was humbled and nearly cried as they did it, but I learned a lesson as the medivac somehow pushed its way through enemy fire to rescue me. We were all together in caring for each other and putting aside our own personal gain or loss for some moral good.

This is not an isolated case; it happens all the time with the military, and in so many challenging situations. There is a bond of common good, and determination of action to accomplish a noble task. If only we could learn from this lesson, compliments of the military, we would accomplish so much more, while enabling a moral responsibility for all of us to act as brothers in a path to better outcomes. •

ABOUT THE AUTHOR:

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

U.S. MILITARY ★ BOOK EXCERPT PART VI

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 eighth chapter in a series of articles about this process.

CHAPTER 8

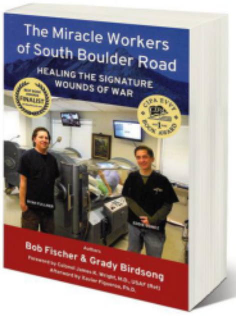
VETERANS TREATED AND HEALED BY HBOT IN THEIR OWN WORDS

In 2012, Charles "Pat" Smith, Department Adjutant of the American Legion of the State of Colorado, invited Colonel R. L. Fischer to meet a young woman who had recently been medically separated from the Army and who had just begun successful hyperbaric oxygen treatments with Dr. Paul Harch at his clinic in New Orleans.

At this meeting was the editor of the Legion's *Observer Magazine,* Darrel Myers, and former American Legion National Commander in 2005, Thomas Bock. The meeting was to gain a deeper understanding of this new treatment that was proving to be effective in healing concussive blast injuries suffered by our combat veterans.

Past Legion Commander Bock prefaced the reason for the meeting by telling Colonel Fischer, "Wait until you meet this young lady. She has quite a story to tell us." Shortly after that, the very attractive young woman arrived with her friend in tow, a shy lanky young man, obviously a veteran recently out of the military. She greeted everyone, thereby introducing herself, and then turned to her companion to introduce him, "You all will have to speak slowly. My friend is a United States Marine." That comment broke the ice, and the group truly enjoyed meeting with and listening to Margaux Mange tell her story from playing high school soccer to becoming a United States Army Military Policeman. Here is Margaux's story.

Sergeant Margaux Mange was one of the South Boulder Road clinic's first patients. Margaux grew up in Lakewood, Colorado, playing soccer throughout her childhood and teenage years. She enjoyed the sport and became a star soccer athlete at Alameda High School. However, Margaux admitted that the primary reason she joined the Army was the promise of playing soccer for them. As she vividly described her motivation for entering the military, "The recruiter assured me that I could play on the All-Army Soccer Team, and since my father was in the Army, it made sense for me to join, even though the United States Air Force had seriously courted me to play for them instead."



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**
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Available at: amazon.com and www.barnesandnoble.com

PROMISING DEVELOPMENTS: *(Left to right)* Colonel R.L. Fischer, Colorado Legion Adjutant Charles “Pat” Smith and 2012 American Legion National Commander, Fang A. Wong. The meeting was arranged to gain a deeper understanding of a treatment that was proving to be effective in healing concussive blast injuries suffered by combat veterans.

JOINING THE ARMY

Margaux began her basic training at Fort Leonard Wood, Missouri, in 2003 and was assigned the military occupational specialty (MOS) of Military Policeman. After completing basic and military police schooling, she was ordered to Kitzingen, Germany, her first duty station. Her soon-to-be Platoon Sergeant picked her up at the train station upon arriving in Germany. He immediately leveled with her in no uncertain terms and, in effect, told her, “I know you joined the Army to play soccer, but that is not going to happen. The Army has other plans for you, and you will soon be going to Baghdad.”

> “We patrolled all over Iraq. Sadr City was an incredibly dangerous area with so many ambushes and improvised explosive devices.”

She did get to play a few months of soccer while going through her military training at Hohensfels, Germany, in Bavaria for FTX and picked up the honors of the most valuable player on the base team. “By the following April 2004, I was in Iraq with the 630th Military Police Company, and we started going on patrols immediately. At first, we patrolled all over Iraq and trained many Iraqi police. There were many missions in and out of Sadr City, Iraq, and it was an incredibly dangerous area with so many ambushes and improvised explosive devices.”

Her MP Company also set up protective concrete barriers around the Iraqi police stations so that insurgents could not shoot into or run speeding cars with car bombs into those facilities. They were also assigned to escort senior commanders in and out of the Green Zone, the Army’s Supreme Command Headquarters in Baghdad. “I remember some of the firefights, the mortar attacks, and some of the deadly IED concussions we experienced. I survived that first year of my deployment because the explosive devices were poorly made, and we could recognize a wire or dead dog [wired with explosives], tipping us off that there was an explosive device nearby.”

When her tour of duty came to an end in April 2005, she returned to Germany and resumed her regular MP duties. Margaux reveals that she “hated my job since it involved writing and issuing tickets. I confess; I only gave out a couple of them in my military police career.”

After being in Germany for a while, Margaux hoped that she could again try out for the soccer team. She was disappointed when she was sent to a school to train as a gunner instead of a driver for her next OIF tour.

PHOTO COURTESY GRADY T. BIRDSONG

WOUNDS OF WAR: Margaux Mange on patrol with 630th MP Company in Iraq; "It didn't affect me badly until March 2007, when my best friend, Ashley, and two others were hit with a fifty-pound explosive device. They were in the truck right behind me. When the IED detonated, it flipped their truck completely upside down and killed all of them instantly."

SECOND TIME AROUND

After this incident, Margaux continued going out on patrols, doing her regular job as a gunner and not thinking anything had happened to her. She was more concerned about the others on the team than herself. As a result, their combat patrols became much more dangerous. As she describes, "It didn't affect me badly until March 2007, when my best friend, Ashley, and two others were hit with a fifty-pound explosive device. I was riding on Truck #5, and they were in the truck right behind me, in Truck #6. When the IED detonated, it flipped their truck completely upside down and killed all of them instantly. Their bodies burned as I watched. The fire must have burned for more than an hour. I still cannot forget that sight!"

THE LONG BATTLE BEGINS

This was the beginning of Margaux's long battle with TBI and PTSD. Her face developed Bell's palsy, a paralysis or weakness of the muscles on one side of the face, which she now thinks came from the mental stress she had suffered. She recalls, "The doctors thought maybe this was happening because I was in the third trimester of a pregnancy or because I had slept on my face wrong … or due to some other cause. They were idiots and wouldn't accept that it was due to stress."

Eventually, she was sent back to Landstuhl. In April 2007, she began receiving further medical attention, and the doctors finally realized that her initial concussion and mental state were more severe than initially diagnosed. Recalling those dreary days, Margaux describes her feelings, "I had atypical nerve pain and trigeminal neuralgia. At that time, my post-traumatic stress was off the charts. I realized I would not be returning to Iraq and felt like I had abandoned my team. I felt like I was a traitor. So when I left them, I told them I would be back in a couple of weeks." Instead, her unit was deployed for thirteen months, and she would not see them until they returned to Germany. She vowed to them through email that she would not drink or celebrate anything without them. "I did not touch alcohol until they returned. I was in so much pain anyway that I couldn't drink if I wanted to, so I slept fourteen hours every day in Bamberg."

"My PTSD was off the charts. I realized I would not be returning to Iraq and felt like I had abandoned my team. I felt like I was a traitor."

Margaux spent her days visiting the hospital three hours away from Bamberg, and there she received a multitude of pills – morphine, Percocet, and more medications. Then the doctors decided her PTSD was so bad that they sent her home to Colorado because that was where her family lived.

Remembering that journey home to Colorado and checking in, Margaux says the Army doctors gave her a choice, "Stay on pills for the rest of my life or try brain surgery." She finally had brain surgery in March 2008. That was the beginning of the end of her active Army duty.

"The surgery was performed to try and alleviate the pain. However, I was in so much pain I couldn't even walk up a flight

PHOTOS COURTESY OF MARGAUX MANGE

DIVING IN: Margaux in the hospital. “I was a robot and numb before the HBOT treatment with Dr. Harch. But after my first forty treatments, I was able to deal with the terrible memories of what had happened to my best friend, Ashley.”

of stairs. It felt like a softball had been inserted inside of my skull. And so I was willing to try anything… that is when I underwent laser surgery at Fort Carson, Colorado, where I would remain for eight months. But it was unsuccessful. The severe headaches continued, and I was medically discharged. Then in 2009, I planned to move to Ohio with my fiancé. Still, before doing that, I had the great fortune to meet a Fort Carson Army representative who assisted wounded warriors like me through the Warriors Transition Unit. Robert B. Alvarez, a Marine Corps veteran, interviewed and processed many wounded warriors like me. He told me he would help me get my life back. I had suffered hard from both the brain injury and the post-traumatic stress, and it was just fate that I ended up in his office. If I had never met him, I would never have gone through hyperbaric oxygen therapy. It was then that Bob Alvarez introduced me to Dr. Paul Harch, the pioneer of HBOT therapy who had his clinic at Southern Louisiana University.”

A LUCKY BREAK

In 2009, Margaux became one of Dr. Harch’s first patients and traveled there to receive HBOT treatment. Margaux tells of the experience, “There I took forty dives, and I have to say it was successful. I started feeling better after about twenty of the sessions. However, I was angry. At the same time I was getting treatment, my Ohio psychiatrist had also sent me there with homework. I have always been a faithful-like patient and listened to what a doctor would tell me. I have always tried to do the right thing and didn’t like people being mad at me. Then, during the first part of the treatments, my anger surfaced. I looked at the homework, and it made me so angry. I was so ticked off at her that I ripped up everything I’d brought. All of those emotions started coming out that I had been hiding. My memories were now resurfacing, and I cried and laughed a lot more.”

> “I had suffered hard from the brain injury and the PTSD. If I had never met Robert B. Alvarez, I would never have gone through HBOT.”

Dr. Harch had warned Margaux that after a few sessions of hyperbaric chamber dives, while her brain was healing physically, her mind would also experience a rollercoaster of emotions during the final recovery process. She recalls, “When I came back and talked with my psychiatrist, I handed her my torn homework pages. She looked at me and said, ‘This isn’t you.’ With all those terrible emotions coming to the surface, we could figure out together what was going on with my post-traumatic stress situation.” When Margaux returned after that session with her psychiatrist, she describes how they began “digging into new stuff. It helped me a lot. Before then, I hated all of my emotions. I was a robot and numb before the HBOT treatment with Dr. Harch. I wouldn’t say I liked that I had to go through the treatments all by myself. But after my first forty treatments, I was able to deal with the terrible memories of what had happened to my best friend, Ashley, when she died on March 3, 2007.”

In February 2010, after Margaux completed her forty dives with Dr. Harch, they determined that her TBI and PTSD were more serious than the mild TBI first diagnosed. This would require many more chamber hours, which she found in Colorado after she returned to live near her father. In August 2010, Ryan and Eddie learned of her unique story and offered to treat her at the Rocky Mountain Hyperbaric Institute “for as long as it takes to heal you.” So, another forty chamber hours were scheduled over the next few months. Margaux continued to return for additional “maintenance” treatments for several years after that (achieving a total of 140 HBOT chamber hours between both facilities). Today Margaux knows she can finally cope with her TBI and its related PTSD. She still volunteers to raise funds for the Rocky Mountain clinic.

PHOTO COURTESY OF MARGAUX MANGE

BREAKTHROUGH

Margaux tells others that the only negative aspect of this treatment is that a person must lie in a tube for an hour every day and that she thinks that people are just impatient with the need to do that. She also believes many people still don’t know about this form of treatment and its benefits. When people are new to the treatment, there are still those who find it hard to believe in its miracles. Taking a pill provides quick relief, but the effects are temporary. Sometimes it isn't easy to get people to understand that medications won’t work in the long run, but the long-term effects of hyperbaric oxygen treatment will be well worth the time it takes.

COMPETITIVE FIRE: Margaux with Prince Harry in Trafalgar Square; She was chosen to represent America’s Walking with the Wounded team that competed in the South Pole Allied Challenge that began in November 2013.

Margaux discovered that the healing began after about fifteen to twenty sessions. At that point, her ability to sleep improved, her migraines lessened, her memory began to return, and her depression and need to isolate and withdraw from others eased up. In addition, her physical wounds improved with HBOT, and the TBI started to heal. However, the post-traumatic stress was an awful situation for her, and as her memory and brain functions began to improve, she had a bad PTSD slip, a brutal one, as Margaux describes it. “You go into a deep dark depression where all of your emotions go down. If you are an avoider, you avoid everything, but you can’t avoid PTSD forever. All of my emotions, every single one of them, came to a boiling point. I don’t know how to describe it, but your mind is not strong enough to shut down all the negative emotions you experienced.”

Sometimes it isn't easy to get people to understand that the long-term effects of HBOT will be well worth the time it takes.

Even though she was physically healing her brain from the concussion, she needed professional help with the mental and psychological wounds she had also suffered. “When the doctor first told me in Germany that I had post-traumatic stress disorder and would not be going back to Iraq or any combat duty, it was the lowest point. I did not know what it was, this PTSD they were talking about. It was devastating for me… I had been planning on a career with the Army.”

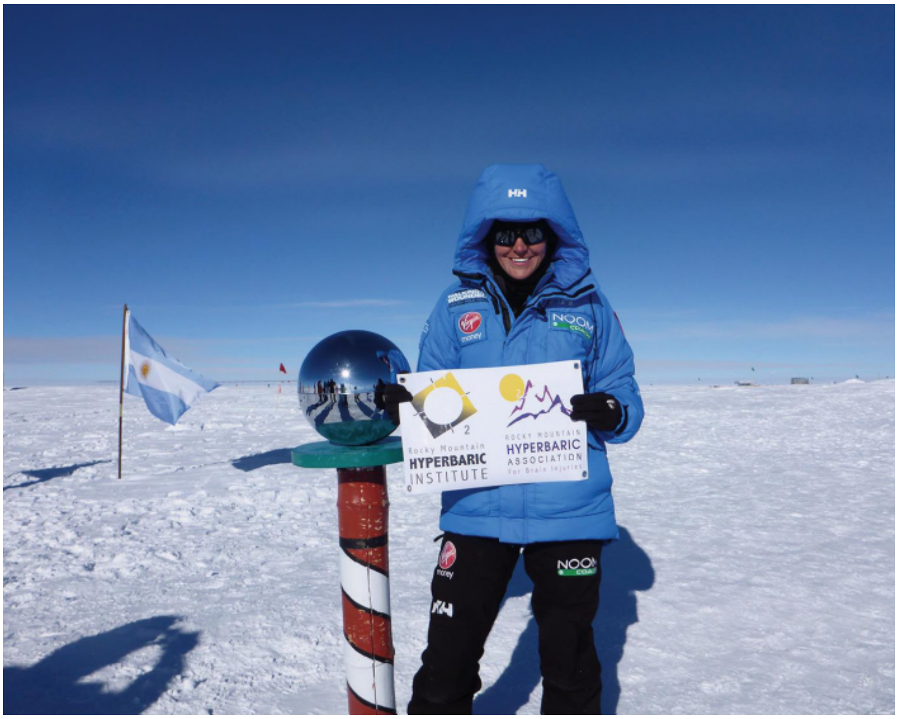
Now that Margaux has gone through over 140 hours of dives, she is not the robot that she thought she might become. Instead, her inner strength and competitive nature have brought her back to the Margaux she always was. Despite dealing with the signature wounds she suffered, she now excels in mountain climbing. She has scaled 19,000-foot Cototaxi in Equador and a more recent ascent of Mount Denali in Alaska that was thwarted by weather at 9,000 feet. In addition, she participated in the cyclists’ Ride to Recovery that toured Washington State and the coast of California, and rode bike tours through Italy and France.

Since 2011, Margaux has competed three times in the Wounded Warrior games held at Colorado Springs. She won five gold medals and three silver medals, just one more proof that our former athlete still has it.

Margaux was chosen to represent America’s Walking with the Wounded team that competed with a European team headed by Prince Harry of Great Britain and an Aussie-New Zealand team in the South Pole Allied Challenge that began November 14, 2013. Not only did Margaux and another American female warrior race against the men of the other teams, but one of Margaux’s team was a blind warrior who needed assistance every step of that long and challenging Antarctic trek.

Once again, the true Margaux was revealed when an opportunity arose, and she was able to guide the blind warrior during several parts of the trek. She had asked to do it because she knew she just had to. It was her small contribution to give back what she had been given. She so vividly relives those minutes and hours. “I asked if I could guide Ivan, a blinded warrior. I got the privilege of guiding him, and I didn’t want any cameras or anyone around… no pictures. I

PHOTO COURTESY OF MARGAUX MANGE



POLE POSITION: Margaux arrives at the South Pole with the Rocky Mountain Hyperbaric Institute logo; Her performance in that grueling race set a new level of fortitude that this young combat veteran consistently demonstrates in her life.

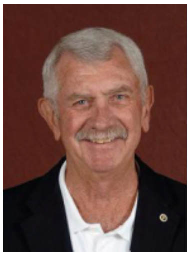
did not want anything to be about me. I wanted to understand how he had been suffering, and I wanted to be able to help. And I enjoyed every minute of helping him! I was sweating because it was very hot, but it felt so good to work and struggle and do this for Ivan."

Margaux met the prince and all the international participants in England, where they were wined and dined before flying out to New Zealand. They then sailed off to the race site in Antarctica. Their arctic trek was filmed from the beginning, and it was apparent that Prince Harry was out to win it all for his team. Camera operators accompanying the racers had as much difficulty with the rugged, inhospitable terrain as the racers did. Harry had managed a considerable lead over the other two teams within the first few days. It became apparent, however, that something was very wrong. Filming revealed that the American team was falling behind by quite a distance. When Prince Harry realized it was due to the team's challenges to assist their blind team member, he decided that all three teams would race together, and Margaux and her friends would get help with their handicapped racer.

Everyone at the Rocky Mountain clinic admires Margaux for her exceptional humility and spirit. Eddie and Ryan were incredibly proud when she displayed the Rocky Mountain Hyperbaric Institute and Rocky Mountain Hyperbaric Association for Brain Injuries banners at the pole. Margaux's performance and gutty grit in that grueling race set a new level of fortitude and courage that this lovely, young combat veteran consistently demonstrates in her life. •

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.

PHOTO COURTESY OF MARGAUX MANGE

Waiting for the View

When times are hard, I'm reminded that I'm living in a valley, but if I keep going and push through, I will soon experience a peak again.

There are good days and there are bad ones. Sometimes, the bad days can start to outweigh the good ones for a while. For the past few weeks, our schedules have been unrealistic at times and we have not given ourselves enough time to take a deep breath. Operating at this pace can take a toll on us and Broden is usually the one that signals us that we need to jump off the highway of craziness and regroup. Last week was one of those times.

Hayden has been in college away from us for about six weeks. The university sent us an invitation to parents' weekend, "Mark, we should do this! Let's drive over to Alabama and see Hayden." Mark looked over at Broden sitting at the table eating his dinner, "Are you sure? We have a lot going on and we are adding more respite hours per month. This is a lot of change." I remembered giving Mark the look of "don't rain on my parade" and "it's in your best interest to agree with me." Mark took a deep breath and nodded his head in agreement, "Looks like we're headed to Alabama at the end of September."

I was so excited. The plan was to see Hayden for the weekend and then he was going to fly to see us for the next weekend. I was going to get some extra time with my oldest kiddo. What could go wrong? We've been doing so well with our weekend outings and Broden has been acclimating to his respite providers. This trip was going to be a success. I could feel it.

On the morning of our drive to Alabama, I showed Broden the calendar, "We're going to eat breakfast, pack the car, and then drive to Huntsville. Broden leaned into the calendar and read the schedule intently. That weekend, Hurricane Ian was just leaving Florida after wreaking havoc across the state and was now in Charleston. We were going to drive west and hopefully avoid most of Ian's wrath. Stress was already high because we had no idea what was in store for us on the first leg of the trip.

As I was packing the cooler in the kitchen, I heard Broden crying in his room. Mark ran across the hall to see what was wrong, "Broden, we still have to pack the car. I promise we will leave soon." Broden grew more upset and Mark started to witness some SIB (self-injurious behavior), "Shelly, get up here. I need your help." I ran up the stairs and walked into Broden's bedroom. He was hysterical. Mark and I worked together to try and calm Broden down, "What's wrong? Do you hurt? Are you mad?" He kept saying, "Hospital." Then we started asking, "Where does it hurt? Show us. Point to what hurts." He pointed to his stomach crying. At first, I panicked, "Let's take him to the ER. Maybe he's sick." Then I took a deep breath and thought through it. He kept glancing over to the calendar.

I walked over to the office and grabbed a piece of paper and wrote on the left side "hospital to see doctor" and then on the right side of the paper I wrote "Huntsville to see Hayden." Broden looked at the paper and pointed to the right side, "Go to Hayden." I looked up at Mark and said, "We need to get moving." We brought Broden down to the kitchen nook for him to eat a snack while I packed the cooler, and then he started crying again and said, "Red." I looked over and Broden's shirt and hands were covered in blood. He had a bloody

NEW POINT OF VIEW: "Broden looked at the paper with his choices and pointed to the right side, 'Go to Hayden.' I looked up at Mark and said, 'We need to get moving.'"

PHOTO COURTESY SHELLY HUHTANEN

nose and it was quite a gusher. As I grabbed a towel from the downstairs bathroom to apply pressure to his nose, I yelled to Mark in the garage, "Mark! I need your help now!" Mark ran into the kitchen nook to see blood all over Broden and the table. He grabbed some damp paper towels to help clean him up. I grabbed a clean shirt for him to wear.

> "Honestly, I don't know how we make it through at times and I can't remember how many moments when I have told myself, 'You just need to quit,' only to realize, I can't quit."

I wanted to quit.

I was exhausted and we weren't in the car yet. The hurricane was on its way and we needed to get to Augusta, as soon as possible, to avoid the weather, "I'm so tired. Should we even go?" Mark and I looked over at Broden as he walked into the garage and sat in the car to wait on us. We both looked at each other in the kitchen looking defeated, "Shelly, I guess we're going."

The rain had already started. I texted Hayden and told him that we were on the road and with some luck, we should be there in about eight hours or so. Once we were on the highway, I looked back at Broden. He was smiling and listening to music on the radio. After seeing Broden calm and noticing that his nosebleed had subsided, I leaned my head back into the seat and took a deep breath, "Ok, now we just need to get there." As soon as I closed my eyes for a moment, Mark yelled out, "Oh crap!" I looked over and snapped, "What now!?" He smacked his hand on the steering wheel, "I forgot to take the exit to Augusta, we've been driving to Charlotte!" I didn't say anything. I just laid my head back and closed my eyes again. I was too exhausted to respond.

After turning around and taking the Augusta exit, we were finally on our way in the right direction. Honestly, I don't know how we make it through at times and I can't remember how many moments when I have told myself, "You just need to quit," only to realize, I can't quit. When times are hard, I'm reminded that I'm living in a valley, but if I keep going and push through, I will soon experience a peak again. That peak will be that much sweeter, because I will remember those exhausting days living in the valley. The peaks are worth the wait, because of the wonderful view. •

PUZZLES & CAMO

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

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