PLUS: UNITED STATES MILITARY SECTION

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MAGAZINE
JULY 2022
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IN THIS ISSUE:

INCREASING ACCESS TO YOSEMITE'S JUNIOR RANGER PROGRAM

PLUS:

TRAVEL TIPS *for* FAMILIES

AND:

CREATING RESILIENCE *in* CHILDREN

TRAVEL ISSUE

ALSO • ACCESSIBLE HOMES:

KEEPING PEOPLE *with* DISABILITIES IN THEIR HOMES *and* COMMUNITIES

EP MAGAZINE
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CELEBRATES

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ON OUR COVER

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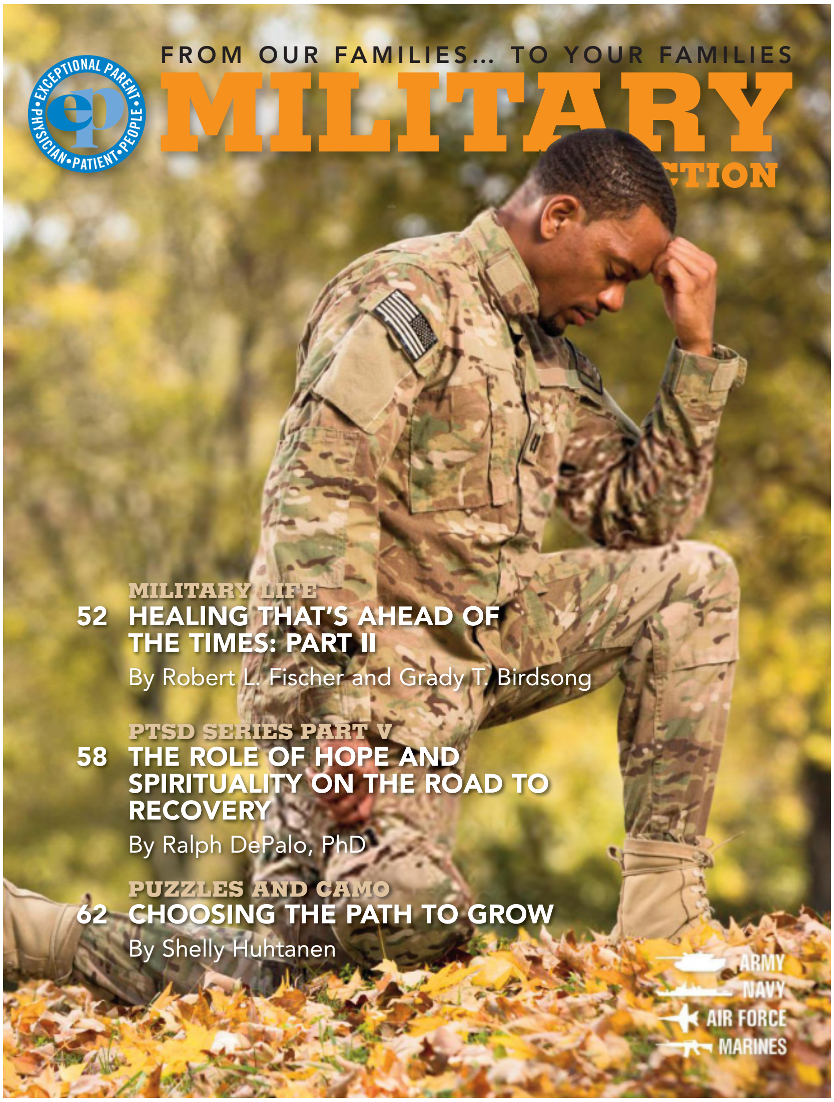

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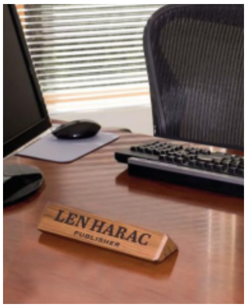
On the Road, Again

As the country prepares to head out on the highway, let's take a moment to consider the difficulties some people have when traveling and see if we can find some solutions.



Temperatures are on the rise, and even though gas prices are too, many of us will be hitting the road during these summer months. Our Annual Travel issue is filled with helpful tips, insightful content and expert advice that will help you get to your destination.

Co-authors Penelope Hatch, PhD, CCC-SLP and Nancy Quick, PhD, CCC-SLP describe the work that they did to help Yosemite Conservancy update their Junior Ranger Guide to allow for children from 4 to 12 with complex learning, communication, motor and/or sensory challenges to experience the parks and the program just as their neurotypical peers do. Their efforts on this inspiring project will help to broaden these new Junior Rangers' horizons, and will ensure the national parks even more lifelong enthusiasts.

> "Our Annual Travel issue is filled with helpful tips, insightful content and expert advice to you get to your destination."

In her article, Garima Jain, N.D., C.N.C., CHW addresses the critical state of equitable, accessible, and inclusive public transportation for individuals with disabilities, noting that, in the U.S., mobility issues affect one in every seven adults.

EP rounds out its travel coverage in this issue with teacher extraordinaire Jenn Adams, who shares some invaluable tips for families planning vacations and venturing out with their children with special needs.

Architect Ramesh Gulatee leads off our Accessible Homes special section with a solid overview of what is typically entailed when a homeowner endeavors to make their home more accessible. Best practices and helpful suggestions are brought into focus as he offers his extensive expertise.

EP is happy to welcome Ayesha Hamilton, Esq. as a contributor. An attorney who focuses on employment law, she founded her law practice fifteen years ago. Her article "Understanding Job Protected Leave" helps the reader distinguish between ADA, FLMA and employer benefits, all with the ultimate goal of providing loved ones with special needs the best care possible.

Elsewhere in this issue, we meet Eddie Mambo, a wonderful character from PBS Kid's *Alma's Way*, as well as a mom who touchingly describes what her own cancer journey has meant for her family.

We are always interested in your input and feedback. We invite you to get in touch at **epmagazinevp@gmail.com** with your thoughts.

EP's audience is steadily growing. To learn about great new advertising and sponsorship opportunities, contact EP's Editor In Chief, Faye Simon, at **epmagazinevp@gmail.com** •

Leonard J. Harac, PhD

Publisher

FROM THE PUBLISHER'S DESK

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

Information and Support for the Special Needs Community

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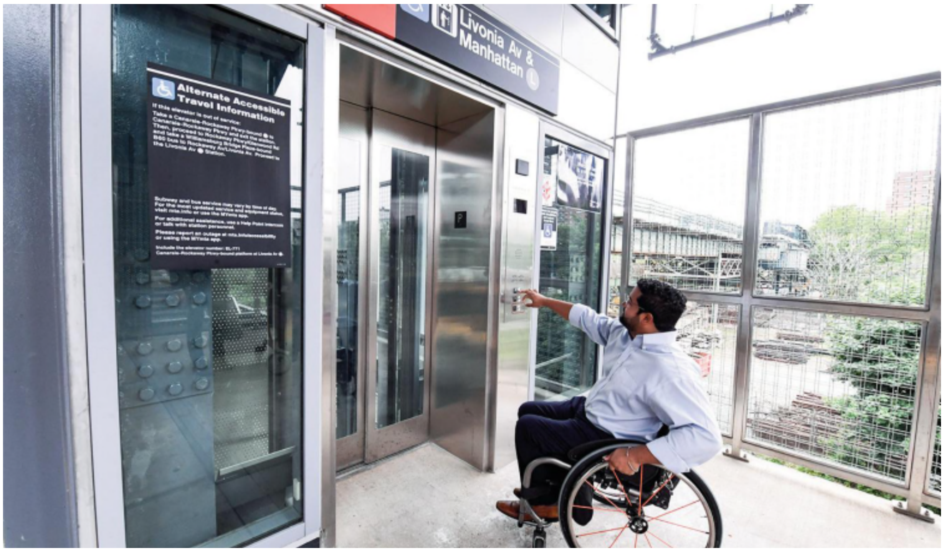
WHAT'S HAPPENING

NEW YORK SUBWAY SYSTEM SETS 33-YEAR TIMELINE FOR MAKING 95% OF ITS STATIONS FULLY ACCESSIBLE

New York City's subway system will finally become more accessible to people with disabilities or mobility challenges – in 33 years. As Michael Gold reports in The New York Times, "New York has lagged for years behind other major American cities in making its subway system accessible to people with disabilities: Just 126 of its 472 stations, or 27 percent, have elevators or ramps that make them fully accessible."



LOOKING UP: New elevators and overpass open to the public at the Livonia Ave station on the L line, on Wednesday, June 1, 2022.

MTA officials announced a decades-long commitment to make 95% of the city's subway system accessible to New Yorkers with disabilities, who are all but shut out from the vast majority of the city's aging subway system.

Only about one fourth of the system's elevators are currently wheelchair-accessible, and regular breakdowns of elevators makes the system even more difficult to navigate for those with mobility issues.

The commitment to build more ramps and elevators comes through a settlement to a pair of lawsuits filed by disability advocates against the transit agency that claim officials continue to violate state and federal law by running a subway system that locks out wheelchair users.

Cities with newer systems like San Francisco and Washington are fully accessible. But even though New York City's transit system is very old, other systems of similar age, like those in Boston and Philadelphia, are far more accessible than the Big Apple's with around two-thirds of those cities' stations in compliance with the standards set by the Americans With Disabilities Act.

The ADA, which was passed in 1990, is a civil rights law established to prevent discrimination based on disability. It states that any public facility that was built after 1993 must be accessible. For the City of New York, given its much older subway system (which is the world's largest transit system by station count), the federal government and the transit agency came to an agreement, which required the city to implement accessible access to 100 "key stations" by 2020, a goal that was achieved. The agreement requires the MTA to contract to build ramps and elevators at 81 stations on the subway and Staten Island Railway by 2025; another 85 by 2035; 90 more by 2045 and another 90 by 2055. It's unclear how long it will take to construct all of the accessibility features after the contracts are issued.

"We need to make a system that is truly accessible for not only our disabled people, but also for older people with mobility issues and that burgeoning population of New Yorkers who are racing around with strollers," MTA chairman Janno Lieber said during an event Wednesday.

The deal ends a years-long legal battle fought by disability advocates in court over the MTA's historically sluggish approach to accessibility.

One lawsuit settled this week claims the Metropolitan Transportation Authority is in violation of New York City's Human Rights Law by not having enough accessible stations. Another argues the agency regularly violates the Americans with Disabilities Act of 1991 by doing construction at stations without also building ramps and elevators.

"Disabled In Action has fought to eliminate barriers to full equality for people with disabilities for more than 50 years and is proud to do so here on behalf of all New Yorkers," Jean Ryan of Disabled In Action New York said in a statement. "All our members need elevators in the subways, and we need elevators in all stations. Elevators are for everyone."

The MTA still faces a lawsuit from advocates surrounding maintenance of subway elevators, which regularly break down or close for repairs with little notice to riders who rely on them. Another argues the agency regularly violates the Americans with Disabilities Act of 1991 by doing construction at stations without also building ramps and elevators.

PHOTO COURTESY NEW.MTA.INFO/PRESS-RELEASE

PATIENTS SEEK MENTAL HEALTH CARE FROM THEIR DOCTOR BUT HEALTH PLANS STAND IN THE WAY

BY ANERI PATTANI

When a longtime patient visited Dr. William Sawyer's office after recovering from covid, the conversation quickly turned from the coronavirus to anxiety and ADHD.

Sawyer – who has run a family medicine practice in the Cincinnati area for more than three decades – said he spent 30 minutes asking questions about the patient's exercise and sleep habits, counseling him on breathing exercises, and writing a prescription for attention-deficit/hyperactivity disorder medication.

At the end of the visit, Sawyer submitted a claim to the patient's insurance using one code for obesity, one for rosacea – a common skin condition – one for anxiety, and one for ADHD.

Several weeks later, the insurer sent him a letter saying it wouldn't pay for the visit. "The services billed are for the treatment of a behavioral health condition," the letter said, and under the patient's health plan, those benefits are covered by a separate company. Sawyer would have to submit the claim to it.

But Sawyer was not in that company's network. So even though he was in-network for the patient's physical care, the claim for the recent visit wouldn't be fully covered, Sawyer said. And it would get passed on to the patient.

FACING HURDLES: After counseling a patient and prescribing ADHD medication, Dr. William Sawyer received a letter from the patient's insurer stating it would not pay for the visit because, under the patient's plan, behavioral health care was covered by a separate company.

As mental health concerns have risen over the past decade — and reached new heights during the pandemic – there's a push for primary care doctors to provide mental health care. Research shows primary care physicians can treat patients with mild to moderate depression just as well as psychiatrists – which could help address the nationwide shortage of mental health providers. Primary care doctors are also more likely to reach patients in rural areas and other underserved communities, and they're trusted by Americans across political and geographic divides.

But the way many insurance plans cover mental health doesn't necessarily support integrating it with physical care.

In the 1980s, many insurers began adopting what are known as behavioral health carve-outs. Under this model, health plans contract with another company to provide mental health benefits to their members. Policy experts say the goal was to rein in costs and allow companies with expertise in mental health to manage those benefits. Over time, though, concerns arose that the model separates physical and mental health care, forcing patients to navigate two sets of rules and two networks of providers and to deal with two times the complexity.

Patients typically don't even know whether their insurance plan has a carve-out until a problem comes up. In some cases, the main insurance plan may deny a claim, saying it's related to mental health, while the behavioral health company also denies it, saying it's physical.

"It's the patients who end up with the short end of the stick," said Jennifer Snow, head of government relations and policy for the National Alliance on Mental Illness, an advocacy group. Patients don't receive the holistic care that's most likely to help them, and they might end up with an out-of-pocket bill, she said.

There's little data to show how frequently this scenario – either patients receiving such bills or primary care doctors going unpaid for mental health services – happens. But Dr. Sterling Ransone Jr., president of the American Academy of Family Physicians, said he has been receiving "more and more reports" about it since the pandemic began.

Even before covid, studies suggest, primary care physicians handled nearly 40% of all visits for depression or anxiety and prescribed half of all antidepressants and anti-anxiety medications.

Now with the added mental stress of a two-year pandemic, "we are seeing more visits to our offices with concerns of anxiety, depression, and more," Ransone said.

That means doctors are submitting more claims with mental health codes, which creates more opportunities for denials. Physicians can appeal these denials or try to collect payment from the carve-out plan. But in a recent email discussion among family physicians, which was later shared with KHN, those running their own practices with little administrative support said the time spent on paperwork and phone calls to appeal denials cost more than the ultimate reimbursement.

Dr. Peter Liepmann, a family physician in California, told KHN that at one point he stopped using psychiatric diagnosis codes in

PHOTO BY ZANDRA WHITE / KHN.ORG

claims altogether. If he saw a patient with depression, he coded it as fatigue. Anxiety was coded as palpitations. That was the only way to get paid, he said.

In Ohio, Sawyer and his staff decided to appeal to the insurer, Anthem, rather than pass the bill on to the patient. In calls and emails, they asked Anthem why the claim for treating obesity, rosacea, anxiety, and ADHD was denied. About two weeks later, Anthem agreed to reimburse Sawyer for the visit. The company didn't provide an explanation for the change, Sawyer said, leaving him to wonder whether it'll happen again. If it does, he's not sure the $87 reimbursement is worth the hassle.

"Everyone around the country is talking about integrating physical and mental health," Sawyer said. "But if we're not paid to do it, we can't do it."

> ***"Most patients don't want to be shipped off to specialists. So when they can't get mental health care from their primary doctor, they often don't get it at all. Some people wait until they hit a crisis point and end up in the emergency room."***

Anthem spokesperson Eric Lail said in a statement to KHN that the company regularly works with clinicians who provide mental and physical health care on submitting accurate codes and getting appropriately reimbursed. Providers with concerns can follow the standard appeals process, he wrote.

Kate Berry, senior vice president of clinical affairs at AHIP, a trade group for insurers, said many insurers are working on ways to support patients receiving mental health care in primary care offices – for example, coaching physicians on how to use standardized screening tools and explaining the proper billing codes to use for integrated care. "But not every primary care provider is ready to take this on," she said.

A 2021 report from the Bipartisan Policy Center, a think tank in Washington, D.C., found that some primary care doctors do combine mental and physical health care in their practices but that "many lack the training, financial resources, guidance, and staff" to do so.

Richard Frank, a co-chair of the task force that issued the report and director of the University of Southern California-Brookings Schaeffer Initiative on Health Policy, put it this way: "Lots of primary care doctors don't like treating depression." They may feel it's outside the scope of their expertise or takes too much time.

One study focused on older patients found that some primary care doctors change the subject when patients bring up anxiety or depression and that a typical mental health discussion lasts just two minutes.

Doctors point to a lack of payment as the problem, Frank said, but they're "exaggerating how often this happens." During the past decade, billing codes have been created to allow primary care doctors to charge for integrated physical and mental health services, he said.

Yet the split persists.

One solution might be for insurance companies or employers to end behavioral health carve-outs and provide all benefits through one company. But policy experts say the change could result in narrow networks, which might force patients to go out of network for care and pay out-of-pocket anyway.

Dr. Madhukar Trivedi, a psychiatry professor at the University of Texas Southwestern Medical Center who often trains primary care doctors to treat depression, said integrated care boils down to "a chicken-and-egg problem." Doctors say they'll provide mental health care if insurers pay for it, and insurers say they'll pay for it if doctors provide appropriate care.

Patients, again, lose out.

"Most of them don't want to be shipped off to specialists," Trivedi said. So when they can't get mental health care from their primary doctor, they often don't get it at all. Some people wait until they hit a crisis point and end up in the emergency room — a rising concern for children and teens especially.

"Everything gets delayed," Trivedi said. "That's why there are more crises, more suicides. There's a price to not getting diagnosed or getting adequate treatment early."

ABOUT THE AUTHOR:

Aneri Pattani is a Kaiser Health News Correspondent who reports on a broad range of public health topics, focusing on mental health and substance use. Her work spans text and audio stories, and she has been heard on NPR and Science Friday. Her stories have received national recognition, including a 2021 award from the Institute for Nonprofit News for reporting on the flawed oversight of addiction treatment facilities in Pennsylvania. She was also part of a team that received the News Leaders Association's 2021 Batten Medal for Coverage of the Coronavirus Pandemic. Before joining KHN, Pattani wrote for Spotlight PA, a collaborative newsroom investigating the Pennsylvania state government. She was a 2019 recipient of the Rosalynn Carter Fellowship for Mental Health Journalism.

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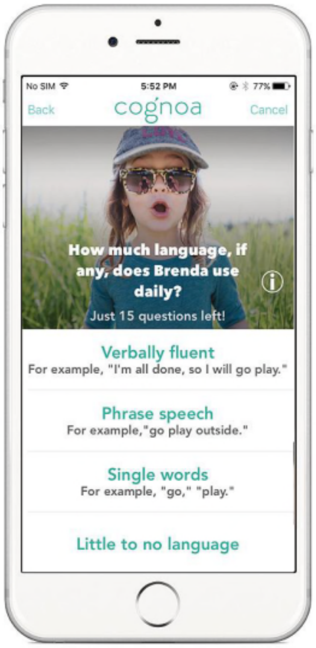
WHAT'S HAPPENING

COGNOA RECEIVES FDA MARKETING AUTHORIZATION FOR FIRST-OF-ITS-KIND AUTISM DIAGNOSIS AID

The U.S. Food and Drug Administration has authorized marketing of a device to help diagnose autism spectrum disorder (ASD). The Cognoa ASD Diagnosis Aid is a machine learning-based software intended to help health care providers diagnose ASD in children 18 months through 5 years of age who exhibit potential symptoms of the disorder.



How much language, if any, does Brenda use daily?

Just 15 questions left!

Verbally fluent
For example, "I'm all done, so I will go play."

Phrase speech
For example,"go play outside."

Single words
For example, "go," "play."

Little to no language

NEW PATH FORWARD: The ASD diagnostic tool is designed to help primary care clinicians and pediatricians evaluate and diagnose suspected cases of autism among children.

"Autism spectrum disorder can delay a child's physical, cognitive and social development, including motor skill development, learning, communication and interacting with others. The earlier ASD can be diagnosed, the more quickly intervention strategies and appropriate therapies can begin," said Jeff Shuren, M.D., J.D., director of the FDA's Center for Devices and Radiological Health. "Today's marketing authorization provides a new tool for helping diagnose children with ASD."

The CDC and Prevention defines ASD as a "developmental disability that can cause significant social, communication and behavioral challenges" and is estimated to affect about 1 in 54 children. While ASD may be detected as early as 18 months old, many children are not diagnosed until later in childhood, which can delay treatment and early intervention. The average age of diagnosis for ASD is 4.3 years. Some delays in diagnosis are due to the need for children to be referred to specialists with expertise in ASD.

The Cognoa ASD Diagnosis Aid is a software as a medical device that uses a machine learning algorithm to receive input from parents or caregivers, video analysts and health care providers to assist physicians evaluate a patient at risk of ASD. The device consists of three main components: a mobile app for caregivers and parents to answer questions about behavior problems and to upload videos of their child; a video analysis portal that allows manufacturer-trained and certified specialists to view and analyze uploaded videos of patients; and a health care provider portal that is intended for a health care provider to enter answers to pre-loaded questions about behavior problems, track the information provided by parents or caregivers and review a report of the results. After processing the information provided by parents, caregivers and healthcare providers, the ASD Diagnosis Aid reports a positive or negative diagnosis if there is sufficient information for its algorithm to make a diagnosis. If there is insufficient information to render a "Positive for ASD" or "Negative for ASD" result to help determine a diagnosis, the ASD Diagnosis Aid will report that no result can be generated.

The FDA assessed the safety and effectiveness of the Cognoa ASD Diagnosis Aid in a study of 425 patients aged 18 months through 5 years in 14 different clinical care sites, with an average age of 2.8 years. The study compared the assessments made by the device directly against the assessments made by a panel of clinical experts who used the current standard ASD diagnostic process. The device provided a "Positive for ASD" or "Negative for ASD" result to aid in making a diagnosis in 32% of patients. For those with a "Positive for ASD" or "Negative for ASD" result, the device results matched the panel's conclusions for 81% of patients who tested positive for ASD by the device and 98% of patients who tested negative for ASD by the device. In addition, the device made an accurate ASD determination in 98.4% of patients with the condition and in 78.9% of patients without the condition.

The risks associated with the use of the device include misdiagnosis and delayed diagnosis of ASD, based on a false positive result (observed in 15 out of 303 study subjects without ASD), a false negative result (observed in one out of 122 study subjects with ASD) or when no result was generated. Both misdiagnosis or missed diagnosis can result in delayed treatment of ASD and delivery of treatment not appropriate for ASD.

The Cognoa ASD Diagnosis Aid is indicated as an aid in the diagnosis of ASD for patients 18 months through 5 years of age who are at risk of developmental delay based on concerns of a parent, caregiver, or health care provider. The device is not indicated for use as a stand-alone diagnostic device but as an adjunct to the diagnostic process. Lean more at **https://canvasdx.com**

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IMAGE COURTESY COGNOA

WHAT'S HAPPENING

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

When fifteen-year-old Tyson attends public school for the first time, his life is changed forever. While helping his father clean up after the football team, Tyson befriends champion marathon runner Aklilu.

GOING THE DISTANCE: Aklilu (Barkhad Abdi) challenges Tyson (Major Dodson) to realize his potential in *Tyson's Run.*

Never letting his autism hold him back, Tyson becomes determined to run his first marathon in hopes of winning his father's approval. With the help of an unlikely friend and his parents, Tyson learns that with faith in yourself and the courage to take the first step, anything is possible.

15-year-old Tyson (Major Dodson), homeschooled and on the autism spectrum, decides to start attending high school when his mom (Amy Smart) can no longer understand the math she needs to teach him. At school, he makes friends but also grapples with some bullying and teasing from classmates. Meanwhile, his dad (Rory Cochrane) isn't thrilled about having his son on the campus where he coaches one of the state's most successful high school football teams.

> ***With the help of an unlikely friend and his parents, Tyson learns that with faith in yourself and the courage to take the first step, anything is possible.***

One day, Tyson encounters Aklilu (Barkhad Abdi), a former marathon runner, and he begins jogging alongside him. The pair strike up a friendship, and Tyson vows to train to run his town's first-ever marathon just weeks away. The training will challenge him as well as his parents' and the town's conceptions of what Tyson is capable of.

Tyson's Run, now available on DVD, Digital, and Video On Demand, follows Tyson as he tries to heal the rift between his parents and the emotional distance from his unfulfilled father by giving them both a second chance to put their family bond first.

"We believe this film will provide a sense of hope and perseverance to everyone that watches," said President of Collide Distribution, Bob Elder. "It is our joy to bring films to the big screen that the entire family can enjoy."

The subject of *Tyson's Run* – autism – isn't merely the on-screen focus. That's because the lead actor, 18-year-old Major Dodson, himself is on the autism spectrum. Dodson, who is known for his roles in *The Walking Dead* and *American Horror Story,* says fans of his work likely don”t know of his past.

"I think it will be a new discovery for most people," Dodson said. "I've come a very far, very long way from how I used to be as a kid. I credit occupational therapy. I credit really good parenting and acceptance over the years of who I am – letting me go out and do my own thing. So I'm very, very independent now."

The release is helmed by Emmy Award-nominated and NAACP Image Award-winning Writer-Director Kim Bass. Bass, a former staff writer on the sketch comedy series *In Living Color* and creator of primetime family series *Sister, Sister* and *Kenan & Kel*, created this feel-good family drama. He said that he was inspired to write the screenplay based on a conversation with a young boy who didn't want to run anymore because he felt he would never be as fast as the other kids.

"It's not about how to be as fast as everyone else," Bass said. "It's about having determination, belief in yourself, faith and keep going ultimately. You can overcome all kinds of things and come out on top, even though you think you've been left behind."

Bass said Dodson was the "perfect choice" for the lead role, beating out more than 200 other actors who were considered. His performance was "vulnerable" and "didn't look like somebody trying to pretend." He stated, "I've imagined this story for several years. Taking it to production was one of my greatest joys. I'm proud and feel privileged to have been part of a film that both entertains and impacts. Now that Universal Pictures Content Group has enthusiastically agreed to bring the film to your home, I am grateful."

PHOTO COURTESY COLLIDE DISTRIBUTION

WHAT'S HAPPENING

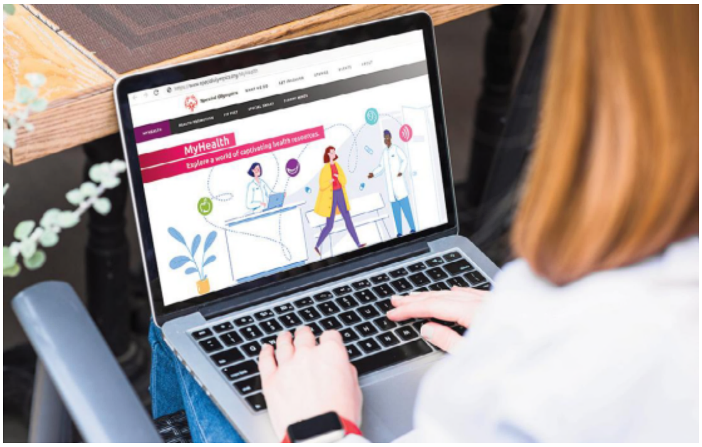
SPECIAL OLYMPICS ATHLETES CAN EXPLORE A WORLD OF CAPTIVATING HEALTH RESOURCES WITH MYHEALTH

Special Olympics just announced the launch of MyHealth – an online hub for health education resources geared towards Special Olympics athletes and other people with intellectual disabilities.

MyHealth – an online hub for health education resources geared towards Special Olympics athletes and other people with intellectual disabilities.

MyHealth offers fun and interactive pages that allow users to learn more about their health at their own pace. For example, people with intellectual disabilities can learn how to identify the signs of stress, dehydration, common dental problems, and much more.

Education and awareness of personal health can be key when identifying and treating health issues that could otherwise be overlooked. This is especially important because people with intellectual disabilities experience greater health disparities and are much more likely to have unidentified and untreated health issues, causing their average lifespan to be reduced by 16-20 years.



HEALTHY OUTLOOK: Starting from the MyHealth homepage, visitors can explore Special Olympics Healthy Athletes programs such as Special Smiles, Healthy Hearing, Fun Fitness and much more.

Check out MyHealth online, built with support from Special Olympics long standing partner JD Finish Line today at **www.SpecialOlympics.org/MyHealth**. More resources will be continuously added to this online space.

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NEW!

No More Embarrasing Mess!

P-GUARD BENEFITS:

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

1. Peel the adhesive backing

2. Press into place under seat

3. Enjoy a more sanitary bathroom

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WHAT'S NEW

LIMIT LEARNING LOSS

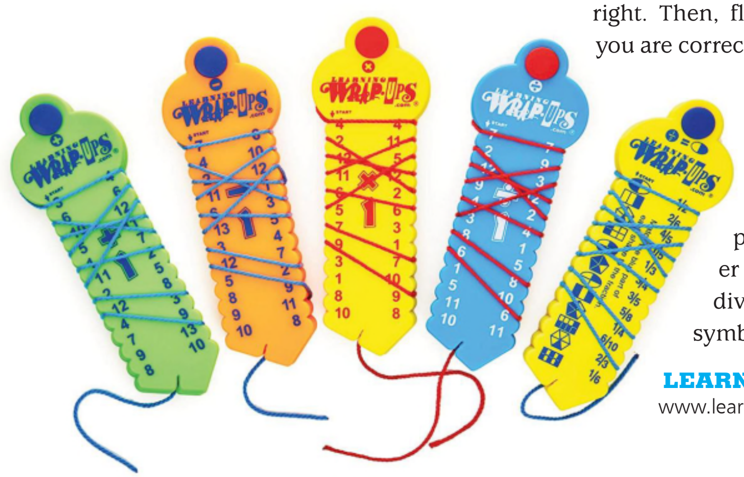
ROLIMATE MAGNETIC FISHING GAME

This educational toy contains seven interesting number and shape matching games. Children will learn numbers, shapes, color, and patterns, then learn how to count and improve their math and sorting abilities. This toy develops fine motor skills and hand-eye coordination, enhances memory with patterns, and encourages cognitive development and problem-solving. Great preschool teaching aid in classroom or home. Ages 3+.

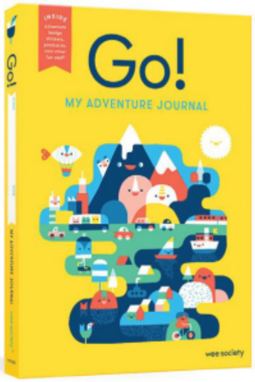
ROLIMATE
www.rolimate.com

LEARNING WRAP-UPS

Learning Wrap-ups Math Intro Set It contains one each of self-correcting addition, subtraction, multiplication, division, and fraction Wrap-ups. Using Learning Wrap-ups is easy; Simply choose the key-shaped board you want to practice, using the attached string, start at the top of the left side, use the operation symbol in the middle to solve, then find the answer on the right side, and slip the string in the notch. Continue this process all the way down the left, matching with the answers on the right. Then, flip it over to see if you are correct. The pattern made with the string will match the pattern on the back if you are right. Youth can learn how to put numbers together with minus, plus, dividing, and times symbols. Ages 3+.



LEARNING WRAP-UPS
www.learningwrapups.com



GO! MY ADVENTURE JOURNAL

This travel journal is filled with a bunch of thought-starters so kids can capture important stuff, like cool things they spot, new things they try and people they meet. There are also adventure badges to earn, stickers, places to keep photos and other treasures, and postcards to send. Whether you're headed to grandma's, camping for the weekend, or taking a summer vacation, Go! is pretty much guaranteed to make your next trip even more memorable. Ages 3+.

WEE SOCIETY, LLC
www.weesociety.com

READING EGGS APP

Reading Eggs makes learning to read interesting and engaging for kids, with great online reading games and activities. Children will learn how to read using interactive reading challenges, guided reading lessons, fun activities and over 2,000 digital story books. This app is recommended as one of the best overall reading apps for kids by parents and teachers, and is available on iPhone, iPad and Android devices. Ages 3+.

EDMENTUM
www.readingeggs.com

HOME ACCESSIBILITY THROUGH BARRIER FREE DESIGN

WORKING WITH A SPECIALIZED ARCHITECT

BY RAMESH GULATEE, ARCHITECT

Most private homes in the United States are lacking in accessibility, particularly for those with mobility impairments. Though the Americans with Disabilities Act (ADA) was enacted in 1990 and has set standard minimum requirements for accessible design, ADA does not apply to private homes.

EP SPECIAL SECTION • ACCESSIBLE HOMES •

ACCESSIBILITY AT HOME

Existing homes come with a myriad of inherent accessibility issues. Individual and/or family situations change over time imposing additional accessibility needs i.e., aging, accidental mishaps, etc. An ideal process in formulating the desirable accessibility options involves making a checklist of issues considered as barriers to home living. This checklist should be developed in discussions with every family member, and should include flexibility as an important element.

TASK AT HAND: Private homes sometimes require alterations to meet the needs of individuals with disabilities. This process is best accomplished with the assistance of architects and contractors who have experience in these types of renovations; Kitchens should feature knee space under sink counter to allow a wheelchair to pull in, and a high recessed base under the cabinets to accommodate the wheelchair's pedals.

PROJECT STAGES

WORKING WITH DESIGN & BUILDING INDUSTRY

At this stage, it is useful to invite an architect specializing in accessibility design for a walk-thru of your home to become cognizant of issues and your concerns. Such discussions allow the architect to begin to envision design options, and potential involvements of other trades, such as electrical, plumbing and heating and air-conditioning etc.

Generally, the architect suggests bringing in trades people that have worked on similar projects and have developed a working relationship. Important questions center on:

a) *Would the remodeling happen while the house is occupied?*
b) *What issues would be caused by temporary interruptions in services i.e., water, electrical, heating and air conditioning,*
c) *What level of noise and dust will there be?*
d) *What are the security concerns?*
e) *What neighborhood issues might there be?*
f) *If parking is available for workforce provisions and material supplies/deliveries?*
g) *How will the trash be disposed?* **and importantly**
h) *What is your level of involvement?*

CONCEPT AND PRELIMINARY DESIGN

Using existing house plans and documents etc., if available, the architect starts the design process by preparing basic drawings that show current conditions, and begins to develop potential options for discussion. Upon your choice of preferred design, the architect and the involved trades compile their understanding of the work, a preliminary estimate of cost, as well as an expected construction timeline. This establishes preliminary scope, schedule and budget for the remodel/alteration project, and upon your approval, forms the basis of preparation of estimated cost documents and construction process.

PERMIT AND BIDDING

The architect and other trades coordinate to prepare a set of plans and associated costs for permit, and see the permit process through, prior to finalizing project cost. This may or may not include specific products, equipment/appliances/fixtures depending on your preferences and contract. Being a remodel of existing conditions project, please bear in mind that the cost is subject to change depending on change in design, product availability, hidden conditions, etc.

ITEMS TO CONSIDER

1. FRONT ENTRY WITH STEPS AND ACCESS TO FRONT ENTRY AREA

Generally, this issue can be resolved with re-grading the path leading to the main entry, and finished with pavers.

Accessibility Option: *A prefabricated ramp (aluminum exterior grade) is an alternate design solution and can be installed quickly.*

2. HALLWAY/PASSAGEWAY WIDTH

Existing homes having narrow hallways/passageways impose difficulties to maneuver with a wheelchair. The preferred option is to widen hallway/passageway to 42" min. or 48" desirable. In situations of placement of narrow shelving or cabinet, increase width 6'0" or more.

3. DOORS AND DOORWAYS WIDTHS:

Narrow doors create issues with the passage of the wheelchair due to maneuvering space around door swings (inward or outward).

Accessibility Option: *Replacing existing door hinges with "offset hinges" allows you to gain about 2" in the door opening, Minimum door width for a wheelchair is 32". (preferably 36") Consider sliding doors with a surface mounted sliding mechanism. This option addresses maneuvering space issues due to door swings. The sliding door option is particularly useful in access to smaller spaces.*

4. BATHROOMS

Most homes typically have bathrooms that present maneuvering difficulty to access the bathroom fixtures, thus creating tripping hazards because of protruding bathroom amenities and wet-tiled floor, etc.

Roll-in or Walk-In Shower: Consider replacing the bathtub by installing a shower base. This transforms the bathroom into a single continuous space, with the shower area doubling as wheelchair maneuvering space, for access to bathroom amenities (WC, Sink etc). At this stage, it may be worthwhile to consider making provisions for grab-bars for current and future needs. It is recommended to select the shower seat that is height adjustable, can be moved along the grab bar rail if needed, and folded up or removed, depending on the user.

Water-Closet/WC: Installation of a wall-hung WC w/flush controls on the wall adds more space in the bathroom, while freeing up the floor space to facilitate maintenance and cleaning. It is advisable to make solid attachment provisions in the wall for the grab-bars. The grab-bars can be pivoting (up/down arms) so they can be moved out of the way when not needed. An advantage of the wall hung WC is that it can be installed at an optimal height for transfer from the wheelchair.

Vanity Sink: Adjustable height sinks are available in the marketplace. Eliminate the under sink cabinet to facilitate access to the sink bowl and faucets. If space permits, plan for a full height utility cabinet, forming one of the walls of the shower.

Floor Heating: Consider low voltage radiant heating in the bathroom floor, topped by ceramic tiles. This option allows keeping the floor dry and warm.

5. KITCHEN: FOOD PREPARATION AND DINING

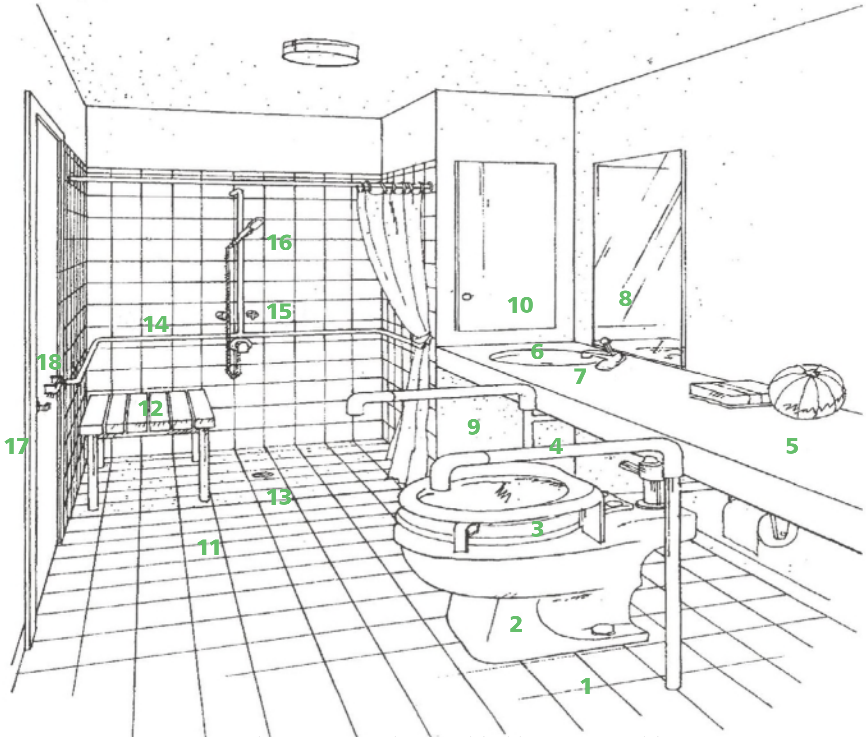
In addition to the bathroom, the kitchen is another space that requires careful accessibility planning consideration, due to frequent and repeated access to appliances.

Countertop: In most homes the kitchen countertop is installed at a height (+34") to match the kitchen sink and the cooktop. A fixed height and under counter cabinets create reach/access issues for individuals with mobility impairments, elderly and children.

Accessibility Options: *Install a height adjustable countertop located adjacent or between the sink and the cooktop. Consider including double stacked wall-ovens in kitchen planning (This creates options for the cooktop as part of an island-style countertop or as part of height adjustable countertop).*

Kitchen Cabinets: (below countertop) Generally, the kitchen cabinets form part of an integral support system with the countertop. This creates knee space issues and precludes height adjustability for the kitchen countertop.

Accessibility Options: *Consider independently framed and supported countertops with provision for height adjustment where needed. Consider individual under counter cabinets on casters (approx. 24" wide units) that can be pulled out from under the countertop and pushed back, when not in use.*



TYPICAL EXAMPLE OF AN ACCESSIBLE BATHROOM

CLEAN DESIGN: Universal design bathrooms feature curbless shower stalls and shower seats for the chairbound.

1. Space for wheelchair either side of WC.
2. WC with recessed base
3. Adjustable height WC seat or seat extender
4. Swing away grab bars
5. 20" - 28" depth counter
6. Washbasin within reach of the seated position on WC
7. Mixing faucet, level handle within reach of the seated position on the WC
8. Mirror, lower edge no higher than 40"
9. 27" high knee space under counter, drainpipe covered or insulated
10. Medicine chest within reach
11. Space for transfer to a shower seat
12. Free-standing shower seat, placement either end of shower or removed
13. No curb for shower stall, the chairbound can wheel directly into the shower, shower stall to slopes to center drain
14. Grab bars, 3 sides of shower stall
15. Controls centered on back wall of shower stall
16. Hand shower
17. Out swinging bathroom door with lever handle
18. Door pull, hinge side of door

IMAGES PROVIDED BY RAMESH GULATEE

Prefabricated under cabinet units with casters are available in the marketplace.

Overhead cabinets: Generally, upper cabinets do not work well since they are not fully accessible.

Accessibility Options: *Sliding rails/accessories are available in the marketplace able for integration into the design and fabrication to facilitate cabinets to be height adjustable with the push of a button located at the face of the counter. Prefabricated overhead cabinets are available in the marketplace.*

SMART HOME POSSIBILITIES

Barrier free accessibility in the home environment is greatly enhanced with the integration of smart home technology. Latest innovations in technology have facilitated wireless access/control and monitoring of our home environment, including lights, temperature, security, appliances, fixtures, and equipment. Many of these can be implemented in existing homes.

Most available devices offer smart-home integration with systems such as Amazon Alexa, Apple HomeKit, Google Assistant, SmartThings, etc. This allows the linking together of devices from different manufacturers. This includes sensors that allow a smart bulb to go on active mode when someone approaches the front door, or turn the temperature down when someone leaves a room. However, for simplicity, it is advisable to stay with one platform and manufacturer for compatibility and ease of programming.

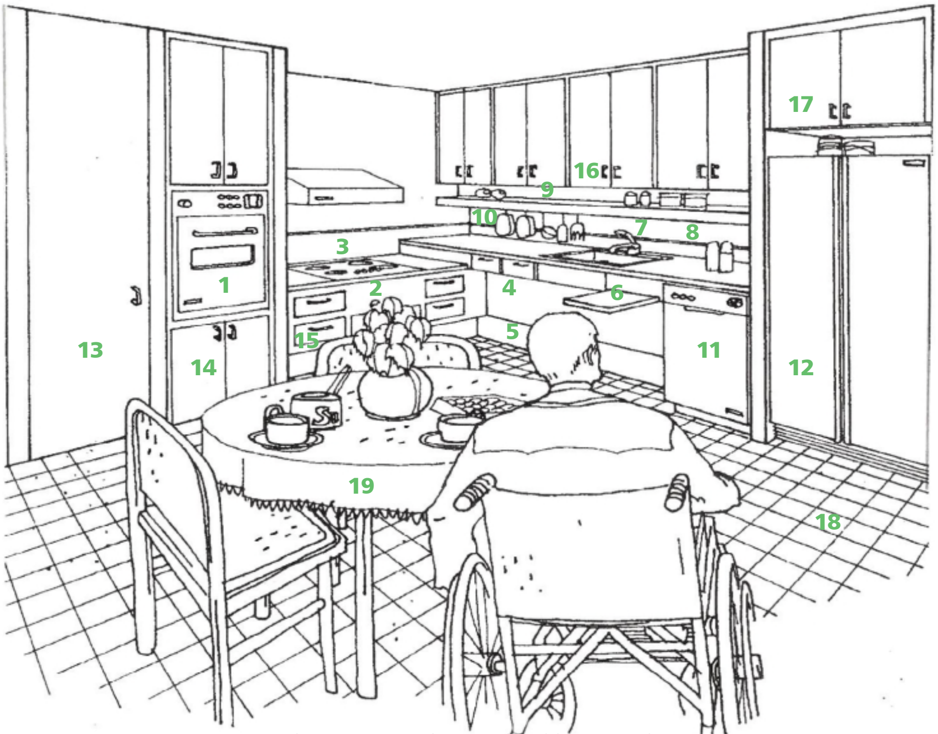
SUMMARY

Private homes sometimes require alterations to meet the needs of individuals with disabilities. This process is best accomplished with the assistance of architects and contractors who have experience in these types of renovations. It is my hope that this article provides some helpful information to guide homeowners through the process of making their homes more accessible and accommodating to the special needs of individuals living therein. •

ABOUT THE AUTHOR:

Ramesh Gulatee, LifeCare Design Studio, LLC is an Illinois based architect with focus on home accessibility. Ramesh has NCARB certification enabling him to work on numerous residential, housing and educational projects across USA. Ramesh has been involved in peer reviews, accessibility audits, and preparation of recommendation reports for Chicago, NY Public Schools and other private sector projects. His knowhow is recognized by the regulatory, and professional bodies where he is appointed as an accessibility specialist and serves on various advisory boards and working groups at state and national levels. Contact information: **rgulatee@lifecaredesignstudio.com www.lifecaredesignstudio.com**

FOOD FOR THOUGHT: Accessible kitchens utilize adjustable height countertops and upper cabinets within reach of all users.



TYPICAL EXAMPLE OF AN ACCESSIBLE KITCHEN

1. Wall oven, for easy access, open at counter height
2. Cooktop controls at the front to avoid burning
3. Cooktop and counter max. 34" height
4. Knee space under sink counter to allow sitting in wheelchair at counter
5. High recessed base under cabinets to accommodate wheelchair pedals
6. Pullout work shelf
7. Mixing faucet at sink, level handle
8. Cove lighting under wall cabinets, bulb replacement within reach
9. Shallow shelf over sink counter within reach range
10. Wall space within reach over sink counter, used for hanging utensils
11. Front loading dishwasher
12. Side-by-side refrigerator doors to allow access to refrigerator and freezer
13. Full height storage cabinet for easy access
14. Cabinet space under wall oven within reach range
15. Drawers under cooktop and counter for easier access
16. Easy grip cabinet door
17. High cabinets for non-chairbound users
18. Smooth non skid flooring, open space for wheelchair passage and maneuvering
19. Round table to avoid corners, legs or pedestal base with no apron to allow for wheelchair

KEEPING PEOPLE WITH DISABILITIES IN THEIR HOMES AND COMMUNITIES

WHERE THE HEART IS: There are important modifications that are not for physical or mobility issues, but rather for individuals with developmental disabilities. Supportive services for individuals with mental illness, as well as those with physical disabilities can help maintain an individual at home.

BY LAUREN AGORATUS, M.A.

Besides home modifications, there are resources to help individuals with disabilities called community based supports, to help maintain independence and avoid the need for institutional care.

EP SPECIAL SECTION • ACCESSIBLE HOMES •

When you hear the words, "home modifications," what usually comes to mind are those modifications related to physical accessibility, such as wheelchair accessibility, including ramps, elevators, and lifts. However, there are important modifications that are not for physical or mobility issues, but rather for individuals with developmental disabilities. For example, a person with autism who wanders may need safety locks, alarms, or wearable GPS, etc. Another individual with Prader Willi Syndrome may need cabinet and refrigerator locks. Prader-Willi Syndrome affects a child's metabolism so that many of the children never feel full and feel like they have to eat all the time. This can unfortunately include non-food items (pica), as well. In this case, refrigerator and cabinet locks may be useful safety items. Medically fragile children may benefit from air filters, whole-house humidifiers, and emergency generators to run medical equipment. Others may need safety items like bed rails. For more information, see Home Modifications: Thinking Outside of the Box from the July 2019 issue of *EP Magazine* (https://reader.mediawiremobile.com/epmagazine/issues/205012/viewer?page=28).

SUPPORTIVE SERVICES CAN HELP MAINTAIN AN INDIVIDUAL AT HOME

Other creative supports can include supportive housing. This includes services for individuals with mental illness, as well as those with physical disabilities. Supportive services can include medication delivery/monitoring, meals, housekeeping, personal care, etc.

SOME INDIVIDUALS WITH DISABILITIES MAY NEED FINANCIAL ASSISTANCE

Financial help may come from supportive housing, Section 8, or HUD. Section 8 and Housing & Urban Development are housing programs for low-income people. They offer vouchers to help move, purchase furniture, rental help including deposit/security and lower rant, and other financial assistance. Centers for Independent Living *(see Resources)* may also help with moving and they also have institutional diversion initiatives. CIL helps teach independent living skills/self-advocacy for community living. These centers can help people with moving costs, groceries, utility setup etc. CIL seeks to help with independent living in the community and keep people with disabilities out of institutions.

HOME CARE SERVICES AND HOUSEKEEPING

For more details on these options, see Creative Housing Options for Independent Living from the July 2017 issue of *EP Magazine* (https://reader.mediawiremobile.com/epmagazine/issues/201468/viewer?page=41).

In addition, new construction using universal design helps people with disabilities or even elderly individuals, to age in place. Some examples of universal design during construction might be: ramp or sloped entrance, automatic doors, elevators in homes, etc. This allows houses to be accessible to everyone regardless of age or ability.

Some communities are built specifically with people with disabilities in mind, see Project Freedom: "A Model for Independent Living in the Community in the July 2018 issue of *EP Magazine* (**https://reader.mediawiremobile.com/epmagazine/issues/203511/viewer?page=18**)

WHAT ARE HOME AND COMMUNITY BASED SUPPORTS?

HCBS, or home and community-based services are supports under Medicaid. These can include personal care assistance, nursing, and other supports to keep an individual in his/her home and out of institutions, as Medicaid has progressively moved out of its institutional bias. HCBS was established because a mother, Julie Beckett, advocated for her medically fragile daughter, Katie who otherwise would have spent her entire life in the hospital. Julie demonstrated that home care on a ventilator would cost 1/6 of hospital care and keep her family together. As we go to press, sadly the disability community lost Julie this month. Due in part to Julie's vigilance and persistence and the many other parents who followed her lead, over 500,000 children are currently being supported by Medicaid HCBS to live where they belong – in their homes and communities.

Just like Medicaid benefits, HCBS services vary by state. These can include, but are not limited to:

- *in-home nursing care, equipment and supplies, (one of the most important benefits)*
- *case management (i.e. supports and service coordination)*
- *homemaker assistance*
- *home health aide*
- *personal care*
- *adult day health services*
- *habilitation (both day and residential)*
- *respite care*

Respite is an essential support for family caregivers. According to the Caregiver Community Action Network, more people enter institutional care due to caregiver burnout than deterioration of their condition. States can propose other "services that may assist in diverting and/or transitioning individuals from institutional settings into their homes and community."

A SPECIAL NOTE ON ALTERNATIVES TO GUARDIANSHIP AND MAINTAINING INDEPENDENCE

In years past, families thought their only option was guardianship, which takes away all individual rights. The individual with disabilities has no power to make any choices. The movement now is toward supported decision-making. The National Resource Center on Supported Decision-Making's motto is "Everyone has the right to make choices!" The Autistic Self-Advocacy Network has a toolkit "The Right to Make Choices."

This topic was spurred by a recent case where a parent contacted me seeking guardianship and was considering putting their teenager in a nursing home. There are other options. •

In loving memory of Julie and Katie Beckett.

ABOUT THE AUTHOR:

Lauren Agoratus, M.A. is the NJ Coordinator for Family Voices, NJ Regional Coordinator for the Family-to-Family Health Information Center, and Product Development Coordinator for RAISE (Resources for Advocacy, Independence, Self-Determination, and Employment). She also serves as NJ representative for the Caregiver Community Action Network as a volunteer. Nationally, Lauren has served on the Center for Dignity in Healthcare for People with Disabilities transplant committee (antidiscrimination), Center for Health Care Strategies Medicaid Workgroup on Family Engagement, Family Advisor for Children & Youth with Special Health Care Needs National Research Network,National Quality Forum-Pediatric Measures Steering Committee, and Population Health for Children with Medical Complexity Project-UCLA. She has written blogs and articles nationally, including publications in 2 academic journals (**https://pubmed.ncbi.nlm.nih.gov/?term=agoratus+l**). Lauren was recently named a Hero Advocate by *Exceptional Parent Magazine* (**https://reader.mediawiremobile.com/epmagazine/issues/207207/viewer?page=18**).

NO PLACE LIKE IT : SUPPORTIVE SERVICES & FINANCIAL ASSISTANCE CAN HELP MAINTAIN AN INDIVIDUAL AT HOME

NCIL
National Council on Independent Living

CENTERS FOR INDEPENDENT LIVING

www.ncil.org

National Resource Center for Supported Decision-Making
EVERYONE has the Right To Make Choices

NATIONAL RESOURCE CENTER ON SUPPORTED DECISION-MAKING

www.supporteddecisionmaking.org/

Medicaid.gov
Keeping America Healthy

MEDICAID HOME AND COMMUNITY BASED SERVICES

Extended School Year

www.medicaid.gov/medicaid/home-community-based-services/home-community-based-services-authorities/home-community-based-services-1915c/index.html

ASAN
AUTISTIC SELF ADVOCACY NETWORK

AUTISTIC SELF ADVOCACY NETWORK

The Right to Make Choices

https://autisticadvocacy.org/wp-content/uploads/2016/02/Easy-Read-OSF-For-Families-v3.pdf

INCREASING ACCESS TO YOSEMITE NATIONAL PARK'S JUNIOR RANGER PROGRAM

BY PENELOPE HATCH, PHD, CCC-SLP AND NANCY QUICK, PHD, CCC-SLP

The Junior Ranger Program, one of the most beloved traditions of the National Park Service, was created to help children discover and learn about the environment they are visiting.

In 2020, Yosemite Conservancy decided to revise their Junior Ranger Handbook with a goal of providing more inclusive representation and expanding access to the park's youngest visitors.

YOSEMITE CONSERVANCY ANNOUNCES A NEW SET OF FREE ADAPTED ACTIVITIES THAT CAN BE USED BY CHILDREN BETWEEN THE AGES OF 4-12 TO BECOME A JUNIOR RANGER.

Recently, Yosemite Conservancy worked with two speech-language pathologists to make the activities accessible for *all* children including those with complex learning, communication, motor and/or sensory challenges. Now, with family or caregivers as partners, children between the ages of 4 and 12 can complete their choice of five or more adapted activities to earn a Junior Ranger badge. Children do not need to speak, hold a pencil to write or draw, or use hearing or sight to complete the adapted activities.

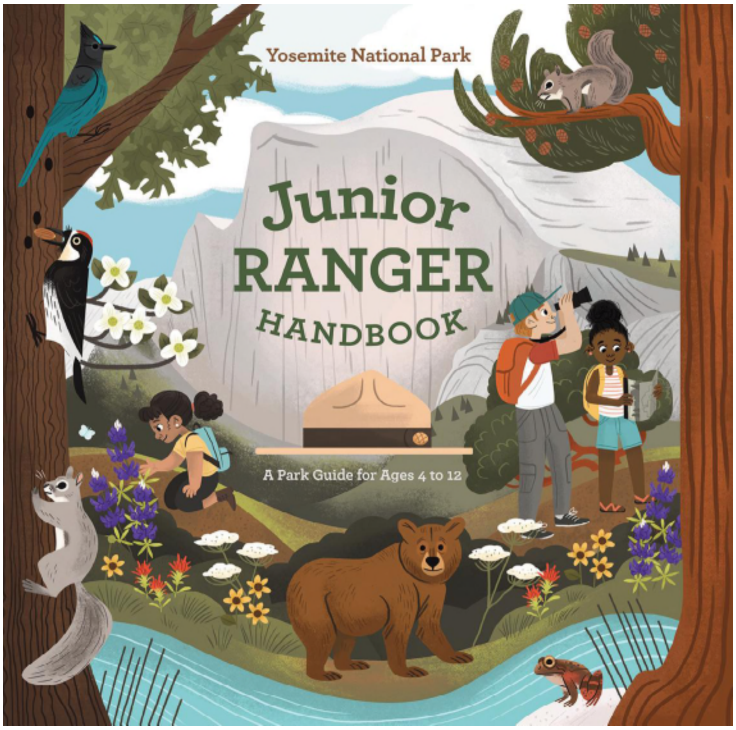
Yosemite is the nation's third oldest national park. It has a multitude of natural and cultural features, meriting its designation as one of 24 World Heritage Sites in the US. Yosemite is truly a national treasure filled with majestic scenery, a variety of wildlife, unique geologic formations, giant sequoia trees, and a history of Native people who have lived there for thousands of years. As a national park, it is meant to be available for access to the public without restrictions based on income, class or ability.

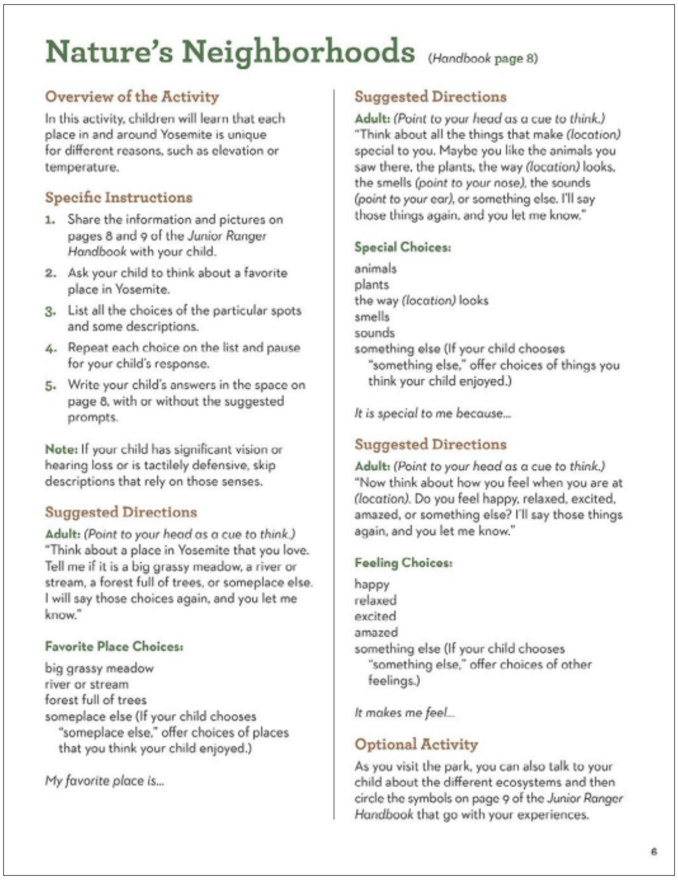
The Junior Ranger Program, one of the most beloved traditions of the National Park Service, was created to help children discover and learn about the environment they are visiting. It exists in most national parks and supports children in experiencing the well-documented benefits of spending time outdoors by participating in fun and educational experiences related to the parks.

In 2020, Yosemite Conservancy decided to revise their *Junior Ranger Handbook* with a goal of providing more inclusive representation and expanding access to the park's youngest visitors. They wanted to make sure that children with a range of communication abilities could complete the activities to earn a Junior Ranger badge. The Conservancy contacted Penelope Hatch and Nancy Quick, two speech-language pathologists at the Center for Literacy and Disability Studies at the University of North Carolina at Chapel Hill, to review and evaluate the accessibility of the activities.

EXPANDED VIEW: The Yosemite Conservancy decided to revise their Junior Ranger Handbook so that children with a range of communication abilities could complete the activities to earn a Junior Ranger badge.

PHOTO COURTESY JOSH HELLING





Nature's Neighborhoods *(Handbook page 8)*

Overview of the Activity

In this activity, children will learn that each place in and around Yosemite is unique for different reasons, such as elevation or temperature.

Specific Instructions

1. Share the information and pictures on pages 8 and 9 of the *Junior Ranger Handbook* with your child.
2. Ask your child to think about a favorite place in Yosemite.
3. List all the choices of the particular spots and some descriptions.
4. Repeat each choice on the list and pause for your child's response.
5. Write your child's answers in the space on page 8, with or without the suggested prompts.

Note: If your child has significant vision or hearing loss or is tactilely defensive, skip descriptions that rely on those senses.

Suggested Directions

Adult: *(Point to your head as a cue to think.)* "Think about a place in Yosemite that you love. Tell me if it is a big grassy meadow, a river or stream, a forest full of trees, or someplace else. I will say those choices again, and you let me know."

Favorite Place Choices:

big grassy meadow
river or stream
forest full of trees
someplace else (If your child chooses "someplace else," offer choices of places that you think your child enjoyed.)

My favorite place is...

Suggested Directions

Adult: *(Point to your head as a cue to think.)* "Think about all the things that make *(location)* special to you. Maybe you like the animals you saw there, the plants, the way *(location)* looks, the smells *(point to your nose)*, the sounds *(point to your ear)*, or something else. I'll say those things again, and you let me know."

Special Choices:

animals
plants
the way *(location)* looks
smells
sounds
something else (If your child chooses "something else," offer choices of things you think your child enjoyed.)

It is special to me because...

Suggested Directions

Adult: *(Point to your head as a cue to think.)* "Now think about how you feel when you are at *(location)*. Do you feel happy, relaxed, excited, amazed, or something else? I'll say those things again, and you let me know."

Feeling Choices:

happy
relaxed
excited
amazed
something else (If your child chooses "something else," offer choices of other feelings.)

It makes me feel...

Optional Activity

As you visit the park, you can also talk to your child about the different ecosystems and then circle the symbols on page 9 of the *Junior Ranger Handbook* that go with your experiences.

6

BROADER HORIZONS: *(Above left)* The *Junior Ranger Handbook; (Above right)* A sample adapted activities page, meant to be used in conjunction with the handbook and purposely created with minimal illustrations to reduce the amount of ink and paper required for printing.

The review revealed several barriers. First, many activities relied on vision and hearing without the option of using other senses to capture experiences and impressions of the park. Second, children were required to communicate about these experiences through speech, signs, symbols or writing with vocabulary or ideas that may not yet be familiar to them. This unintentionally excluded children who are beginning communicators and still learning to use language. It also created a barrier for children who have difficulty holding and controlling a pencil for writing and drawing. According to Yosemite Conservancy's Chief of Yosemite Operations, Adonia Ripple, "The level of adaptation needed was enlightening."

In response, the Conservancy asked Hatch and Quick to create additional activities that would give *all* Junior Ranger candidates the same or similar experiences while removing access barriers. The result is a collection of free adapted activities that can be downloaded from the internet. The adapted activities were purposely created with minimal illustrations to reduce the amount of ink and paper required for printing. They are meant to be used in conjunction with the *Junior Ranger Handbook*. Anyone who is interested can visit the National Park Service's Accessibility web page for Yosemite to download the adapted activities and link to the *Junior Ranger Handbook*: **www.nps.gov/yose/planyourvisit/accessibility.htm**. As of April 2022, the *Junior Ranger Handbook* has been free to all children who want to participate when they visit the park.

Some of the Junior Ranger adaptations addressed sensory barriers. A child now has the option to use senses such as touch and smell to complete activities that formerly required vision or hearing. One example is the activity titled "Discover Yosemite," where the child can choose from a list of things they smell (e.g., smoke, wood, pine trees) in place of or in addition to things that they see and hear. In another activity focused on the geological formations in the park, the child can choose descriptions of how different rocks and sand feel rather than how they look. Now, all children can participate in the Junior Ranger activities by experiencing Yosemite using the senses that provide the most information for them.

Other adaptations support parents and caregivers in acting as communication partners using strategies they may already be using at home. For example, rather than having the child come up with a response on their own, each adapted activity has a list of choices to offer so that vocabulary is less of a barrier. "Something else" is always one of those options in case the child wants to express something other than what the communication partner offered. Any behavioral response from the child, whether it is a facial expression, gesture, vocalization, or body movement, is honored as indicating a choice. The communication partner writes the child's responses in the *Junior Ranger Handbook* which is turned in to a Park Ranger when all activities are completed.

Finally, the writing requirement has been replaced by strategies like moving arms to "air draw" and using eye gaze to show the communication partner where to draw or write on the page. The child now can direct these activities without having to hold and control a pencil, pen or marker to complete them.

The adapted activities have been available since the summer of 2021. They provide a chance for intergenerational learning and exploration with older siblings, parents, grandparents and other family members. Approximately 5% of people who have visited the Junior Ranger web page have downloaded them. This demonstrates a greater interest than anticipated as well as a wonderful opportunity to increase the accessibility of Yosemite to all children and their families.

IMAGES COURTESY YOSEMITE CONSERVANCY

PEAK EXPERIENCES: Half Dome at Sunset; Yosemite is truly a national treasure filled with majestic scenery, a variety of wildlife, unique geologic formations, giant sequoia trees, and a history of Native people who have lived there for thousands of years. As a national park, it is meant to be available for access to the public without restrictions based on income, class or ability.

Plans for the future include preparing guidelines for the National Park Service that other parks could use to adapt their Junior Ranger activities. Yosemite Conservancy Board member, Jan Avent commented that the adapted activities create, "a wide-open path for all children. No more looking at what everybody else does and not being able to participate. That's what accessibility is. It's not making it easier; it's letting people be who they are and do the same thing that everybody else is doing."•

ABOUT YOSEMITE CONSERVANCY

YOSEMITE
CONSERVANCY.

Yosemite Conservancy is the only nonprofit dedicated to supporting Yosemite National Park. As Yosemite's official philanthropic partner and cooperating association, the Conservancy works closely with the park to fund high-priority projects and provide enriching educational programs. In the 1920s, the Yosemite Museum Association formed to help build a museum in Yosemite National Park. Today, Yosemite Conservancy helps people connect with the park, including through adventures, art, theater, and books, and funds restoration, research, wildlife management, visitor education, and more, ensuring Yosemite's grandeur through the ages. Learn more at **www.yosemite.org**

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Individuals Quoted in the Article: Jan Avent, Yosemite Conservancy Board Member; Adonia Ripple, Chief of Yosemite Operations, Yosemite Conservancy.

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EP's ANNUAL TRAVEL ISSUE

Travel Tips For Families

BY JENN ADAMS

It's summertime and many families use this time of the year for traveling. There are tons of places that are perfect for families to visit and get some rest and relaxation. I often find parents asking me for tips on how to make vacations a bit smoother for everyone. It's tricky enough keeping children occupied, but then let's add traveling with a child with a disability. Here are some tips to make your vacation run smoothly!

Planning Ahead of Time

When planning a vacation with kids, it is important to consider their needs and interests. Choose a destination that is kid-friendly and has activities that will keep them entertained. If attending a museum, amusement park, or another attraction, ask if they have a sensory area, and if they have a wristband for quick access to rides for children with disabilities. Many places now have areas for accommodating the needs of children with disabilities. It's common for children to have difficulty waiting for things to happen, especially when they are really excited. So, this can help. Call ahead and ask what services they have and decide if that works for your family.

Using Visual Schedules

When you are traveling with kids, it is important to have a schedule. This will help keep the kids on track and allow them to know what is going on. For a child with a disability, I suggest implementing a visual schedule of the activities, it works well if it is written out as a checklist or using pictures. Your child crosses the activity off or puts the picture in a bag when the activity is completed. Something small could be kept in a pocket or purse, and just be used when it's time to transition to something else. Providing that prompting before a change is going to happen, helps prepare the child for it.

Creating a Safe Space

Children who are prone to sensory issues may experience certain difficulties while traveling. When they become overstimulated, it is important to have a calm and safe space for them to go. This space should be away from the source of the stimulation and should be quiet and peaceful. This might be a shaded area at a park or zoo. It could also be a dedicated room that many new facilities are creating.

It is also important to have someone there to help the child calm down and feel safe. If visiting friends or family for parties or dinner, ask if you can create a safe and calm place for your child. This should be a place away from the activities that is quiet and has a few of their favorite things.

ILLUSTRATION COURTESY BIT.LY/3QNUU8M

Have Fun Items Ready

Create a box of fun activities that is only available when you are unable to give full attention to your child. The box needs to be individualized for your child with the things you know they enjoy best. For example, if your child is into playdough, get a small new activity set that can keep their interest or get their mind off of a potentially overstimulating situation. Other items that work great are: fidgets, small stuffed animals, and your child's favorite snacks. Sometimes when you are in an unfamiliar place but have familiar items nearby, it can be comforting to the child. Usually keeping these items in a backpack that you carry around from place to place can be convenient. Using the backpack for your child that may have sensory needs, to help them get some input, is a great idea as well! Sensory input is when our sensory organs respond to stimuli. In this case, the backpack is the stimuli, providing deep pressure which can often be a calming relief to many people. Think of the backpack working for your child like a weighted blanket or a massage.

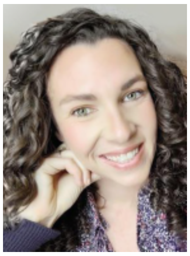
Create Visuals for Everything!

If traveling by plane, create visuals of all activities, (security, showing your ticket, putting the seat belt on). Load your carry-on with their favorite items (like mentioned earlier). It also can be helpful to book a seat that has your whole family in one row. Make sure your child's seat has extra legroom. This can provide your child with space to move especially on a long flight. Make sure that your child is dressed in comfortable clothes and shoes. Perhaps bring a small weighted blanket if your child has sensory needs.

Have a visual for when your child may be agitated or upset, with reasonable choices on it to support them when they: might need a break, are hungry, or are tired. Understand that when you are on vacation there are many new and exciting experiences, but this also means there is lots of change and overstimulation that can happen as well.

Going on vacation can be very exciting! It can be a great opportunity to explore new places, meet new people, and try new things. Vacations can also be a great chance to relax and rejuvenate. Use these tips to make your vacation with your family the best it can be for everyone!

ABOUT THE AUTHOR:



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

EQUITABLE, ACCESSIBLE, AND INCLUSIVE PUBLIC TRANSPORTATION FOR INDIVIDUALS WITH DISABILITIES

IMPROVED POSSIBILITIES AND OPPORTUNITIES

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

Humans have always been on the move, with early humans moving in search of food and shelter, to humans today where the community mobility and participation are essential to quality of life for virtually everyone. According to the report from the Centers for Disease Control and Prevention, the most common disability type is mobility, which affects 1 in 7 adults. [1]

Persons with mobility difficulties are more likely to be poorly educated, living alone, impoverished, obese, and having problems conducting daily activities. Among persons with major mobility difficulties, 30.6% reported being frequently depressed or anxious, compared to 3.8% for persons without mobility difficulties.[2]

The Americans with Disabilities Act (ADA) is a federal civil rights law that was passed in 1990 and protects people with disabilities from discrimination. Title II of the ADA protects individuals with disabilities from discrimination in public transportation services such as: city buses, commuter rail, subway stations, Amtrak and paratransit services. Title III of the ADA applies to private transportation services such as hotel shuttles, private buses, vans, and taxis. The Americans with Disabilities Act (ADA) applies to both public and private ground transportation providers who are required by law to provide the following.[3]

PHOTO COURTESY METRO.NET/RIDING/RIDERS-DISABILITIES

- ***Rider information*** *on services in accessible formats for persons with different types of disabilities (e.g. information in large print, braille or alternative and electronic formats).*
- ***Assistance equipment and accessible features*** *such as lifts, ramps, securement devices (straps for securing wheelchairs on board), signage, and communication devices.*
- ***Adequate time to board and exit*** *from the vehicle.*

- ***Accompaniment by service animals*** *such as any guide dog, signal dog or other animal individually trained to provide assistance to an individual with a disability, regardless of whether the animal has been licensed or certified by a state or local government.*
- ***Priority seating and signs*** *on fixed-route systems (transportation that operates along a prescribed route according to a fixed schedule). Such transportation must have signs designating seating for passengers with disabilities. At least one set of forward-facing seats must be marked as priority seating.*
- ***Architectural requirements*** *such as:* ***stop announcements*** *(at transfer points, major intersections, destination points and per riders' requests),* ***announcement of destination and route information*** *(such information must also be provided on the front and boarding side of the vehicle),* ***lifts and ramps*** *so that a passenger who uses a wheelchair or mobility device can reach a secure location onboard,* ***illumination, contrast, and slip-resistant surfaces, fare box*** *to ensure passenger flow, and* ***turning room, handrails, and pull cords*** *for accessibility.*
- ***Other requirements*** *on all trains, airlines, and subways include: level boarding and narrowing the gap between train doorways and station platforms, curb ramps on sidewalks and entrances, functioning elevators, Braille in elevators, an emergency evacuation plan, accessible restrooms, including: grab bars, raised toilet seats and insulated lavatory pipes, accessible alarms, water fountains and collection equipment.*

There are many challenges in the present public transportation system that need to be addressed; those who cannot afford or do not drive cars often lack viable transportation options. Individuals with disabilities, particularly in rural communities, are at a transportation disadvantage, as there are few public transportation options available.

Challenges in the present public transportation system: In spite of the requirements of the ADA, there are persistent gaps in compliance that continue to create significant barriers for people with disabilities. There are many challenges in the present public transportation system that need to be addressed, especially when our nation's investments in transportation infrastructure have disproportionately favored cars and highways. Those who cannot afford or do not drive cars often lack viable (and affordable) transportation options. Individuals with disabilities, particularly in rural communities, are at a transportation disadvantage as there are few public transportation options available. Accessible and affordable transportation options that bring employment, health care, education, housing, and community life within reach, are critical for independent living. According to the Bureau of Transportation Statistics, nearly 25 million people have a travel-limiting disability, which means 1 percent of all Americans, and among them about 3.6 million people are restricted to their homes because of a disability.[4]

Essential steps to an inclusive and equitable transportation system can be created for people with disabilities by increasing awareness and by changing attitudes. Changes in attitude, commitment and action are required at all levels: politicians and officials, engineers and contractors who design and build roads, pedestrian facilities, and public transport systems, the operators of transport services, and fellow travelers. Some important examples are:

- *Assumptions should never be made about what individuals with disabilities need, instead they should be* ***consulted and engaged*** *in deciding what they require.*
- *Individuals with disabilities* ***must be factored into*** *transportation planning policies, design, and budgets right from the start instead of retrofitting accessibility features later, which is both difficult and more expensive.*
- ***Universal design approach*** *"design for all" features, such as: low-floor buses with ramps, larger destination signs, floor markings, additional grab bars, audible stop announcements, and monitors that show upcoming stops have greatly enhanced accessibility. However, they must be maintained periodically, and equipment such as lifts and other wheelchair and scooter securing equipment must be kept in good working condition.*
- ***Training and education*** *must be provided to everyone engaged in the design, delivery, operation and use of transport, including the senior managers to transport employees in direct contact with the travelling public, including bus drivers,*

train station staff, airline staff, etc. This will provide them with the tools necessary to serve individuals with disabilities, which will help reduce discrimination and discomfort for individuals using public transportation. Direct public transportation providers must have an understanding of different types of disabilities and how they affect ability to travel, including hidden disabilities, such as autism and mental health issues. This will provide insight to direct service providers into travel difficulties including sensory impairments.

- *The disability and broader civil rights community, must continue to work together for a transportation system that meets the needs of all individuals and must advocate for* ***vigorous oversight and compliance*** *with the ADA, to hold the transit agencies more accountable.*

Equity in transportation is an important civil rights issue. It is critical to the independence of people with disabilities and their ability to contribute economically, socially, and politically.

Equity in transportation is an important civil rights issue. It is critical to the independence of people with disabilities and their ability to contribute economically, socially, and politically. Unfortunately, adults with disabilities are twice as likely as those without disabilities to have inadequate transportation (31% vs. 13%).[5] Of the nearly 2 million people with disabilities who never leave their homes, 560,000 never leave home because of transportation difficulties.[6] Leaving people out has real costs to the nation. Keeping people with disabilities at home keeps them out of jobs, away from shopping, and out of community life, and it prevents them from making valuable contributions to our society as individuals, as workers, as consumers, and as taxpayers. •

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

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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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UNDERSTANDING JOB PROTECTED LEAVE

DOUBLE COVERAGE: Depending on the circumstances, the employee with a disability or the employee providing care to an individual with a disability may be entitled to a job protected leave under the ADA, FMLA, or both.

BY AYESHA HAMILTON, ESQ

Employees with disabilities may at times need to take a temporary leave of absence from work to receive care or treatment related to their disability. Likewise, a caregiver or other person who has a relationship with an individual with a disability may need to take a leave of absence from work to provide care to an individual with a disability. Depending on the circumstances, the employee with a disability or the employee providing care to an individual with a disability may be entitled to a job protected leave under the Americans with Disabilities Act of 1990 ("ADA"), the Family and Medical Leave Act ("FMLA"), or both. Whether the job protected leave will be paid or unpaid depends on the employer's leave policy.

JOB PROTECTED LEAVE UNDER THE ADA

The ADA provides certain job-related protections to individuals with disabilities and individuals who have a relationship or other type of association with a person with a disability. Under the ADA, a disability is defined as a physical or mental impairment that substantially limits a major life activity. The individual's medical condition must fit within this legal definition of a disability in order to receive the job protections granted by the ADA and typically, this is a very fact specific analysis.

One of the job protections provided by the ADA is that it requires employers to provide a *reasonable accommodation* to an employee with a disability, who requests such an accommodation. A reasonable accommodation is a change or adjustment that allows the individual with a disability to perform their job duties. A reasonable accommodation can be requested at any time. It can be requested during the application and interview process or at any point during the employment. There are no special forms that need to be filled out to request an accommodation, or specific words that need to be said. All an employee with a disability needs to do is notify the employer that a change is needed because of the individual's disability. A reasonable accommodation request could be something as simple as an employee with a vision impairment notifying their employer that they have a hard time reading their computer screen, or an employee presenting the employer with a doctor's note outlining work restrictions.

One common type of accommodation is to take time off work for treatment for a disability. A temporary leave of absence may be considered a reasonable accommodation, if it will allow the employee to return to their work following the treatment or care of their disability. An employee with a disability who needs a disability related leave of absence can request the accommodation by notifying the employer of the need for the leave or by providing the employer with a doctor's not requesting the employee be granted time off due to their disability.

> “A TEMPORARY LEAVE OF ABSENCE MAY BE CONSIDERED A REASONABLE ACCOMMODATION, IF IT WILL ALLOW THE EMPLOYEE TO RETURN TO THEIR WORK FOLLOWING THE TREATMENT OR CARE OF THEIR DISABILITY.”

LEAVE IN PEACE: The FMLA provides job protected leave to employees who need to care for their spouse, child, or parent who has is an illness, injury, impairment, or physical or mental condition that requires inpatient care or continuing treatment.

After a reasonable accommodation request is made, the employer and employee should engage in an interactive process, and work together to figure out the best options for the employee. The employer is allowed to request documentation from the employee if their disability is not obvious. The employer can also ask the employee to explain why they need a reasonable accommodation. The employee is not entitled to the accommodation that they prefer. An employer has complied with the ADA so long as they grant an accommodation that is reasonable.

Employers are not always required to grant an accommodation under the ADA. An employer does not need to grant a reasonable accommodation if it would cause an undue hardship to the employer. Also, if an employee cannot perform the essential functions of their job duties, even with a reasonable accommodation, then they are not entitled to job protections under the ADA. Employees who work for very small employers may not be entitled to job protections under the ADA as well, as it only applies to employers who have 15 or more employees.

JOB PROTECTED LEAVE UNDER THE FMLA

Employees with disabilities may also be entitled to job protected leave under the FMLA. While the ADA provides job protected leave specifically for individuals with disabilities, the FMLA provides job protected leave to employees with a serious health condition, who cannot perform the functions of their job; to employees who need to care for their spouse, child, or parent who has a serious health condition; or for other qualifying reasons. A serious health condition under the FMLA is an illness, injury, impairment, or physical or mental condition that requires inpatient care or continuing treatment by a healthcare provider. An employee with a disability may have a health condition that qualifies as both a disability under the ADA and a serious health condition under the FMLA.

An employee who needs FMLA leave must provide notice to the employer, either written or oral, of their need for leave. The employee should provide the employer with enough information so the employer knows that it may be a job protected leave under the FMLA. The notice should be given to the employer at least 30 days prior to the FMLA leave if the employee knows about the need for leave far enough in advance. Otherwise, the employee should give the employer notice of the need for leave as soon as possible. The employer may ask for additional information to determine if it is an FMLA qualifying leave.

They may require the employee to complete a certification to verify the dates and reason for leave. The certification may need to be completed by a healthcare provider. The employer may challenge the employee's medical certification and may get a second or third opinion. The employer should then inform the employee whether they qualify for a job protected FMLA leave or if they are not eligible.

Not everyone is eligible for FMLA leave. The FMLA applies to all employers who are public agencies – such as federal, state, or local governments and their agencies – but only applies to private employers who have at least 50 employees. The employee must also have worked for the employer for at least 12 months, as of the first day of leave, and have worked for at least 1,250 hours during the 12 months immediately before the leave. If the individual's employer is not covered by the FMLA or the individual is not otherwise eligible under the FMLA, they may still be entitled to job protected leave under the ADA.

Under the FMLA, an employee is entitled to up to 12 weeks of job protected leave in a 12-month period. The FMLA leave can be taken all at once or at different times over the 12-month period. Once 12 weeks of leave is taken, any additional leave needed within the 12-month period is no longer protected leave under the FMLA. Unlike the FMLA, job protected leave under the ADA does not have a set time limit and would be determined on an individual basis, based on what is considered a reasonable accommodation for each employee's circumstances.

Some state legislatures have also enacted their own versions of the ADA and the FMLA. These state laws may be broader and provide job protected leave to even more individuals than the federal laws.

JOB PROTECTED LEAVE VS. PAID LEAVE

An employee may be entitled to job protected leave, but that does not mean they will be paid for that time off. An employer may provide an individual with a disability, a job protected leave, but there is no requirement that the employer also pay the employee for that time off.

Many employers have paid time off or paid leave policies. To the extent that an employee's job protected leave fits within the employer's paid leave policy, the policy should be applied towards the leave, just as it would for an employee who does not have a disability. An employee may also be able to be paid for their job protected leave through their short-term disability policy if they have one.

The bottom line: As an employee, you need to initiate the conversation with your employer when you are asking for leave or an accommodation, and must engage in the "interactive discussion" about the type of leave and/or accommodation you are requesting. •

Please contact the Hamilton Law Firm LLC if you have any questions or are experiencing difficulties in the workplace as relates to a request for leave or accommodations.

ABOUT THE AUTHOR:

Ayesha Hamilton, Esq. is an attorney licensed to practice law in New Jersey, New York and Pennsylvania. She founded her law practice over 15 years ago and focuses on employment law. The Hamilton Law Firm team provides knowledgeable, compassionate and professional legal services to their individual and business clients from their offices located in Princeton, New Jersey. In addition to her law practice, Ayesha serves as a trustee on the board of directors for the New Jersey State Bar Association as well as the Mercer County Bar Association. She also serves on the Diversity Committee and the Commission on Racial Equity in the Law for the NJSBA and is the chair of the Mercer County Bar Association's Diversity Committee and co-chair of the Civil Practice Committee. In addition, she serves on the employment law committee of the New Jersey Association of Justice and is also a member of the National Employment Lawyers Association-NJ. In 2020, she was appointed to serve on the State Bar's Judicial and Prosecutorial Appointments Committee (JPAC) vetting judicial and prosecutor candidates for the NJ Governor's office. Ayesha was named the NJSBA Solo/Small Firm Attorney of the Year for 2021

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WHEN MOM HAS CANCER, KIDS ARE PART OF THE JOURNEY

BY JONI RODGERS

Once upon a time, I was a power mommy who had everything under control. That fairy tale imploded in 1994, when I was diagnosed with non-Hodgkin's lymphoma, a virulent blood cancer. I was 32 years old. My son Malachi was 7; my daughter Jerusha was 5. As my husband Gary and I muddled through the physical, emotional, and financial devastation of chemo, we struggled to keep our kids' world from falling apart. We didn't always get it right, but we learned three key lessons that made us better parents in the long run.

COMMUNICATE

Our kids were smart enough to know something was up. We knew if we weren't open about it, they'd be certain of only two things: 1) Something's terribly wrong. 2) Grownups lie. Better to have them know that, through all life's uncertainties, they could always count on straight answers from us. When they asked, "Are you going to die?" I answered truthfully: "Not today."

CREATE OPPORTUNITIES FOR EMPOWERMENT

When chemo turned my stomach inside out, Jerusha would stand outside the bathroom, yelling, "Joni Rodgers! You stop that!" And when I couldn't stop, she just cried. Someone she loved was in pain, and it made her feel helpless. As much as I wanted to protect her, I had to open the door. Holding a cold washcloth against my forehead made her feel proactive, trusted, and able to make a difference.

FIND TANGIBLE WAYS TO HONOR FEAR AND LOSS

It was scary for my kids to see my appearance change dramatically during chemo. When my hair started falling out, I let them help me divide it into ten long braids and cut them off close to my scalp. Malachi and I used them to make a dreamcatcher with a metal hoop, found feathers, dried grass, and other yard treasures. Before chemo, Jerusha loved to brush my hair. After I was completely bald, I let her "tattoo" flowers on my head with watercolor markers. These little rituals helped us sort through some big feelings.

It was a lot to process – for all of us. It took a while for Gary and me to understand that we had to accept ourselves, each other, and life in general, as perfectly imperfect. We never took family time for granted, never hesitated to express our love. Every semester, we took the kids out of school for a day trip, to see a movie, or just hang out for a mental health day.

FAST FORWARD 25 YEARS

Today Malachi is a horticulturist in Denver. His wife is a psychotherapist, and they have a completely wonderful 5-year-old daughter. Jerusha traveled the world for several years after college, and now works for a credit union in Germany. They grew up to be kind, creative adults who tell me that this difficult part of their childhood made them stronger and more empathetic.

The same is true for Gary and me.

I wish we'd had a chance to know what our family would be like if we'd never been touched by cancer, but I have to acknowledge that this difficult time of turbulence and growth made us better parents, because it made us better people. •

ABOUT THE AUTHOR:

Joni Rodgers is a critically acclaimed novelist, a bestselling memoirist and a sought-after celebrity ghostwriter. Her iconic titles include *Bald in the Land of Big Hair, Crazy for Trying* and *Sugarland.* An EGOT ghostwriter – having worked with Emmy, Grammy, Oscar, and Tony winners – she's had multiple titles debut on the New York Times bestseller list, a recent title at #1 and the newfound control writers can wield over their careers by releasing the Sixo Collection – fresh editions of her first six books. She lives on the beach in Washington State and is celebrating turning sixty and surviving cancer. Her memoir *Bald in the Land of Big Hair* (HarperCollins 2001) is available on **www.jonirodgers.com** and wherever books are sold.

How one student's hearing loss led her on a path to independent study, research and academic pursuits.

LIFE AND STUDIES COALESCE

FOR MONTCLAIR STATE UNIVERSITY GRADUATE

BY SYLVIA A. MARTINEZ

It was the beginning of one of her favorite Red Hot Chili Peppers' songs that led to Montclair State University graduate, Evyn Stewart '22's hearing test and unilateral hearing loss diagnosis, at a young age.

Stewart, who was 8 or 9 at the time, says much of the diagnosis went over her head, but she recalls what led up to it: She was listening to "Slow Cheetah" in the car when her father cranked up the volume.

"I didn't know that the lead singer had said a little blurb in the beginning of the song, and I was like, 'Oh, that's so strange,'" she says.

A hearing test revealed hearing loss in her left ear. "After that hearing test, it made perfect sense why I would be missing that part of the song at a certain volume, because I was missing the low end and the high end of certain frequencies on the audiogram.''

That song, diagnosis, and decades of visits to an ear, nose and throat doctor and audiologist, led Stewart to an independent study in Montclair's Communication Sciences and Disorders department this semester – as an undergraduate in a graduate-level lab.

A Linguistics major in the College of Humanities and Social Sciences, Stewart worked in Montclair's Communication Sciences and Disorders Clinical Biofeedback Lab, also known as MSU-CBL, studying adolescents with unilateral hearing loss, and presented her research findings at the New Jersey Speech, Language and Hearing Association's Annual Convention in April.

The 21-year-old tackled the study with the same grit and grace – and a good dose of humor – with which she handles her hearing loss. Stewart has seen her pediatric ENT since she was two. She suf-

A SOUND COLLABORATION: Evyn consults with Associate Professor of Communication Sciences and Disorders Elaine Hitchcock in the biofeedback lab, where the Montclair senior conducted her independent study.

PHOTOGRAPHS COURTESY MIKE PETERS

OUTSTANDING IN HER FIELDS: *(Above left)* Evyn played field hockey since she was old enough to hold a stick. Following their mom's lead, Evyn and her sister also played college-level hockey. *(Above right)* Evyn works with grad student Ashley Martino, a research participant in Stewart's independent study.

fered from ear infections, and had to have tubes put in her ears as a toddler to fourth grader. She did without them for a short period, but an ear infection led to a perforated eardrum in her left ear.

> “You could say I've been taking hearing classes for 21 years. I looked into the field more and shadowed my audiologist, and then volunteered in the biofeedback lab, too. All of that is why I wanted to go into audiology.”

“That was the first of four perforations, and so I currently have a tube in my ear. I get it replaced every four years or so,” she says, joking that she's going to have to find a “big girl ENT” soon. The tube, she explains, “stabilizes my eardrum and equalizes the pressure. There's a bunch of scarring in my ear and on my Eustachian tube, and that's what led to my unilateral conductive hearing loss.”

Stewart also has been playing field hockey since she could hold a stick, and was a member of Montclair's field hockey team for four years. Her hearing loss, she says, was her biggest challenge on the field.

“Definitely I felt the impact in sports. I had a hard time telling directional sound. If I had a teammate on my left side, then I definitely had a harder time knowing if they were calling for the ball, but the other thing is, we weren't out on the field whispering, right?” she laughs. “They're [also] going to say my name.”

Indoor high school tournaments where fields were side by side were “doubly hard,” she says. She could not tell if a whistle was blown by a referee on her field or nearby. At the advice of a mom who recognized her confusion, because her daughter also had hearing loss, Stewart bought some whistles that sound like train whistles.

“I would give those to the refs if I knew that we were going to be in a complex with multiple fields next to each other, and so that was helpful,” she says.

In some ways, Stewart thinks she's developed other skills to compensate and learned to adapt.

“I have definitely done different things and just became accustomed to different methods,” she explains. “So, my game sense is huge for me, just knowing, predicting where the ball would end up, and what play would happen, versus where it is. That's how, directionally, I would get myself situated. And I definitely don't think I would have that aspect, if I didn't become so dependent on it.”

INDEPENDENT STUDY

Stewart was on track to become a speech pathologist, however a summer course in audiology, volunteering in the lab, and her independent study, changed her career trajectory. The way she sees it, her hearing loss has immersed her in the field of audiology.

“You could say I've been taking hearing classes for 21 years,” she says, smiling, “but it never really hit me as a profession, until that class. And then, I had an ENT appointment that summer, and I talked to my audiologist who has been doing my hearing tests since I was pretty young. My favorite part of going to the ENT was the hearing test, because they're not poking and prodding in your ear. I looked into it more and shadowed my audiologist, and then volunteering in the biofeedback lab, too. All of that is why I wanted to go into audiology.”

University faculty and staff helped Stewart achieve her goal of an independent study, a hurdle that required lots of research, work and persistence to gain registrar approval, since she was an undergrad and not a graduate student. Adjunct Professor of Communication Sciences and Disorders, Laura Ochs recommended the volunteer opportunity and Stewart worked closely with and assisted Michelle Turner, a speech-language pathology (SLP) doctoral student with whom she was paired, with research prior to her independent study.

NEXT STEPS: Evyn Stewart '22 completed an independent graduate-level study in speech-language pathology. She applied to a dozen audiology schools across the country and will be attending Salus University in August.

Speech-language pathologist and Associate Professor of Communication Sciences and Disorders, Elaine Hitchcock last year received a National Institutes of Health grant to research the telepractice delivery of speech, and currently leads the research and clinical opportunities in the Clinical Biofeedback Lab. Hitchcock, who supervises Stewart's research study, says that Stewart showed enthusiasm and commitment from the beginning, and has demonstrated maturity and independence unexpected in someone so young. Stewart, who has worked as a restaurant hostess and a kayak/paddleboard tour guide in Ocean City for the past three summers, trekked to the MSU-CBL for her volunteer service.

In her graduate-level study, Stewart researched the very thing with which she was diagnosed: unilateral hearing loss in adolescents. She compared how their speech perception compares to their "typical hearing peers."

"How many students, not graduate students, undergraduate students would drive two and a half hours to be a volunteer?" Hitchcock says of Stewart's weekly trips to the biofeedback lab over the summer. "What we identified pretty quickly was that Stewart was a highly skilled student. For an independent study, you have to want to work with them, as the professor. They have to be somebody that you feel like you can trust, that you're not chasing down and that will do quality work. That's the kind of student you really want to support. Evyn was still an undergraduate – and a varsity athlete – and did an amazing job."

In her graduate-level study, Stewart researched the very thing with which she was diagnosed: unilateral hearing loss in adolescents. She compared how their speech perception compares to their "typical hearing peers." Under Hitchcock's guidance, she worked with research participants on various tasks, in order to record how they say, produce and repeat sounds or words, which was then contrasted with people who have no hearing impairments.

During the research, she was working with another Montclair student, Ashley Martino, officially known as "Participant 05" in the study. Martino, 22, has some hearing loss in her left ear due to a cholesteatoma, a cyst or skin growth behind the eardrum. A graduate student in Speech-Language Pathology, Martino was recruited as a research participant by another professor, who was aware of her hearing loss. She says she has a hearing aid she does not wear. "My whole life, I've learned to adapt," she says.

Stewart handed her headphones and ran her through a series of tests. In one test, Stewart had her repeat a list of "crazy made-up words," beginning with single syllables, followed by double and triple and finally quadrisyllabic words, which Stewart recorded. The goal, she says, was to compare Martino's and other research subjects' perception of the words they hear, with their pronunciation of them, and see how they may differ.

Stewart says that someone with unilateral hearing loss may have difficulty deciphering between 'b' and 'p' sounds, something with which she also struggles. "So, when I ask them to say 'bo-ta-go' or whatever the made-up word is, they might say 'po-ta-go' because they didn't hear the 'b' sound from the initial output," she says.

The research is important because while there has been research on bilateral hearing loss among students, there has not been much on the impact of unilateral hearing loss in young adults, says Hitchcock. "Let's see if there's anything uniquely different in our findings that may inform the research in one direction or the other," she says.

GRAD SCHOOL BOUND

Stewart applied to a dozen audiology schools across the country and will be attending Salus University in August. ”When she does, she will have three graduate level credits under her belt”, says Hitchcock, who is happy for her, even though she chose audiology over SLP.

"It's not about me," Hitchcock says. "My job is to give them opportunities. It's her life, she should do what she wants. She was still here with me for a whole semester and then some, learning, growing and finding her path in life – it's amazing."

One of the first people with whom Stewart shared her decision to pursue audiology? Her audiologist of many years.

"She was really excited," Stewart says smiling.•

ABOUT THE AUTHOR:

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

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PHYSICAL CHALLENGE AWARENESS:

ALMA'S WAY FEATURES EDDIE MAMBO, WHO HAS CEREBRAL PALSY

BY DR. MARY LOUISE RUSSELL

*In my role as a medical consultant for **Alma's Way,** the animated series from Fred Rogers Productions on PBS KIDS, I was called upon to assess numerous activities for the character Eddie Mambo, Alma's cousin.*

Eddie is a boy with spastic diplegic cerebral palsy, with particular challenges with spasticity and weakness of his legs. I need to ascertain if proposed activities for Eddie could be performed safely as portrayed, or if modifications to these activities would be needed. I consider assessment of Eddie from three perspectives: mine as a pediatric rehabilitation physician, that of a child with cerebral palsy, and that of a child without a motor function challenge.

Cerebral palsy is a diagnostic category for which affected patients may have various functional challenges. Eddie, with his particular type and severity of cerebral palsy, has his greatest challenges with movement of his legs. Other patients with cerebral palsy, who may have either a different form of cerebral palsy and/or a more severe form of cerebral palsy than Eddie, may have challenges with control of mouth muscles, back muscles, and arm muscles. Eddie represents a child with one form of cerebral palsy, spastic diplegic cerebral palsy.

As a pediatric rehabilitation physician, I am aware that people with cerebral palsy have a wide range of movement capabilities, as well as challenges. To portray one child with cerebral palsy, we needed to delineate specific features of this child's movement function. One very well validated assessment of motor function for children with cerebral palsy is the Gross Motor Function Classification (GFMFC), which first was presented in 1997. We decided that Eddie would function at a GMFC level of 2. Children at this level are noted to be able to walk without assistive devices

IMAGES COURTESY PBSKIDS.ORG/THINK IT THROUGH MEDIA, LLC

HEY MAMBO: *(Opposite page)* Eddie is not only a child with cerebral palsy, he has interests such as music, dance, baseball, and soccer. *(Above)* Eddie has a family, friends, schoolmates, and teammates, and is depicted as a helpful, enthusiastic, talented boy.

in most settings and to climb stairs with the aid of a railing. Such children may ambulate with physical assistance, a handheld mobility device or use wheeled mobility over long distances. They have only minimal ability to perform gross motor skills such as running and jumping *(Palisano, R. et al, 1997).*

As the medical consultant, I assess story scripts and preliminary drawings and videos of Eddie participating in various activities. The process of doing so has broadened my own horizons to consider the total functional tasks for a child with cerebral palsy. The child with cerebral palsy needs to do more than lie on an examination table to undergo range of motion assessment and maneuver up and down a clinic hallway. The child with cerebral palsy lives in a home, goes to school, participates in play and service activities in their community. During the course of my work for the show, I have faced very specific questions, such as: How does Eddie comfortably kneel while wearing his ankle foot orthotics (leg braces)? How does he safely splash in a puddle while using his crutches? Wrestling with such questions provided me with increased awareness of both the capabilities and the challenges faced by a child with cerebral palsy.

The portrayal of a child with cerebral palsy in *Alma's Way* provides a viewer with cerebral palsy with a sense of representation, of acknowledgment. Eddie is not only a child with cerebral palsy, he is a son, a cousin, a friend, a teammate, a musician. He has interests: music, dance, baseball, and soccer among them. Sometimes, accommodations are needed for him to pursue his interests, but pursuit of his interests still is possible, even enjoyable. Eddie gives to his family, friends, teammates, and community.

The portrayal of a child with cerebral palsy gives a child without motor challenges increased awareness and acceptance of differences. The child with cerebral palsy is seen as a person who can do many things, sometimes with accommodations or assistance. This child shares many of the same interests as the unaffected child. Like the unaffected child, the child with cerebral palsy has a family, friends, schoolmates, teammates. Eddie Mambo is depicted as a helpful, enthusiastic, talented boy. His walking challenges do not diminish these, or other positive qualities he possesses. Any child watching the show could want to have Eddie Mambo as a friend. In the future, would a viewer of *Alma's Way* wish to befriend a child with cerebral palsy whom they might encounter? I certainly hope so. Two lives could be greatly enriched through such a friendship. Facilitating such mutual enrichment is one of the goals for those who work on *Alma's Way.* I am grateful to have been part of such an effort. •

*New episodes of **Alma's Way** will be premiering from July 11 to July 14.*

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ABOUT THE AUTHOR:

Dr. Mary Louise Russell is a pediatric rehabilitation physician at the West Virginia University Medical Center. She has also worked with children who have conditions that adversely affect their ability to move at the Children's Hospital and The Children's Institute in Pittsburgh, where watching children in their therapy sessions has been a joyful part of her duties. Dr. Russell completed a pediatrics residency at Children's Hospital of Columbus, OH, and a physical medicine and rehabilitation residency at the University of Minnesota Medical Center. She attended medical school at the Medical College of Pennsylvania.

EMABARKING ON THE SPECIAL EDUCATION JOURNEY

BY RAJA MARHABA

Special education can be emotional, stressful and a financially burdensome experience. There are many factors that take place when a parent commences the journey of advocating for his/her children. Parents should be prepared and have some knowledge of what an Individual Education Plan (IEP) means. It's easy to say I want an IEP for my child, but does a parent truly know what that entails?

IEPs can be simple or complex. It all depends on the child and the school. The parent must have a clear understanding of what their rights are and what an IEP means. It is important to know that an IEP is a legal contract. The school has an affirmative obligation to provide a Free and Appropriate Public Education under IDEA ACT, Special Education Law https://sites.ed.gov/idea/about-idea/. The school must implement the services stipulated in the IEP. If they do not, then they will be in violation of the IEP. The statute of limitations that enable parents to take action against a school for failing to provide a Free and Appropriate Public Education, is two years.

Look for discrepancy with the scoring, report cards, teacher comments throughout the years. For example, on an academic test like the Woodcock Johnson IV, a reading comprehension subtest could have a standard score of 90 in 2021 and in 2022 the same test may have decreased to 80. The parent should ask the IEP team why did the score decline?

BEING PREPARED : DOCUMENTS TO REVIEW

Before an IEP meeting, a parent should prepare by reviewing the following documents (review at least three years' worth of documentation to see if there has been progress or regression based on grades, assessment scoring, teacher comments, standardized school testing, etc.). Most of the documentation that will be reviewed should be similar from year to year. Below is a list of the documentation that needs to be reviewed:

1. THE IEP

2. REPORT CARDS

For example, in the area of reading and language arts, see if the grades decreased or not. Please pay attention to teacher comments on the report cards.

3. STANDARDIZED STATEWIDE TESTING

4. TEACHER COMMENTS

In emails, student agenda book; Read the teacher comments and see if they are similar to past comments or have changed.

5. ASSESMENTS

Private and public. Comprised of many types of testing, such as: psychoeducational or occupational therapy, assistive technology, adapted physical education, speech and language, etc.

AT THE READY: It sounds like a lot of work to place and label essential documents in a binder to facilitate referring to them during an IEP meeting, but it is very important because the review in each area will give a parent a clear picture of the areas the child is struggling in.

Compare past years documents to current and see if the numbers decreased or increased with the scoring across the board.

It may be easier if all the above documents are placed in a binder and labeled accordingly, to facilitate referring to these documents during an IEP meeting. The above sounds like a lot of work, but this is very important, because the review in each area will give a parent a clear picture of the areas the child is struggling in. Each time you speak with a teacher about concerns you have for your child, write down the date, time, and a brief paragraph of the conversation. This should be done for students who are having significant challenges in the school environment. Sometimes the school says one thing about a student and the parent sees it differently. The parent may want to include a "note" tab in the binder to refer to. If it is not in writing, it never happened. By documenting phone conversations, the parent is memorializing that a conversation did take place.

EACH TIME YOU SPEAK WITH A TEACHER ABOUT CONCERNS YOU HAVE FOR YOUR CHILD, WRITE DOWN THE DATE, TIME, AND A BRIEF PARAGRAPH OF THE CONVERSATION.

The notes will also show historically, the area the child is struggling with. These are the areas the parent can, not only point out to the IEP team, but note why specific goals and objectives need to be created or have not been met. During the IEP, it is important for a parent to ask as many questions as possible, to better understand the school's test results in the reports. If the assessor provides an answer that is not clear to the parent, the parent should ask for further clarification.

During the IEP when the assessors are reading their report, it is imperative that the parent asks questions about any test they do not understand. Ask the assessor what the numbers mean, what areas were assessed, what the test measured, and how the tests were implemented. Assessments usually take place in a quiet room between the assessor and the student, making it very comfortable for the student. Due to the fact that the testing is implemented in a 1:1 ratio, it takes away the typical classroom environment, where the student is subjected to 25-35 peers. Although the assessor cannot administer a test in the classroom, it should be noted that the environment in which the test was administered is not typical, and therefore, the results may fluctuate.

The point I am trying to make is that in a quiet place the test results may be better than in a classroom with a lot of distractions. That has to be taken into consideration when the assessor states the student performed wonderfully on a particular test and that the student may not need a particular service. In actuality, the student may indeed need the service, because in a classroom, the student may not have the same success, as with 1:1 in a quiet room. But because the assessor made a positive statement on a test result that the student performed well, it may disqualify a student for a particular service.

The numbers on the psychoeducational or other type of standardized assessments are important. For example, when it comes to standard scoring the mean (which is average) is 100, and 15 points below 100 or above one hundred, is one standard deviation. One standard deviation is equivalent to one grade level above or below the mean. If a student receives a standard score of 80 in reading comprehension and that student has an IQ of 135, then the question would be "If my child's IQ is 135, why did he/she score 80, which is twenty points below the 100 (the mean)." This should be a red flag and may implicate that the student is having significant challenges in reading comprehension.

There are other types of scores in addition to standard scoring, such as scaled, percentage, grade equivalent, z-scores, t-scores, and stanine scores. During an IEP, the school may provide a diagram to the parent of a Bell Curve, which has all the types of scoring. I would suggest that the parents ask the psychologist what all the low scores mean in the testing. Low scores are red flags if the student has an IQ of 100 and above and the difference between the IQ and the academic test scores is 15 plus points than that would indicate a red flag and the parent should question the psychologist. For example, if a student has an IQ of 120 and a standardized test score in math is 80 then the schoolwork will also reflect the struggles in math. Subtracting the 120 from the 80 is 40. 40 divided by 15 is 2.6 standard deviation meaning the student is working two years below grade level. These numbers tell a story once the dots are connected.

LOW SCORES ARE RED FLAGS IF THE STUDENT HAS AN IQ OF 100 AND ABOVE AND THE DIFFERENCE BETWEEN THE IQ AND THE ACADEMIC TEST SCORES IS 15 PLUS POINTS.

Scores for students with cognitive disabilities such as IQ scores below 80 are treated differently. The score calculation noted above will not apply to these students. The tests the assessor administers on this target population will need to measure functional abilities versus learning disabilities.

The information provided in this article is based on my personal experience with the national special education system. I am not an attorney nor a psychologist, just a parent who has walked the walk, and now is sharing her firsthand experience in an effort to empower parents. •

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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CREATING RESILIENCE IN CHILDREN

BY ALI GRECO, PSYD

Trauma response is how we remember traumatic events. We remember in our bodies, in our minds, in our dreams, and our waking life. Our ability to process that experience is at the foundation of recovering. Relying on strong bonds with caretakers, using their strength and comfort, and finding ways to recall the story of the trauma in a way that creates meaning, can help children of every developmental stage recover and build resilience for the future.

My son was asked to write a short story about an impactful event in his life for a school project. He surprised me by writing about almost being hit by a car when he was 3, an event he had never referenced, and I had no idea had been so meaningful to him as he looked back on his life, so far. In his retelling, as we were getting him into the car for preschool, he decided to run away down the sidewalk. I ran after him yelling, to get him to stop, and inches from being hit by a car backing down their driveway, I scooped him up and saved him. He recalls my crying and how terrified I looked. He wasn't sure what had just happened, just that I was reacting really strongly. It was that reaction that left an impression, that stayed with him as he matured.

As a child with autism, my son wasn't speaking fully at 3 years old, when this event occurred. He was a lover of routine and rarely deviated from our schedule and pattern. So, the running down the sidewalk was a shock to us both. That shock was long lasting, even when it was no longer conscious. His story, full of drama, fear, and redemption, recalled for me how attachment style, developmental stage, and meaning, all contribute to resilience.

According to attachment theory (Bowlby; Ainsworth, and others), when caregivers are responsive and consistent, children feel secure, and can use that base of safety to explore the world. When that attachment is less secure, or not available, the lack of safety creates fear and conflict for the child, This can be seen in behaviors, from withdrawal to tantrums, to harm to others. In my son's 3-year-old mind, he could run down the sidewalk as a game, knowing that I would chase him. He could experience a moment of spontaneity, at an age where he was beginning to expand his understanding of the world beyond our house. When his game of chase turned into a near-tragedy, he took his cues from my reaction. He knew my loss of composure, my tearful explanation of what just happened, and to NEVER DO THAT AGAIN, were markedly different from his usual experience of me. His trust that I would chase him, was repurposed to his trust that I would keep him safe, and that I would be terrified if I could not.

The story he would later tell about that event, demonstrated

the meaning that he had made of that traumatic event. He cast me in the role of hero. The recognition that he had someone who would protect him, even from himself, was the way he turned what could have been a story about a mistake he made, or even a moment of defiance, into one of redemption and safety. While not fully conscious of having written this script, the event and its impression stayed with him as deeply rooted examples of how much he was loved.

This process of making meaning out of daily events, mundane and tragic, is how all of us write the narrative of our lives. How we tell stories, the way we retell and recall events and remember the past matters. As children develop, no matter their pace or eventual progress, we give them a solid foundation when we find ways to reinforce feelings of mastery, strength, and safety, in the framing of events. Telling my son, afterward while we ate ice cream, how I appreciated his bravery when getting his haircut, though he screamed and cried throughout, was not a way to minimize the disruption of his behavior, but instead, was a way to reinforce what to remember when telling the story, about what getting his haircut meant for him. A moment of bravery, rather than a moment of terror or failure. Story telling isn't inherently verbal here; picturing events, feeling the events in our bodies, connecting emotions to each other and to those of another loving person, are all part of the process of making meaning from our lived experience.

> **"As children develop, we give them a solid foundation when we find ways to reinforce feelings of mastery, strength, and safety,in the framing of events."**

Our job as parents is a big one, caring for the physical, emotional, and spiritual needs of our children, while helping them reach their potential in a world that is not set up for their success, and is often actively hostile. Resilience, that ability to bounce back, to recover and move forward, is made in small increments, inch by inch. By focusing on giving your child a sense of safety through consistency, boundaries, and responsiveness, and by using storytelling to reinforce that safety, you build up reserves of esteem that make recovering from the inevitable damage of living in our world, possible, and even likely.•

ABOUT THE AUTHOR:

Ali Greco, PsyD is a clinical psychologist and a leader in user experience design and research at SonderMind, a leading behavioral health provider. She is the parent of a special needs teenager who has taught her more about life than grad school ever could! Ali brings all her experiences together to solve problems in behavioral health to make getting the right care easier.

SUCCESS&HAPPINESS

BY TROY DOUCET

Every parent wants the best for their children. We want them to find happiness and success in their life. We want them to grow up to achieve great things and have valuable experiences.

All these things are possible for every child, including every autistic child. Disabilities aside, every child can grow up to find happiness and success in their life. It comes down to what we value and how we measure it.

If we think about happiness as living a meaningful life surrounded by those we love, then every child can find it, no matter their disability. A child does not need to be rich or famous to feel loved. A smile and kind words can provide all the happiness in the world.

Conversely, it is hard to find happiness if it is always out of reach. If we set the goalpost at one point and reach it, what do we tend to do? We move the goalpost a little further. We end up chasing happiness rather than living life as we find it. If we set the goal at perfect, we can't expect to obtain it.

As an autistic child (later diagnosed at 42), I found it frustrating when adults encouraged me me to act more neurotypical, versus accepting my neurodivergence. An example is suggestion after suggestion on how I could act differently to stop being bullied. While the adults meant well, the problem was with the bully, not with me. Growing up, I would have appreciated more support for my strengths, and fewer attempts to change weaknesses that were beyond my control.

FOSSIL FUEL: Learn about your autistic child's special interest. Ask questions and interact with them about the subject that they care most about. They will feel loved, value your interest, and bring you closer together.

A good starting point to helping any child find happiness and success is to accept their strengths and weaknesses as they are. We can still challenge our kids to be better people, but we can also focus our efforts on their strengths. Rather than setting goals against what might never be (or focusing/working on weaknesses), we can build them up through improving on existing strengths.

For a closer relationship, I recommend learning about your autistic child's special interest. It could be trucks, bugs, or dinosaurs. It doesn't matter what their interest is, it only matters that you have taken the time to learn about it. Ask questions and interact with them about the subject that they care most about. They will feel loved, value your interest, and bring you closer together. They will probably also pick up some valuable communication skills while they are at it.

Lastly, as you think about happiness and success for your loved one, remember to listen to their hopes and dreams. Work with their strengths to help them achieve what they want in life. This may not be a perfect, typical, or idealized version of that dream. But finding happiness is not about finding perfection. It is about pursuing a meaningful life with the people we love. •

ABOUT THE AUTHOR:

As an autistic person, Troy Doucet focuses on helping broaden society's understanding and acceptance of neurodiverse people. He talks about his experiences with autism to help normalize the inclusion of neurodiverse people in business and society. He is an attorney, lives in Ohio, and is married with three daughters. He can be reached at **troydoucet.com**

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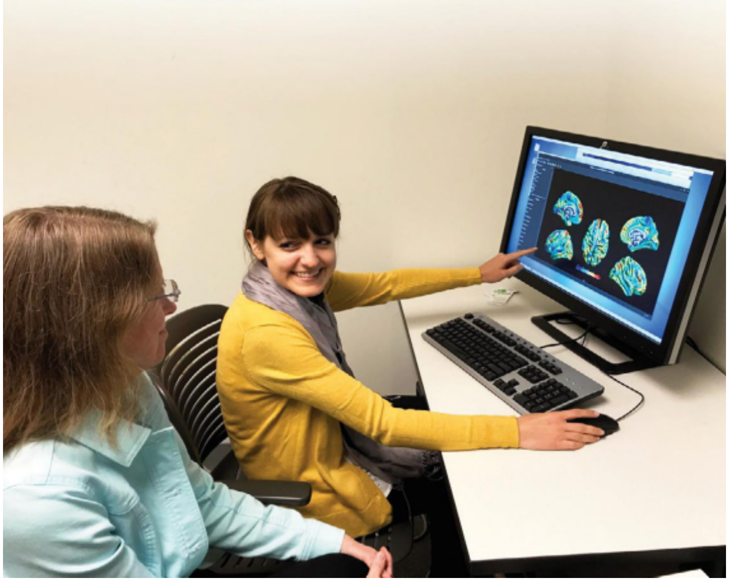

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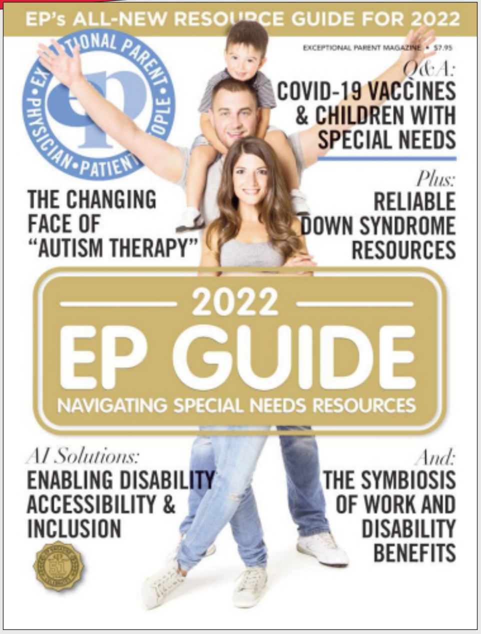

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FROM OUR FAMILIES... TO YOUR FAMILIES

MILITARY

CTION

U.S. MILITARY ★ BOOK EXCERPT PART II

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.*

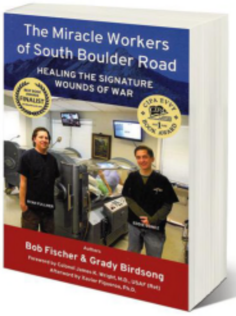
These Miracle Workers are healing lives with one of America's most successful integrated hyperbaric oxygen treatment and PTSD counseling programs. The following is the second chapter in a series of articles about this process.

CHAPTER 2

RYAN FULLMER

Upon entering the Rocky Mountain Hyperbaric Institute, it is easy to misjudge who is in charge, with the hustle and bustle of patients, technicians, and family members milling around. Yet, that first impression of this clinic also reveals the efficient and orderly management of two types of clientele, the civilian patients and the military veterans who seek treatment for their post-service injuries.

The first impression of Ryan Fullmer is that he is another patient in the clinic since his quiet, unassuming, low-key manner and attire mask his astute management style; that is until he spots a problem or senses he must intervene to keep the daily activity on schedule. Only then does it become apparent that he is the director of this unique business.



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

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

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

His position also becomes evident when he briefs a new patient or a confused veteran for the first time. He quietly explains the program and shows them what they can expect when entering the hyperbaric chamber in his sparkling clean chamber room.

You may also find him presenting his introductory video to a visitor or a family member interested in what the process offers. His clinic treats and heals the whole spectrum of these signature wounds, both physically and mentally.

Ryan is a master of his workplace. His knowledge of HBOT is almost dumbfounding since there is virtually no technical detail and no aspect that he cannot explain in clear and concise detail. It is then that others become enthused with his dedication and knowledge of hyperbaric therapy and its proven healing results.

When did this modest, unassuming individual become interested in such a different treatment program as hyperbaric therapy? Indeed, he did not learn about America's medical community, where hyperbaric oxygen treatment ranks low, including acupuncture, chiropractic, and other alternative medicine therapies.

CHAMBER MASTER: Ryan Fullmer, Director of the Rocky Mountain Hyperbaric Institute; His clinic treats and heals the whole spectrum of these signature wounds, both physically and mentally.

How did a seriously disabled young man survive his severe stroke and then take on a huge challenge that would result in helping so many other lives and their futures? Ryan's personal story is a remarkable one.

RYAN'S JOURNEY

Ryan, born in April 1975, is the third son of four boys to Jon and Pat Fullmer. At the time, the Fullmer's lived in Salt Lake City, Utah. His mother's family originated from this area. Ryan's mother was active in the church and cherished being close to her large family. Ryan remembers that Christmastime "was my best memory of living in Salt Lake, with tons of family and good times."

Ryan's father, Jon, was beckoned by his father to move to Gunnison, located in the mountains of central Colorado, to help with the family hardware store. Gunnison is well-known for its long winters, snow, and cold weather. "Much to my mother's chagrin, we packed up and moved to Gunnison, only to arrive during a blizzard with a lot of snow on the ground. We found eventual relief from that boredom and began sledding, skiing, snowmobiling, and doing all those fun snow activities."

How did a seriously disabled young man survive his severe stroke and then take on a huge challenge that would result in helping so many other lives and their futures?

Ryan had a typical childhood in Gunnison, where he participated in Cub Scouts, baseball, and piano lessons. Education was equally crucial because Ryan's mother was an English teacher, and his father was an accountant. Poor grades were not tolerated. Both parents were very involved in their sons' education, including attending church regularly. When the boys were not in school or working part-time at the hardware store, they were assigned various duties, like taking out the trash, chopping wood, or shoveling snow. "I went to school, then worked at the store evenings and weekends. Whenever I would beg for an allowance, my father would say, 'You don't need an allowance. You have a job.'"

"I was a typical young kid, in good health, with a normal routine growing up… nothing ordinary. Right after my eighth birthday, I attended a friend's birthday party. He'd invited some of our school buddies to help him celebrate. It is hard to remember everything that transpired at the party because this happened thirty years ago. I do remember the mountains of birthday cake, hotdogs, and presents. After the party, some of us hung out and played Donkey Kong on the Atari. Suddenly, I came down with a wickedly bad headache as I had never experienced before. I didn't want to

PHOTO COURTESY GRADY BIRDSONG

COLORADO KID: Ryan, brother Eric and Dad, Jon Sr., skiing (*Above, left*); Fullmer family of Gunnison, Colorado, 1988; *(upper left to right)* Robert, Jon Sr, Patricia, John Paul *(lower left to right)* Ryan and Eric.

quit, so I kept playing the game. The headache then started to become more intense. Was it something I ate? I wondered. 'Chris, help me get up,' I gasped out to my friend. The headache had become almost unbearable. Try as I might, I could not stand up. Why won't my arm work? I thought."

Ryan Fullmer's recollection over thirty years ago becomes real as he recalls his first "brain attack." The next few days were a blur, filled with the whirling activity of multiple doctor visits and excessive sleeping. Physically, Ryan struggled with the simplest movements as he tried to stand up, fell over, and tried to stand up again. "I was not able to walk. My left arm was unusable."

Healthcare in Gunnison, Colorado, in 1983, was adequate but had not seen specialization care yet. Although the ER doctor in Gunnison didn't know precisely what was causing Ryan's condition, he sent him home with instructions for his mother to "Give him aspirin, and he'll be fine." Ryan's mother was not satisfied with the doctor's inability to figure out what was wrong, so she took Ryan back to the emergency room after a few days. During this second visit, they diagnosed Ryan with brain cancer. "Not the kind of news a parent wants to hear about their young child," Ryan reminisces.

The hospital policy required that patients like Ryan be airlifted to a more specialized facility. That facility was in Grand Junction, Colorado, and a raging blizzard was in progress. Ryan was hastily taken by ambulance to Montrose, Colorado, just south of Grand Junction, and then airlifted to Saint Mary's in Grand Junction. During this time, Ryan lapsed in and out of consciousness. After a series of CAT scans, it was ultimately determined that little Ryan Fullmer had suffered a massive ischemic right hemisphere stroke. An ischemic stroke, or "brain attack," is caused by a blood clot that interrupts the blood flow to the brain. In Ryan's case, he had lost the whole left side of his body.

Those years were filled with tests, inpatient stays, physical therapy, and medical evaluation. "I became a guinea pig in a lab. I would hear, 'An eight-year-old shouldn't have a stroke.'"

The next few years were filled with tests, inpatient stays, physical therapy, and medical evaluation. "I became a guinea pig in a lab. Often I would hear, "An eight-year-old shouldn't have a stroke. That is an old-person injury.'" Ryan was destined for many challenges during his childhood. Slowly, Ryan began to walk again but had not regained the full use of his left arm by the time he was ten years old. "It was a tough time for me."

Ryan continued going to physical therapy. He recounts those days, "My parents kept pushing me to do physical therapy. But, of course, I still went to school every day. They never treated me like I was defective or different from the other kids. When

PHOTOS COURTESY PATRICIA FULLMER, RYAN'S MOTHER

BEFORE THE STORM: Ryan at age 7; He had a typical childhood , and participated in Cub Scouts, baseball, and piano lessons.

I graduated from high school, I decided to attend Dixie State University in St. George, Utah. During that time, I received a tendon transfer procedure on my left arm and, after recovering from the operation, my arm was somewhat useable for the first time in twelve years." It wasn't until later in life that events began to unfold in even more hopeful ways.

BREAKTHROUGH

"New Hope for Stroke Patients" was the newspaper headline. A friend had found the article in the Denver Post and alerted Ryan. Ryan immediately called about the seminar held in Denver; he was the third person to answer the call for stroke patients. His mother went with him to Denver to attend a workshop on hyperbaric oxygen therapy. Ryan found the seminar very exciting, and it filled him and his family with hope. "I was the second person to sign up for treatment. The positives were that it was safe, effective, and had no side effects, but the downer was that those forty treatments would cost $20,000. And on top of that, I had to do all of the treatments in forty consecutive days."

Within the first few treatments, Ryan's headaches faded, his stiffness relaxed, and he experienced a further improvement when his foggy brain activity disappeared.

Ryan, with new enthusiasm, found a place to stay and settled in for the treatment process. He showed up with headaches, depression, limited use of the left side of his body, and a foggy brain. The staff thought that his stroke, which had happened fourteen years prior, would not be helped. However, they were willing to give his case a try. Ryan had nothing to lose, and within the first few treatments, his headaches started to fade, the stiffness in his left side relaxed, and he immediately experienced a further improvement when his foggy brain activity disappeared.

This was a revelation to Ryan. "My left ankle had not moved in fourteen years, and within the first two sessions, my ankle started working little by little." He began to walk better and more steadily and felt that the physical therapy was worthwhile. After he was there for a while and began to feel good about the improvement he was experiencing, he recalls, "I started studying everything I could get my hands on in the clinic that pertained to hyperbaric oxygen. I spent all day at the clinic, helping out where I could. I would talk to patients, do laundry, clean the area, and read everything. I was a sponge, and the brain fog was gone for the first time in a long time, and I could retain what I was reading."

The clinic owners needed help since this was a startup operation, so they hired two women from Florida. One of the women was a certified hyperbaric technologist with a lot of experience, and the other was a registered nurse. They also happened to be mother and daughter. Ryan, as a patient, naturally gravitated toward them because they were eager to help and willing to teach him more about this new treatment. Most importantly, Ryan noticed that all of the patients going through the program were getting better. Then a true miracle happened for Ryan.

THE BEGINNING OF A MIRACLE

One of Ryan's most vivid memories at this clinic began when he met a patient who had been shaken violently as a baby and suffered a severe traumatic brain injury. That patient was in a wheelchair and was Ryan's age – 22 at the time. He could not walk, use his arms, stand on his feet, or feed himself with a knife or fork. He spoke in broken tone patterns that only his mother could understand. "It was tragic and heartbreaking for me to witness his condition and hear that the staff did not think this treatment would help him."

To everyone's amazement, this fellow started to improve. He started swallowing better, making eye contact and talking more clearly. He even began using his arms. Ryan reminisces, "Keep in mind that this was a person who doctors and neurologists had written off. Nobody knew what to do with this guy. In 22 years, he had never improved. I felt for him because nothing had worked for him until that point, like me. In time, he could feed himself and started to speak better. He began smiling. He even recognized me and spoke my name. I was there the day he took his first step… most of us had to compose ourselves. I was forever changed!"

PHOTO COURTESY PATRICIA FULLMER

All of the patients who had signed up for this program showed remarkable progress.

Ryan finished his 40 treatments and was feeling great. He headed home to Gunnison to go back to work. However, his homecoming became bittersweet and was much different than before. Even though he loved working at the hardware store and being around his family, his head was still back at the clinic in Denver. He wanted to do more treatments and work with the people he had met at the clinic. Counting nuts and bolts and stocking shelves seemed mundane after the discovery of, and his experience with, hyperbaric therapy. On blind faith, Ryan unceremoniously turned in his resignation to his father and returned to Denver.

When he showed up at the clinic, Ryan wasn't entirely disappointed that they weren't hiring. He agreed to exchange work for treatments. Cleaning, doing laundry, and running errands kept him in the game. He did not mind doing the menial chores because he had found his place in life. He was doing what he loved and was feeling better and better as time passed. Ryan remembers, "One day, a new patient was starting. He was an older brain-injured, retired Army Vietnam combat veteran. He was in bad shape and was scared about going in the "tube" [chamber]. After several failed attempts by the staff to get him in, I volunteered to work with him. Because I had spent so much time inside the chamber, I knew everything about it and how to run it. The staff and his family were amazed at how I put him at ease, explained what was going on and why, and then talked him through the whole treatment process."

Soon after, Ryan was hired as a chamber tender and spent his days running six chambers, sometimes by himself. The clinic was a bustling center and doing approximately thirty to thirty-five treatments a day. "No doubt I was tired, but it doesn't seem like work when you are doing something that you love."

A GAME CHANGER

In a short while, Ryan enrolled at the College of Oceaneering to take their diving and hyperbaric medicine course. This would require a year of study and a supervised internship of 500 hours. After completing all of these requirements, Ryan sat for the certified hyperbaric technologist (CHT) exam in Texas, passing it in October 2002.

After completing the CHT certification, the clinic where Ryan had been working closed its doors for financial reasons. With no other clinics hiring in the area, Ryan went back home to Gunnison and resumed his hardware store duties. Over the next few years, he began dabbling with several clinics in Santa Fe, New Mexico, and Salt Lake City. As Ryan recounts these experiences, "I didn't care for how these clinics were run, especially when it came to safety. Safety had been ingrained in me, and I would not compromise my safety practices, so it became difficult to find the right employment in this field that I loved so much." Ryan finally received certification as a safety director in hyperbaric therapy in 2004.

A SHORT STINT WITH HYPERBARIC THERAPY

One day, Ryan's phone began ringing off the hook. A wealthy Boulder, Colorado, home audio manufacturer

HOPE FOR HEALING: The second chamber in Charlie Hansen's manufacturing facility; Charlie offered Ryan to move to Boulder and treat Charlie once a day in the chamber. They would let him use the chamber the rest of the time for his patients in exchange.

PHOTO COURTESY GRADY BIRDSONG

named Charlie Hansen had been hit by a motorcycle while he was on a bicycle ride. As a result, his spine became severed, and he was expected to be a paraplegic. He certainly did not want to be disabled. Charlie began researching spinal injuries and discovered that hyperbaric oxygen could be advantageous in this acute stage. He purchased a chamber from Hyperbaric Clearing House that was being shipped to him directly and knew he would need a certified person to show him how it worked. In asking questions about operating the chamber, Hyperbaric Clearing House gave him Ryan's phone number.

Charlie hired Ryan to come to Boulder for a week and train him and his people on the chamber's operation. The relationship was certainly a good one. As Ryan remembers, "I treated Charlie for a week, wrote their policy and procedures, trained one of his manufacturing workers, and went home. Every day they called me with one concern or another. They were concerned about the oxygen being a fire hazard."

> This was one of the most challenging decisions he had to face up to this point in his life. "Even though I swore that I would never move to the city to run a clinic, I decided to do it against my family's wishes. I left so much in Gunnison... not all risk is financial."

The chamber became a bit temperamental. After weeks of constant phone calls, Charlie and his people realized they were in over their heads with the chamber and its operation. Finally, Charlie offered Ryan to move to Boulder and treat Charlie once a day in the chamber. They would let him use the chamber the rest of the time for his patients in exchange. Ryan reflects, "Wow, what an opportunity and a dream come true. But, hell no, I thought, I can't stand to live in big cities! Where will I live? What about my beloved dog, Puppy? I thought of a thousand excuses, including how can I quit my father again? I was sure he was getting tired of the hyperbaric scene by then."

AN OFFER NOT TO BE REFUSED

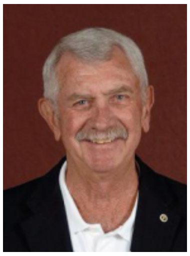
Ryan resisted for a short time in the name of personal inconvenience. Every one of his protests was met with, "We are not going to take no for an answer. Keep throwing up excuses!" Ryan then fired back with a serious concern. This had to be addressed if a hyperbaric clinic could become operational. "I need a medical director who can prescribe hyperbaric treatment," Charlie replied, "Oh, her name is Dr. Julie Stapleton, and she can't tell us no either!"

This was one of the most challenging decisions he had to face up to this point in his life. Ryan remembers, "Even though I swore that I would never move to the city to run a clinic, I decided to do it against my family's wishes. I left so much in Gunnison… you know… not all risk is financial."

Dr. Julie Stapleton reluctantly agreed to refer three of her brain-injured patients to Ryan and maintained that they had to show improvement after their hyperbaric treatment for her to stay involved. Charlie had set up this entire arrangement with Dr. Julie. That was in August 2007. It was agreed that if her patients progressed and showed evidence that they were healing, she would stay on with the program. Ryan now states, "Did it work? Did Dr. Julie stay on? She is still here and a pioneer in this hyperbaric treatment therapy!" •

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.

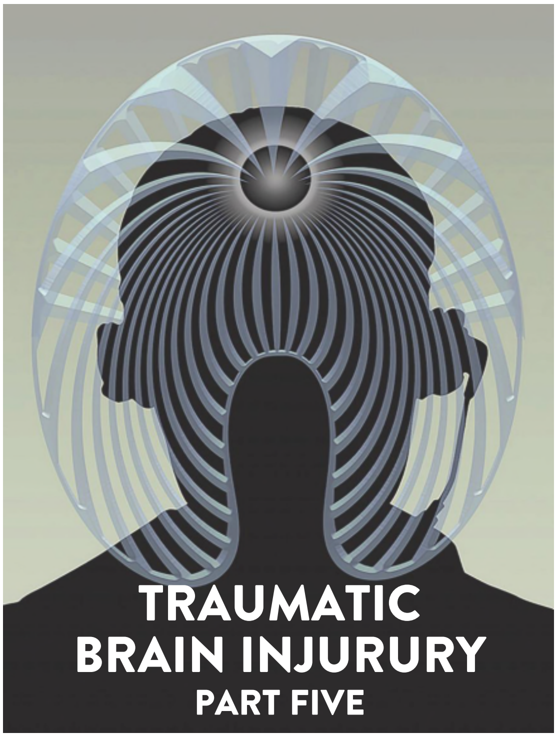
U.S. MILITARY ★ PTSD SERIES PART V

The Role of Hope and Spirituality on the Road to Recovery

BY RALPH DEPALO, PHD

Editors Note: EP continues its exploration of the effects of combat on servicemembers who have returned home and are attempting to cope with traumatic experiences while reintegrating into the daily life of family, community, and work. This series focuses on traumatic brain injury (TBI), post-traumatic stress disorder (PTSD), and related health issues. In this month's article, researcher Dr. Ralph DePalo explores the role that hope and spirituality can play in a servicemember's life by reviewing the literature which chronicles the findings of noted professionals working in the areas of hope and spirituality and the connection that these have to recovery. The article also examines hopelessness and its connection to depression. Understanding the psychological workings of the process of being hopeful or hopeless can help servicemembers cope with a newly acquired condition or disability. For family members, understanding hopefulness and hopelessness can shed light on what a loved one is going through so that more effective support can be offered.

Record numbers of returning military members are being diagnosed with post-traumatic stress disorder (PTSD). Lack of hope and feelings of despair are prevalent with this disorder. Finding hope in the midst of despair is a great challenge. A service member should seek professional help to navigate the internal feelings that he or she confronts on the road toward recovery.



Hope is endemic to human existence. Hope engenders the possibility that future good is possible. Although hope and its fruits are abstract, these abstrac tions become realities because of humanity's need for the vitality of life even in the face of trying circumstances.

Intangible possibilities often become the base of reality for those facing uncertain futures. It is hope and all it encompasses that a person clings to for stability. This makes it a real touchstone for existence. To hope is to acknowledge the future. This crucial connection between hope and life is captured poignantly in Biblical references like Proverbs 13:12: "Hope deferred makes the heart sick, but desire fulfilled is a tree of life." The metaphor of hope as the tree of life is one that is frequently used. Spirituality researcher, Dr. E.R. Mudd, wrote that "…without hope we can exist and plod away, but in a hollow and somewhat robot-like manner. We need hope to connect us to the tree of life." Hope is essential for more thanHope is essential for more than just physical and psychological wellbeing. J. Epperly affirms in his 1983 article on the spiritual needs of cancer patients that, "a sense of hope helps maintain the body's recuperative capabilities… The maintenance of hope at whatever stage is a spiritual need." Because of its intrinsic connection to the future, hope is clearly a component of spirituality.

Author and researcher J. Bruhn acknowledges the "therapeutic value" of hope and describes it as "a way of coping." When hope is gone, despair, its antithesis, remains. A chronic condition can easily lead one to embrace such despair. The reality of living with a newly acquired disability must be replaced by the reality of hope so that the servicemember challenged with a disability can attempt to set reasonable and attainable goals. In his article entitled "Guidelines for Spiritual Assessment," author R.L. Stoll makes an interesting point when he states that unrealistic goals such as "cure and freedom from pain, discomfort, and distress" will lead to nothing but "doubt and disillusionment." Therefore, Stoll notes that hope must be based in reality so that a person can work "through the hard, cold facts and adapt so that life can be meaningful now and in the future."

When one's hope is shattered, there are three major behavioral responses that have been identified by researcher E. Fromm. Those who exhibit the first response resign themselves to fate. They may have begun with average optimism, but when hope crashes, they lose their capacity to dream. A second group opts for isolation as a protection against the profound hurt of unfulfilled hope. Fromm also mentions that a third reaction comprises a leaning toward self-destruction since the energy once directed toward hopeful goals has no other positive channel. Again, according to Fromm, frustration stemming from an inability to achieve goals may result in one's directing destructive drives against oneself because that drive is no longer subverted by other goals.

Ironically, to have hope, one must first have a sense of its opposite – despair. In his article entitled, "An Invitation to Live," which appeared in the *American Journal of Nursing,* M. Vaillot points out, "…there is no hope, unless the temptation of despair is possible, and without hope, one is left with despair and hopelessness. The man who hopes uses trial, this tension which could reach the breaking point, in order to grow into being. For hope does not stop at things, it reaches out to being." The juxtaposition of hope and despair is the key to appreciating and fighting for one's existence. And hope itself is not one-dimensional. Hope must work in tandem with faith, again establishing that spiritual connection. As J. Hinton concludes: "an attitude of faith integrated into the ego coincides with successful defenses of effects."

Understanding the two-sided and seemingly contradictory view of hope as both concrete and abstract is essential to an appreciation of hope's value. K.J. Dufault notes that concrete hope consists of objects of hope that are within the person's realm of experience— things such as freedom from pain or other physical symptoms or the ability to perform certain tasks. The researcher also explores the transcendental nature of hope in the abstract, saying that abstract hope can be equated with transcendent hope. Transcendent hope is characterized by more esoteric and abstract goals while concrete hope tends to incorporate philosophical and theological meanings.

Hope is essential when a person combats the most primal fears of separation and abandonment, which can rise into a servicemember's mind during recovery. Hope is a connection to others even if bolstered vicariously. This communal instinct of hope, the symbiotic nature of its essence, is another facet worth exploring. In his book, *Images of Hope,* author W.F. Lynch says "…hope is an interior sense that there is help on the outside of us… The act of taking help is an inward act, an inward appropriation, which in no way depersonalizes the taker…" The author goes on to examine the symbiosis of hope and states, "…hope is not just about the future but a present reality as well. It is an experience of mutuality in the present. In this sense, we hope *with* as well as hope *for.*" It is the presence of this mutuality that is the secret of all our hopes, and it is the absence of this mutuality that makes a person hopeless and despondent. The experience of mutuality transforms our dread of abandonment and our terrors of isolation into communities of hope. Lynch goes on to say that "…the promise of a 'hallowed presence' is embodied hope that enables the seriously ill to live through the terrors of relationlessness." Lynch's concept again affirms and asserts hope's spiritual nature. In an article for the *Journal of Pastoral Care,* H. Anderson mentions, "…the kind of mutuality that generates hope includes but transcends hopelessness. It creates an environment in which we are held, in which our pain is held, in which the life long human need for attachment is maintained and nourished. The mutuality and sharing implicit in hope is captured by the language one uses when discussing it. Talking about the dynamics of hope, P. Pruyser says, "The language of hoping does not accentuate action verbs, but verbs of relationship. A hope is found, it is given, it is received… one hopes with, through, and sometimes for someone else. Hoping is basically shared experience… generated in relationship."

"Because of its intrinsic connection to the future, hope is clearly a component of spirituality."

P.G. Taylor and M.D. Gideon describe hope as "a true vital sign – its presence can be as essential as a heartbeat." But when its vital presence is inattentive and missing, hopelessness fills the gap. J. Bruhn's work, mentioned earlier, also offers that "Hopelessness is also a way of coping. Hope and hopelessness reflect one's estimate of probability of achieving certain goals. Such estimates depend on whether a person has achieved a similar goal in the past and how effective plans have been proven to be in achieving goals." F.T. Melges and J. Bowlby comment that "a hopeless person believes that plans of action are no longer effective in reaching long-term goals and may, as a consequence, feel helpless."

In cases of hopelessness, depression can be an insidious and immediate problem. Melges and Bowlby acknowledge that the hopelessness and despair of a severely depressed person is characterized distinctively by certain beliefs and behaviors. The depressed person can no longer perceive and differentiate an effective connection between a plan of action and the aim he or she has set. This, in turn, leads to a loss of self-confidence, which results in the person's depending more on others. Lastly, there develops a reluctance and hesitancy to set long-range goals since previous investment of time and energy has resulted in disappointment, failure, frustration, and defeat. Depression, according to Melges and Bowlby, is most acute when that connection between action and goals is truly separated, perhaps because of a wounded servicemember's new physical or cognitive challenges.

The importance of this connection and its impact on depression is reiterated by others as well, although the terminology of discussion may vary. Psychoanalyst E. Bilbring suggests that when the ego is shocked into the reality of its own helplessness in terms of personal aspirations, a person will lose the incentive and motivation to pursue goals when the results seem so futile. Again, once the connection between action and results is lost, depression follows. R.S. Lazarus uses the term "reinforcers" and states that depression is a function of insufficient reinforcers. D. Maddison and G.M. Duncan talk about the "frustration of personal striving" resulting from illness or disability that inhibits and suppresses the fulfillment of plans. Researcher Martin Seligman discusses the direct correlation between helplessness and depression as do A. Beck and A.H. Schmale, who define hopelessness as a core characteristic of depression. Seligman takes things one step further and identifies two types of helplessness. One is universal and precipitated by factors and elements within the environment and the other is personal and fueled by a catalyst for both "internal and external helplessness." Since the connection between helplessness, hopelessness, and depression has been clearly linked, it is reasonable to assume that a servicemember challenged with post-traumatic stress disorder could become profoundly depressed since the depth of depression leaves no room for spirituality, which is at the core of hope.

R.J. Lifton says that "…despair predisposes to depression, prevents or delays recovery from it, (and) leads to its recurrence. When severe depression combines with despair, suicide is likely to be a serious option. To commit suicide, a person has to feel that the future is devoid of hope." S.M. Jourard suggests that a person commits suicide because his or her perception has become so distorted and twisted as to feel that others want him to stop living. These extreme and distorted thoughts, once again, show the communal nature of hope. When the relationship to community of man, present and future, is lost, the notion of spirituality is also obliterated and annihilated. One can no longer look to others in an effort to gain assurance that some hope still exists. According to W.F. Lynch, "…hopelessness engenders isolation, shame, and withdrawal. Hopelessness is a silent admission of total defeat and a reluctant resignation to the status quo, to a life devoid of human love."

> **"Therefore, in other words, it may be that if a servicemember with a chronic disability has a why, then he/she can face the how of coping with that disability. Thus, the spiritual question regarding a chronic condition becomes its purpose, not its mechanism."**

Hope has its roots in spirituality. Spirituality is a phenomenon that is evident in the lives and traditions of all cultures and people. M. Burkhardt states that "spirituality is understood to involve a personal quest for meaning, to relate to the inner essence of a person, to include a sense of relationship with self, others, nature, and ultimate other, and to be the integrating factor of the human person." D. Ley and I. Corless mention that "the concept of spirituality transcends such separations and manifests itself as a state of "connectedness" to God, to one's neighbor, to one's inner self. It has variously been described as man's relation to the infinite, as the capacity to be energized from beyond ourselves, and as the basic quality of a person's nature—what the person is and what the person does. Inherent in all of these definitions is a sense of dynamism, of movement, or reaching out."

The literature is filled with references to the term *spiritual*. R. Dunphy discusses the term spiritual as "…the dimension of the human experience which transcends the immediate awareness of one's self. It is manifest in a variety of experiences: when someone questions the purpose of existence, when someone is filled with a sense of personal limitations and an awareness of the need to depend on a greater power, or when someone feels the joy of loving a friend unconditionally." S. Granstrom discusses the term spiritual as a broader concept than that usually referred to in the formal sense and, therefore, not necessarily having a religious, denominational connotation.

M. Hay suggests three categories that are universal to all spirituality, which accounts for the way in which spiritual development occurs in human experience. First, spirituality occurs in the context of communities of which one is a part. Secondly, spirituality results in an enhancement of one's inner resources for dealing with the challenges of life, including that of dying. And, finally, spirituality's objective is the giving of meaning to one's reality. This is to say that the scope of spiritual concerns encompasses matters of community, inner resources, and meaning.

Hay also discusses spirituality as an experience and capacity for "transcending one's working realities (physical, sensory, rational, and philosophical), in order to love and be loved within one's communities, to give meaning to existence, and to cope with the exigencies of life." Hay points out that when a person's capacity to transcend "working realities" is reduced through suffering, spiritual diagnoses may be made and treatment alternatives considered.

Spirituality has been described as a continual search through a relationship between an individual and God, to find the answer to the question of "what is the meaning of life?" This search may be directed through an adherence to an established religion, and acknowledgment of a higher being transcends one's physical being, or even through the principles of agnostics or atheists. The common denominator is the quest for meaning.

Victor Frankl, who lived through the Holocaust, has provided poignant arguments regarding the integrative resources of survivors in seeking meaning amidst the tragedy of the Holocaust. His existential philosophy seeks to find and realize values as a way of giving meaning to existence. He himself, a survivor of concentration camps, proved that even under extreme situations, human beings can make moral choices. He found in the camp a few prisoners who transcended their condition, and he used this as evidence for a positive and even optimistic philosophy. "We who lived in concentration camps can remember the men who walked through the huts comforting others, giving their last piece of bread. They may have been few in numbers, but they offer sufficient proof that everything can be taken from a man but one thing, the last of human freedoms, to choose one's attitude in any given set of circumstances, to choose one's own way." Frankl also quotes Nietzche in *Man's Search for Meaning*. "If we have a why we can endure any how." Therefore, in other words, it may be that if a servicemember with a chronic disability has a why, then he/she can face the how of coping with that disability. Thus, the spiritual question regarding a chronic condition becomes its purpose, not its mechanism.

J.H. van den Berg suggests that "the part of life that is now neglected is the life of the spirit." He hypothesizes that the helping relationship can be of greatest assistance to people by offering them an opportunity to discuss the more spiritual aspects of life. Within this helping relationship exists "an essential constituent" that Kohut describes as empathy. Kohut described empathy as "the capacity to think and feel oneself into the inner life of another person." Kohut also describes empathy as threefold: "The recognition of the self in the other is an indispensable tool of observation, without which vast areas of human life… remain unintelligible; the expansion of the self to include the other, constitutes a powerful psychological bond between individuals; the accepting, confirming, and understanding human echo evoked by the self, it is a psychological nutrient without which human life as we know it could not be sustained."

The importance of hope on the road to a servicemember's recovery cannot be underestimated. Spirituality is the seat of hope, giving one a sense of meaning in the face of adversity. With hope, future recovery becomes possible. •

ABOUT THE AUTHOR:

Dr. Ralph DePalo received his B.A. in Gerontology from Iona College. He went on to receive his Master's Degree from Fordham University and received a full scholarship from the National Institute of Mental Health in Gerontological Community Mental Health. He received his analytic post-graduate certificate in psychoanalytic training from The Alfred Adler Institute in New York City. He obtained his PhD in Clinical Social Work from New York University's Ehrenkranz School of Social Work. Dr. DePalo currently is an adjunct associate professor at New York University. He teaches advanced Clinical Practice with Individuals and Families in the Graduate School of Clinical Social Work and psychology in the undergraduate School of Continuing Professional Studies liberal arts program. His current research interests are post-traumatic stress disorder, spirituality, depression, and aging.

Choosing the Path to Grow

Was it a little stressful having Broden there at graduation, wondering if he was going to make it? Yes, it was, but we had to try. If we don't try, then how are we going to grow as a family?

Raising children challenges you in ways that one could never imagine, and when they have special needs, those challenges can push you into spaces that seem extremely uncomfortable. Sometimes as a parent, you feel so uncomfortable you might forget that there truly is a reason for everything. I've learned to remind myself that personal growth is like a muscle. When you work a muscle, there may be tiny tears in the fibers. One can feel soreness after working that muscle, but in order to build strength, pain is going to be felt. Personal growth can hurt just like a worked muscle, and it can be messy, but if we do not take chances and do not lean into the uncomfortable pain, how do we learn what our children are capable of achieving, if we shy away from that feeling of pain and discomfort? Over these past few weeks, I've experienced quite a bit of discomfort and I keep telling myself that it's necessary. I'm leaning into it hoping to later look back on these experiences to only realize it was for the better.

It started with my last parent meeting with Broden's BCBA (Board Certified Behavior Analyst), Jaime, "You told me that Hayden is graduating in a few weeks. Is Broden going?" I told her that my plan was to ask a neighbor to sit with Broden at the house because we had family coming to the event. There would be so much going on and frankly, the unpredictability of the length of the event, the formality, and amount of people who would be attending, would be too much for Broden. Jaime responded, "Do you think Hayden would want his brother there? This is an important milestone in his life. Broden is part of your family. Why don't I come to graduation and I'll help Broden through the event so everyone can be a part of it?" My gut reaction was, "Uh… no thank you. If you add any more stress to the fact that Hayden is leaving me to head to college, I will have a nervous breakdown."

POMP AND CIRCUMSTANCE: At my last parent meeting with Broden's BCBA Jaime, she asked "Do you think Hayden would want his brother there? This is an important milestone in his life. Broden is part of your family."

After that initial thought came to my mind, I paused and looked at Jaime. I trust her. She's part of my trusted village. I could tell she was trying to lead me down a path of growth, because she knows me so well. Obviously, I would choose the path of least resistance, but is it the path towards personal growth not just for me, but for Broden? I grudgingly agreed to her request. As I left her office she said, "Make sure Broden is dressed comfortably. If you have ever attended a graduation in the south, you'll under-

PHOTO COURTESY SHELLY HUHTANEN

stand why I am giving you this advice.”

Jaime is wise. My family arrived to Hayden’s school that morning for graduation. It was hotter than Hades. The humidity was so thick, it could be cut with a knife. I was grateful for taking Jaime’s advice. I had Broden wear a short sleeve collard shirt. We slowly walked through the parking lot towards a large crowd that was slowly building for the event. We walked onto the football field lined with rows of chairs, “Where is the most strategic place to sit? Do we sit to the far left or far right if we need to make a run for it?” I started to panic as I wondered if Jaime had arrived. How are we going to find her through this crowd? About five seconds later, I looked up and I saw Jaime calmly walking towards me with a big smile on her face. Broden saw her and started to walk towards her. Our party of eight found a place to sit off to the left side, near a path where Broden could walk if he needed a break.

> “As Hayden came over with diploma in hand, I said, ‘Take a picture with Broden before he goes to the car with Jaime.’ Hayden smiled and looked surprised that Broden had made it through the graduation, ‘Come here buddy.’ Hayden put his arm around Broden and they took a picture together.”

Right before the event started, the sun started to beat down on us and Broden was visibly uncomfortable. I screamed inside, “This isn’t going to work. Hayden hasn’t even arrived on the field to be seated!”

My Aunt Ellen looked over to the right and saw a group of chairs under a tent. I had previously assumed it was for VIPs or for special guests. Aunt Ellen asked, “Why don’t we sit over there?” I kept thinking, “Are we even allowed to be over there?” My mom walked over and asked someone under the tent if we could sit there out of the sun. To my surprise, she waved us over. After a sigh of relief, our entourage took up two rows under the tent and the temperature dropped about 10 degrees. Broden started to calm down and sway his body back and forth as the violins played. As the processional music started, we all leaned over to see if we could get a glimpse of Hayden. I was so proud. My son made it. He did the work and it finalized the fact that he was moving on. He chose a path of growth. He’ll be attending college in another state away from us. Seeing him in his graduation cap and gown, walking towards us on the field, made it seem more real to me.

Graduation seemed to drone on before experiencing the 10 seconds that our family had been waiting for, to see Hayden walk across the stage to receive his diploma. At one point during a speech, Broden leaned back and yawned while projecting a loud sigh of boredom. My eyes widened as I sunk into my chair with embarrassment. Jaime leaned over to me, “Broden is doing what everyone wishes they could do right now. Everyone came to see their kiddo walk across the stage!” Towards the end, it was evident that Broden had sat long enough, so Jaime took him for a little walk until the end. As Hayden came over to us with his diploma in hand, I said, “Hayden take a picture with Broden before he goes to the car with Jaime.” Hayden smiled and looked surprised that Broden had made it through the graduation, “Come here buddy.” Hayden put his arm around Broden and they took a picture together.

Jaime was right. Was it a little stressful having Broden there at graduation, wondering if he was going to make it? Yes, it was, but we had to try. If we don’t try, then how are we going to grow as a family? It helps to have a small trusted village to know when it’s time to push a little bit further, to feel some discomfort and see how far we can go. I’ll treasure that picture at graduation with both of my boys together, a picture that would not have been taken if it wasn’t for Jaime’s nudge and support. Growth can hurt, but it’s worth it to try. •

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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