**PLUS: UNITED STATES MILITARY SECTION**

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## PHYSICAL FITNESS TRAINING for SPECIAL NEEDS

**PLUS:**

## CAN PETS IMPROVE BRAIN HEALTH?

**EP'S ANNUAL MOBILITY ISSUE:**

# WHEELZ!

## AARON FOTHERINGHAM: THERE ARE NO LIMITATIONS

**AND:**

## END OF THE SCHOOL YEAR TIPS for TEACHERS and PARENTS

EP MAGAZINE
1971 2022
51
YEARS
CELEBRATES

Extreme
WCMX Athlete
Aaron Fotheringham

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## FEATURES

### ON OUR COVER

Aaron "Wheelz" Fotheringham recently thrilled a huge national audience showcasing his amazing skills on NBC's *America's Got Talent: Extreme.* The five-time Guinness World Record holder shares his inspirational story with EP's readers in our Annual Mobility Issue. Helpful articles on physical fitness, pet ownership and accessible home design round out this month's mobility coverage, along with important pieces on speech therapy, parent-teacher relations, and financial planning. *Coverage begins on page 18.*

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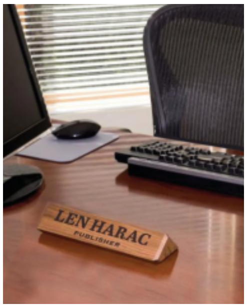
# Getting There

## According to the NIH, about 10% of noninstitutionalized U.S. residents, representing an estimated 19 million people, reported at least some mobility difficulty.



Getting from point A to point B is something that most of us do every day and pretty much take for granted. But there is a large segment of our society, of all ages, that encounter great difficulty with mobility. Whether it be maneuvering from bedroom to bathroom to wash and dress, or traveling across the country, the disabled community continues to face significant obstacles in getting from place to place.

According to the National Institutes of Health, about 10.1% of noninstitutionalized U.S. residents, representing an estimated 19 million people, reported at least some mobility difficulty, with 3.1% (estimated 5.82 million) noting major problems (**www.ncbi.nlm.nih.gov/pmc/articles/PMC1495195**). Mobility issues make it harder for people with disabilities to go out and visit with friends and family and continue doing their activities independently. Adults who lose their mobility are less likely to remain living at home; have higher rates of disease, disability, hospitalization, and death, and have poorer quality of life.

> "The disabled community continues to face significant obstacles in getting from place to place."

In our Annual May Mobility Issue, EP examines this important topic using a multi-pronged approach. In an informative article that illustrates his chosen methods teaching physical fitness, the CEO and Founder of Special Strong Daniel Stein explains that exercise improves his clients' physical, mental and overall well-being as well as helping to maintain an optimal level of mobility. Henry Mahncke, PhD examines the relationship between pet ownership, physical activity, and brain health, while architect Ramesh Gulatee outlines best practices for designing accessible homes or additions.

Last but not least, our Editor In Chief, Faye Simon, interviews one of the very best wheelchair athletes in the world, Aaron "Wheels" Fotheringham. Born with Spina Bifida, Wheelz was an originator of the sport of Wheelchair Motocross and has set five Guinness World Records in his amazing career. When asked if he has any advice for people with mobility challenges, Wheelz has these wise words: "There are obviously things a disability stops you from being able to do, like, I can't walk, but life did give me a different set of wheels."

With more and more interest in our magazine, our newsletters, and our social media feeds, we have been hard at work developing new ways to introduce advertisers and corporate clients to our motivated audience. To learn about these effective new formats, 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

## BIDEN CANCELS $7B IN FEDERAL LOANS FOR DISABLED STUDENTS THROUGH DATA-SHARING PROGRAM

The Biden administration recently announced that it has cancelled $7 billion in federal student loan debt for about 350,000 borrowers with disabilities through a data-sharing initiative between the Social Security Administration and the U.S. Department of Education. If you plan to apply for forgiveness under the plan, you'll need to follow certain steps to see if you qualify.

**PAYING IT FORWARD:** The administration's updated policies will restore the promise to provide debt relief to teachers, nurses, firefighters, and others serving their communities.

The first thing you need to know is that there are three ways to qualify for a total and permanent disability discharge. These involve veterans, those who meet Social Security disability criteria and those with a doctor's certification. Here's a quick rundown:

- ***Veterans:*** *You might qualify for forgiveness if you have a service-connected disability that is 100% disabling or an individual unemployability rating qualifies you as disabled.*
- ***Social Security Disability:*** *You might qualify if you receive benefits from Social Security Disability Insurance or Supplemental Security Income.*
- ***Doctor's certification:*** *You might qualify if you have certification from a medical doctor that you're unable to take part in any "substantial gainful activity" because of a medically determinable physical or mental impairment that can be expected to result in death, has lasted for a continuous period of not less than 60 months or can be expected to last for a continuous period of not less than 60 months.*

To apply for student loan forgiveness, you'll need to submit a Total and Permanent Disability Discharge application on the Federal Student Aid website (www.disabilitydischarge.com) and provide supporting documentation of your total and permanent disability. The exceptions are if the Education Department contacts you directly based on information received from the SSA or U.S. Department of Veterans Affairs. In this case, you don't have to provide supporting documents.

In response to the COVID-19 pandemic, most federal student loans and their interest rates have been paused since March 2020. This moratorium was recently extended until September 1. Once payments resume, you won't have to pay federal student loans while your application for student loan forgiveness is reviewed.

If you don't qualify for student loan forgiveness due to your disability, you might still qualify for forgiveness in other ways.

For example, the Education Department announced changes that will result in immediate debt cancellation for at least 40,000 federal student loan borrowers and move an additional 3.6 million borrowers closer to some form of loan forgiveness. This forgiveness plan mainly involves borrowers who qualify for Public Service Loan Forgiveness (www.studentaid.gov/manage-loans/forgiveness-cancellation/public-service) or Income-Driven Repayment plans (www.studentaid.gov/manage-loans/repayment/plans/income-driven).

### AUTOMATIC CANCELLATION FOR THOSE WHO RECEIVE SS DISABILITY BENEFITS

Last year, the Biden administration announced a new initiative to streamline student loan relief for certain disabled borrowers. By allowing the Social Security Administration to share data with the Education Department about borrowers who were receiving Social Security Disability benefits, the administration could identify borrowers who would qualify for the TPD discharge program, and then cancel their student loans automatically.

The administration announced that through this data sharing initiative, the Education Department has cancelled approximately $7 billion in federal student loan debt for 350,000 borrowers.

"Working together with @SocialSecurity, Federal Student Aid has provided much-needed relief for 350,000 borrowers with approximately $7 billion in student loans," said Richard Cordray, Chief Operating Officer of Federal Student Aid, in a tweet. The Department anticipates that another 15,000 to 20,000 borrowers may receive TPD discharges every quarter going forward via the same data sharing program.

# WHAT'S HAPPENING

## DELAYS FOR AUTISM DIAGNOSIS AND TREATMENT GREW EVEN LONGER DURING THE PANDEMIC

BY ANDY MILLER AND JENNY GOLD

Wylie James Prescott, 3, had to wait more than a year after his autism diagnosis to begin behavioral therapy, even though research shows early treatment of autism can be crucial for children's long-term development.

His mother, Brandie Kurtz, said his therapy wasn't approved through Georgia's Medicaid program until recently, despite her continued requests. "I know insurance, so it's even more frustrating," said Kurtz, who works in a doctor's office near her home in rural Wrens, Georgia.

Those frustrations are all too familiar to parents who have a child with autism, a complex lifelong disorder. And the pandemic has exacerbated the already difficult process of getting services.

This comes as public awareness of autism and research on it have grown and insurance coverage for treatment is more widespread. In February, Texas became the last state to cover a widely used autism therapy through Medicaid. And all states now have laws requiring private health plans to cover the therapy, applied behavior analysis.

**THE HARDEST PART:** Brandie Kurtz of Wrens, Georgia, said her son Wylie James Prescott had to wait more than a year after his autism diagnosis to begin behavioral therapy, even though research shows early treatment of autism can be crucial for children's long-term development.

Yet children from Georgia to California often wait months — and in many cases more than a year – to get a diagnosis and then receive specialized treatment services. Therapies that can cost $40,000 or more a year are especially out of reach for families who don't have insurance or have high-deductible health plans. Children from minority communities and those who live in rural areas may face additional barriers to getting help.

"You would never allow a kid with cancer to experience these waits," said Dr. Kristin Sohl, a pediatrician at University of Missouri Health Care and chair of the American Academy of Pediatrics' Council on Children With Disabilities Autism Subcommittee.

During the early months of the covid-19 pandemic, many families canceled in-home services, fearing infection. Virtual therapy often didn't seem to work, especially for nonverbal and younger children. With fewer clients, some providers laid off staff or shut down entirely.

And treatment services always face high turnover rates among the low-wage workers who do direct, in-home care for autism. But covid made the staffing problem worse. Companies now struggle to compete with rising wages in other sectors.

The Centers for Disease Control and Prevention estimates that autism affects 1 in 44 U.S. children, a higher prevalence rate than ever before. Autism symptoms can include communication difficulties and repetitive behaviors and can be accompanied by a range of developmental and psychiatric health conditions.

Early diagnosis of autism can make a difference, Sohl said. Symptoms of some kids who begin their therapy by age 2 or 3 can be greatly reduced.

Diagnoses are typically done by developmental-behavioral pediatricians, psychologists, psychiatrists, and neurologists, all of whom are in short supply. The shortage of developmental pediatricians is especially acute. Even though they do three more years of fellowship training than a general pediatrician does, developmental pediatricians typically earn less.

General pediatricians with training can also do assessments, but insurers often require a specialist's diagnosis before paying for services, creating a bottleneck for families.

"If we solely rely on specialists, we're setting ourselves up for failure because there aren't enough of us. We need the insurance companies on board," said Dr. Sharief Taraman, a pediatric neurologist and president of the Orange County, California, chapter of the American Academy of Pediatrics.

Even in a metro area, getting a child an appointment can take months. "We cannot get these families in fast enough," said Dr. Alan Weintraub, a developmental pediatrician in suburban Atlanta. "It's heartbreaking."

Some parents pay cash for an evaluation with a private specialist, worsening disparities between kids whose parents can afford to skip the wait and those whose parents cannot.

Once a child has been diagnosed, many face an equal – or longer – wait to get autism therapies, including applied behavior analysis, a process that aims to improve social, communication, and learning skills. These sessions can take more than 20 hours a week and last more than a year. ABA techniques have some critics, but the

PHOTO COURTESY BRANDIE KURTZ/KHN

American Academy of Pediatrics says that most evidence-based autism treatment models are based on ABA principles.

Accessing such treatment largely depends on insurance coverage – and for many families how well Medicaid pays. The Georgia Medicaid program reimburses well for ABA, Georgia doctors said, while Missouri's pay is low, leading to a scarcity of options there, Sohl said.

In California, Medicaid reimbursement rates vary by county, and wait times for ABA range from about three to 12 months. In the rural northern reaches of the state, where few providers work, some families wait years.

> ***Diagnoses are typically done by developmental-behavioral pediatricians, psychologists, psychiatrists, and neurologists, all of whom are in short supply. The shortage of developmental pediatricians is especially acute.***

During the first year of the pandemic, Claire Hise of Orange County was thrilled with the ABA therapist who worked with her son. But in January 2021, the therapist quit to go back to school. The company she was working with sent others. Hise had to train each new therapist to work with her son, a difficult process that always took more than a month. "It's a special relationship, and each kid with autism is an individual," Hise said. "It takes time."

By then, they were out the door, replaced by another after no more than four to six weeks. Sometimes the family waited weeks for a replacement. Hise tried switching to another company, but they all had a six-month waitlist. "He's already so far behind," Hise said. "It's really a year I feel we've lost."

The average age of diagnosis in the U.S. is about 4 years old, but Black and Latino children on average are evaluated later than white kids. "The impact on families having to wait for diagnosis or treatment can be devastating," said Kristin Jacobson, founder of the Autism Deserves Equal Coverage Foundation, an advocacy group in California. "They know in their gut something is seriously not right and that there is help out there, and yet they are helpless to do anything about it."

Araceli Barrientos helps run an autism support group in Atlanta for immigrant families, for whom language barriers can cause additional snags. It took her over a year to get her daughter, Lesly, diagnosed and two more years to secure further treatment.

Dr. Michelle Zeanah, a behavioral pediatrician, draws families from 60 mostly rural counties to her clinic in Statesboro, Georgia. "There's a massive shortage of people willing and able to do an autism diagnosis," she said.

Getting insurance to pay for autism treatment can be another frustrating process for families. Therapy denials can be triggered by clerical errors or missed paperwork. Insurer approvals can be especially difficult for older children, who can be less likely to get treatment services than younger ones, said Dr. Donna Londino, a child and adolescent psychiatrist at Augusta University in Georgia.

Many children with autism also need speech, occupational, and physical therapy, all of which are generally easier to secure than behavioral therapy. But even then, Weintraub said, the insurers push back: "They really dictate how many services you can have. These families, literally, meet obstacles at every turn."

David Allen, a spokesperson for AHIP, an insurance industry trade group formerly known as America's Health Insurance Plans, said insurers often require prior authorization to ensure that autism services are "medically necessary and evidence-based" and that patients are treated by "providers with appropriate education and training in treating autism."

Tracy-Ann Samuels of New York said she paid out-of-pocket for speech and occupational therapy for her son, Trey, now 15. Two years ago, after 18 months on a waiting list, he finally got ABA services covered by insurance.

"He's doing so great," she said. "My son was nonverbal. Now he's talking my ear off."

### ABOUT THE AUTHORS:

Andy Miller, interim Southern Bureau Editor, has been a health care journalist for 29 years. Miller graduated from Duke in 1973 and received a master's in education from Duke in 1979. He was a social studies teacher and basketball coach before switching careers to journalism. He entered the master's in journalism program at University of North Carolina in 1984. He was hired by the Atlanta Journal-Constitution, where he had editing and reporting positions before switching to health care in 1992. He covered that beat until 2009, when he retired. He launched Georgia Health News in 2010, where he continued as editor and CEO until Georgia Health News joined KHN.

Jenny Gold, Senior Correspondent, covers the health care industry, the Affordable Care Act, and health care disparities for radio and print. Her stories have aired on NPR and been published by USA Today, The Washington Post, and many other news organizations. She was previously a Kroc Fellow at NPR, where she covered health and business, and a broadcast associate at the CBS Evening News. She is a graduate of Brown University.

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# WHAT'S HAPPENING

## ACADEMY AWARD WINS FOR 'CODA' BRING ELATION, SPARK AWARENESS FOR DEAF COMMUNITY

CODA lands three Academy Awards from the Academy of Motion Picture Arts and Sciences, with wins for Best Picture, Best Supporting Actor for Troy Kotsur, and Best Adapted Screenplay for Siân Heder. The winners were revealed at the 94th Annual Academy Awards ceremony in Los Angeles on March 27th.

*CODA* was named Best Picture, star Troy Kotsur took home Best Supporting Actor, and writer-director Siân Heder accepted Best Adapted Screenplay as history was made at the 94th Academy Awards in late March. *CODA* is the first motion picture starring a predominantly deaf cast to win an Oscar, Troy Kotsur is the first deaf male actor to receive an Oscar and *CODA* is the first film released by a streaming service to win an Academy Award.

*CODA* premiered at Sundance Film Festival last year, where Apple bought the distribution rights and went on to make the film publicly available on their own streaming service in August. The film tells the coming-of-age story of Ruby Rossi as the only hearing member of a deaf family living in Massachusetts. "CODA" stands for "child of deaf adult(s)."

**NOW HEAR THIS:** Troy Kotsur is the second deaf actor to win an Oscar for playing a deaf character. Previously, Marlee Matlin won for her leading role in *Children Of A Lesser God*.

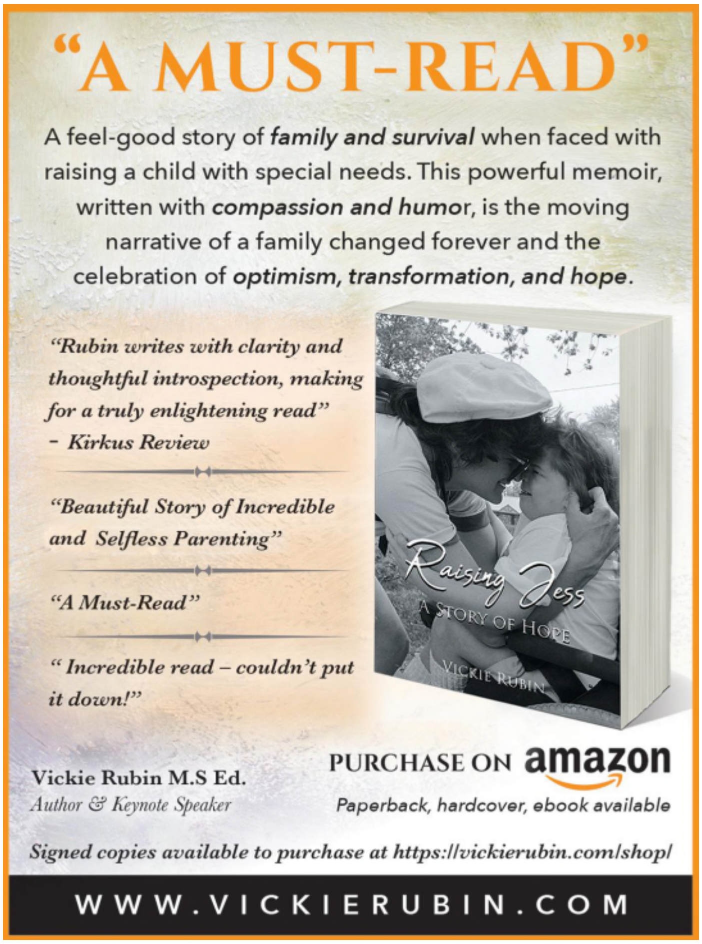
*CODA*'s Academy Awards success punctuates an incredibly successful awards season and, while *CODA* is clearly critically acclaimed, the film has also been highly regarded by the deaf community for its unprecedented and refreshingly authentic representation. The representation of deaf people, and disabled people more generally, has been problematic in film and television over the years, relying on cliched performances by non-disabled actors, or overly broad or inaccurate depictions.

"People think that deaf people are monolithic in terms of how they approach life. And this film bursts that myth," says Marlee Matlin, the first deaf star to be cast in the film. Matlin made her feelings on representation clear from the beginning: she insisted on working with deaf actors, or she wouldn't participate.

In his acceptance speech for Best Supporting Actor, Troy Kotsur also recognized the importance of representation in *CODA*. Thanking the most formative institutions in his career, Kotsur is amazed at the film's reach. "It's amazing that our film has reached out world-wide… [and] I want to thank all of the wonderful deaf theater stages, where I was allowed and given the opportunity to develop my craft as an actor," Kotsur said. He brought home a BAFTA Award, SAG Award, Film Independent Spirit Award, and Critic's Choice Award in the Supporting Actor category in addition to the Academy Award.

Kotsur thanked writer-director Siân Heder for her role in creating an authentic connection between the deaf and hearing worlds. "[Siân Heder] brought the deaf world and the hearing world together… and [her] name will forever be on that bridge," said Kotsur.

In Heder's acceptance speech for Best Adapted Screenplay, she thanked her collaborators in the deaf and CODA communities for being her teachers in bringing this film to life. "Writing and making this movie was truly life changing, as an artist and as a human being," professed Heder. She admits it wasn't an easy process, simultaneously thanking Sundance and Apple for their part in bringing the independent film to a global audience.



# WHAT'S HAPPENING

## ELECTRIC BIKE TECHNOLOGIES IS DONATING POPULAR LIBERTY TRIKE TO CHILDREN WITH LIMITED MOBILITY

Electric Bike Technologies, Inc. (EBT), the maker of the Liberty Trike, a unique folding and active-mobility tricycle, announced today that it will be donating 20 Liberty Trikes to children with limited mobility due to Spinal muscular atrophy (SMA), Duchenne muscular dystrophy (DMD), and other physical challenges.

SMA and DMD are both genetic diseases that attack the muscles. SMA starts in the central nervous system and affects all the muscles in the body. Due to the degenerative nature of the disease, babies, kids and adults with SMA will experience a decline in muscle strength over time although the rate and severity can vary among individuals. DMD is characterized by the progressive loss of muscle. It is a multi-systemic condition, affecting many parts of the body, which results in deterioration of the skeletal, heart, and lung muscles.

EBT's decision to donate the trikes started in 2019 when Kimberly Heinrich, the mother of Allison - a little girl battling SMA – emailed the company for advice on any electric trike that might help Allison get some much-needed physical therapy and keep up with her siblings on family bike rides. “When she's on the trike, she’s just a different kid. She’s not the kid on a mobility scooter or wheelchair. She feels like everyone else,” said Kim.

> *“We arrive, and she walks 30 feet and has to sit down,” recalled Allison’s mother Kim. “But then Allison got on the trike. Within seconds, she was like a different kid. She’s just insanely happy, happier than I’ve seen her before, and she becomes this instant rock star on the bike.”*

To date, EBT has directly donated 34 Liberty Trikes and through generous outside contributions, an additional 32 Liberty Trikes were given to kids. This has resulted in a combined total value of $103,716.

The Liberty Trike is designed for anyone that wants to get around actively or effortlessly on three wheels. The compact design makes it portable for taking on trips and easy to navigate in confined spaces. The electrical system and powerful hub motor enable the Liberty Trike to travel over most terrains and up reasonable inclines with ease.

“As a father of three young children myself, this was an easy decision. Liberty Trike was originally designed with senior riders in mind, but once we saw how Liberty could benefit these kids and their families, we had to make this happen. We look forward to doing even more for years to come,” said Jason Kraft, CEO at Electric Bike Technologies.

**READY TO RIDE:** Allison Heinrich with her Liberty Trike; Children born with SMA face a lifetime of challenges, even with early treatment. Mobility products like electric tricycles can boost physical activity and lift spirits.

Electric Bike Technologies is committed to donating 20 Liberty Trikes this year. Kimberly Heinrich, as Charitable Coordinator with EBT, will help in that effort. She will be working diligently to review applications and find the most suitable families for these Liberty Trikes.

*To learn more about the initiative, visit Liberty Trikes For Kids at* **www.libertytrike.com/pages/donate-liberty-trike-for-kids**
*To apply for a Liberty Trike (and watch Kim's interview), visit Kids Charitable Application at* **www.libertytrike.com/pages/liberty-trike-application**
*Visit Electric Bike Technologies at* **https://electricbiketechnologies.com** *Visit Liberty Trike at* **www.libertytrike.com**

### ABOUT ELECTRIC BIKE TECHNOLOGIES

Liberty Trike is part of Electric Bike Technologies, Inc., a company that specializes in developing, manufacturing and distributing affordable high-quality electric bicycle drive systems, motors, batteries, components, and accessories. Contact Robert Irving at 215-514-6215 or **robert@electricbiketech.com**

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# WHAT'S HAPPENING

## FOR MOTHER OF CHILD WITH SPECIAL NEEDS, CAROLINE'S CART MAKES GROCERY SHOPPING EASIER

Caroline's Cart provides parents and caregivers a viable option to transport a child through a store while grocery shopping, without having to maneuver a wheelchair and a traditional grocery cart at the same time.

**SWEET CAROLINE:** Caroline's Cart is also fit for adults with disabilities and is now offered at Target, Publix and Kroger stores across the nation.

Caroline's Cart is a shopping cart created for special needs children. It is named after Caroline, the special needs daughter of Drew Ann and David Long. Drew Ann Long saw the need for Caroline's Cart after realizing her daughter would outgrow a typical shopping cart. Knowing what was needed, she founded Parent Solution Group, LLC, designed the cart, applied for a patent, and enlisted the services of legal and business professionals to help her bring the cart to market.

Her mission was to make Caroline's Cart available to retailers everywhere, providing a quality product for special needs children that further enables their participation in mainstream society with their family through the common activity of grocery shopping. There was only one place that shared her dream and had the technical know-how to make a cart worthy of her daughter's name. That company was Wanzl North America, headquartered in Newton, NC, North America's largest shopping cart manufacturer.

Caroline's Cart has now become a reality. Retailers such as supermarkets, hypermarkets, shopping centers, and malls offering Caroline's Carts will provide a valuable service to the families of over 1 million severely disabled children in the US. These customers will find shopping to be easier, and the goodwill they feel toward their store will translate into customer loyalty.

Drew Ann's hope is that one day all retailers will provide an equal opportunity shopping experience for parents and caregivers of special needs children by furnishing them the option of a Caroline's Cart. All families deserve to have this option, so they can enjoy the freedom of shopping with their special needs child.

*Find an award-winning Carolines Cart in a store near you by visiting* **https://technibilt.com/carolines-cart/find-a-store**

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## NRPA FAMILY HEALTH & FITNESS DAY IS JUNE 11, 2022

Family Health & Fitness Day will be held on June 11, 2022. Celebrated the second Saturday in June each year, this special day promotes the importance of parks and recreation in keeping communities healthy and active.

Park and recreation agencies everywhere are encouraged to participate by sharing ways families can get active on June 11 – whether through participating in virtual programs at home or in their local parks. Members of the healthcare and public health communities are encouraged to participate, as well, even as sponsors.

Various research studies have confirmed that community parks and recreation, green spaces and time outdoors are critical for creating healthy, active and sustainable communities. As we have witnessed throughout the coronavirus (COVID-19) pandemic, parks and recreation has played a critical role in supporting our mental and physical well-being, and Family Health & Fitness Day is a great opportunity to celebrate this.

Park and recreation departments nationwide offer year-round opportunities for families and individuals to stay active and healthy. In fact, living close to parks and other recreation facilities is consistently related to higher physical activity levels for both adults and youth.

Many communities host special events on this day, while others simply encourage their residents to visit a local park or recreation center where they can participate in a variety of family friendly activities, such as walking, hiking, biking, kayaking, golfing, swimming, tennis and more.

*Check your local park and recreation website for June 11 events or visit* **www.nrpa.org** •

### ABOUT THE NATIONAL RECREATION AND PARK ASSOCIATION

NRPA NATIONAL RECREATION AND PARK ASSOCIATION

The National Recreation and Park Association (NRPA) is the leading not-for-profit organization dedicated to building strong, vibrant and resilient communities through the power of parks and recreation. With more than 60,000 members, NRPA advances this mission by investing in and championing the work of park and recreation professionals and advocates – the catalysts for positive change in service of equity, climatereadiness, and overall health and well-being. For more information, visit **www.nrpa.org**

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# WHAT'S NEW ON THE MOVE

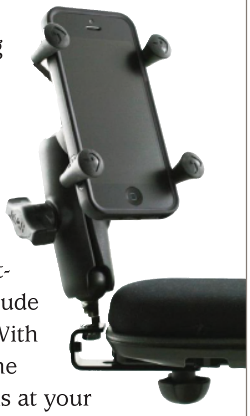
## YBIKE PEWI

The YBIKE Pewi Walking Buddy Ride-On is super fun and designed to help children develop motor skills, balance, coordination, and space awareness. For riding, pushing, sitting, and supported walking, this versatile design accommodates your child's developmental stages. The YBIKE Pewi provides support for your child to build strength and confidence to start walking on their own. The Award-winning design features a lightweight durable aluminum frame, molded plastic seat with soft foam pad, easy grip handle, leg clearance for free movement and multi directional 360 non-marking caster wheels. It provides lasting fun and functionality. Suggested age 9 to 36 months.

**LEARNING TREE TOYS**
www.learningtreetoys.com

## RAM X-GRIP PHONE HOLDER

The RAM X-Grip Phone Holder provides a secure mount for a wide variety of smartphones. The popular spring-loaded phone holder features an 'X' design that expands and contracts to provide a perfect fit for your device – even if it's in a case. Universal fitment for all wheelchairs with tracks on seat and/or armrest. Easy swivel and quick release capabilities without changing ball and socket positioning and can be reconfigured to accommodate a variety of mounting positions. The base also features an adjustable knob that lets you swivel the mount in and out of position with ease. The compact design of the RAM universal wheelchair mounting system stays within the chair's armrest width, offering peace of mind when navigating through tight spaces and doorways. All RAM mounting compontents include a lifetime warranty. With the RAM X-Grip Phone Holder, connectivity is at your fingertips. Suggested Age: 5 +.



**RAM MOUNTS**
www.rammount.com

## SENSORY BUCKLE PILLOW

Build fine-motor skills and coordination with the Sensory Buckle Pillow. This sturdy pillow is highly portable and a great sensory toy for car rides and road trips. It features zippers, lacing loops, and six different real-life clasps to practice. It's great for building fine motor and dressing skills. One side features colorful zippers, while the other features a shoelace and numbered lacing loops over soft fleece. The edges of the pillow are lined with clasps and straps – kids will love practicing buttoning, using velcro, attaching a carabiner, and buckling the plastic clasps. Suggested Age: 3+.

**NATIONAL AUTISM RESOURCES**
www.nationalautismresources.com

## PLAYABLE ART BALL

The incredible Playable Art Ball is a mesmerizing sensory item that twists and moves to create a wide variety of designs and shapes, some of which appear to defy gravity. This item features twenty brightly colored 1.5" birch wood balls that are interconnected. This is a fun, quiet activity that can be taken anywhere. The larger size of the balls make them easy to manipulate, while challenging the brain and aiding in hand dexterity. Suggested Age: 3+.

**AUTISM COMMUNITY STORE**
www.autismcommunitystore.com

# HOPE · STRENGTH · LOVE
# LIFE WITH SPINA BIFIDA

*Spina Bifida is the most common, permanently disabling birth defect compatible with life in the United States. Typically occurring in the first month of pregnancy, Spina Bifida happens when the spine, or neural tube, does not completely close. When the neural tube doesn't close, the backbone protecting the spinal cord doesn't form as it should. This often results in damage to the spinal cord and nerves.*

## NO ONE KNOWS FOR SURE WHAT CAUSES SPINA BIFIDA

While there is no single known cause, scientists and doctors believe Spina Bifida (SB) occurs from a complex mix of genetic and environmental factors present very early in the pregnancy, by the fourth week. A Spina Bifida diagnosis might cause a parent to ask, "how did this happen?" What's important for parents to know is that neural tube defects like Spina Bifida are not entirely understood, no one knows for certain what causes them, and Spina Bifida is not caused by a parent's actions.

## EVERY PERSON IS UNIQUE INCLUDING THOSE WITH SPINA BIFIDA

Every day there are approximately eight babies born in the US with SB or a like birth defect. Approximately 166,000 individuals in the United States have Spina Bifida. Every single person with SB is affected differently, and it is impossible to predict a child's outcome before or at birth. Outcomes have improved over the last 50 years due to medical advancements. In addition, cultural attitudes toward individuals with disabilities continue to grow and progress. The result has been greater awareness, increasing support and improving services. Many with SB attain advanced education and have careers and families of their own. They become doctors, teachers, artists, athletes, and parents. While some individuals with SB have significant disabilities, others are less affected. However, Spina Bifida is only one part of their lives and does not define them. With appropriate supports in place – medical, emotional, educational – children born with Spina Bifida do reach their full potential.

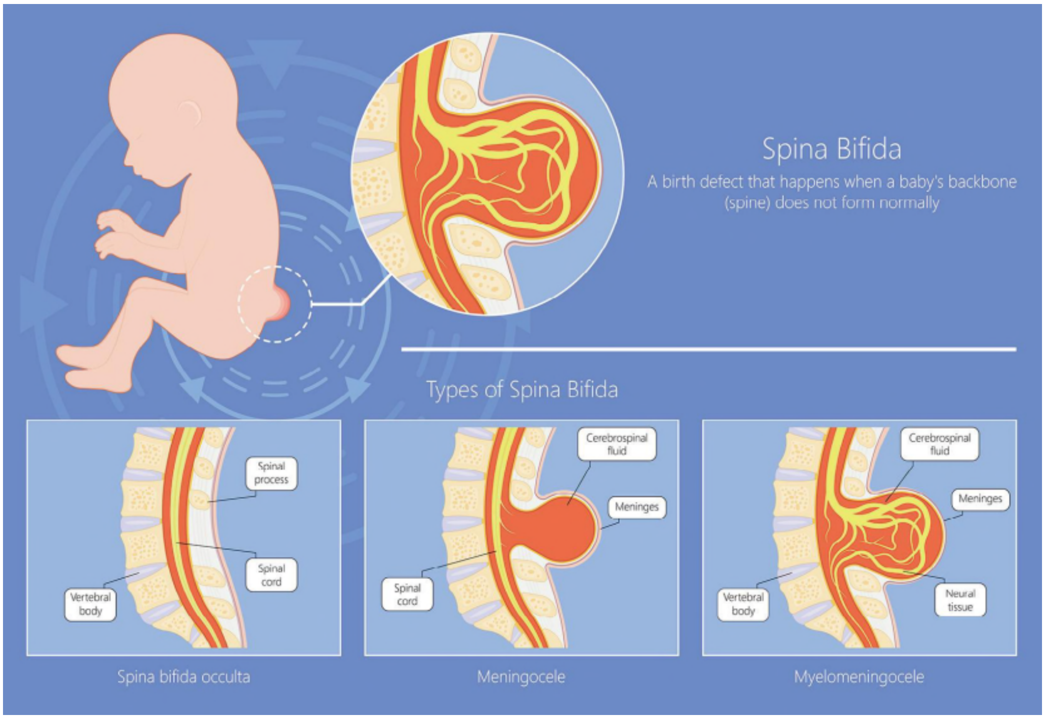
## A SPINA BIFIDA DIAGNOSIS

When parents find out they are going to have a child with Spina Bifida, it is very important for parents to take an active role in managing their child's care. Parents need to know about Spina Bifida and understand the health issues and treatment options to make the best possible choices for the health and happiness of their child.

AN EP SPECIAL SECTION
SPINA BIFIDA

**THE ROAD AHEAD:** Meeting the complex needs of a person affected by Spina Bifida can be challenging at times. Finding resources,and planning for the future can help.

- *Parents should talk with health care providers and expect to maintain a life-long dialogue. It is recommended that as soon as you receive a SB diagnosis, you meet with a pediatric neurosurgeon at a Spina Bifida Clinic (***www.spinabifidaassociation.org/clinics***) as soon as possible. You will also want to meet with a maternal-fetal specialist or perinatologist to closely follow your pregnancy.*
- *Parents can learn about Spina Bifida by reading CDC's Facts (***www.cdc.gov/ncbddd/spinabifida/facts.html***) and Spina Bifida Health Issues and Treatments (***www.cdc.gov/ncbddd/spinabifida/treatment.html***) pages.*
- *Parents can connect to a community of those living with Spina Bifida. The Spina Bifida Association (SBA) provides information on Spina Bifida and can be helpful in recommending clinics and health care providers who are experts in the care of children and adults with Spina Bifida.*



**EARLY DAYS:** No two babies with spina bifida are exactly alike. Health issues will be different for each baby. Some babies have issues that are more severe than other babies. With the right care, babies born with spina bifida will grow up to reach their full potential.

## POST-NATAL CARE

Babies with Spina Bifida should be delivered at a medical center that specializes in SB so they may receive the care that will help ensure the best possible outcome. Babies requiring surgery will be monitored in a neonatal intensive care unit. The average length of stay is 2 weeks, but this varies based on need. When the baby is discharged from the hospital, he or she will have periodic follow-up appointments with a pediatric neurosurgeon, orthopedist, urologist, and possibly other specialists. Appointments will be frequent in the first year, and usually less often as time passes.

## HOW IS SPINA BIFIDA MANAGED?

As type and level of severity differ among people with Spina Bifida, each person with the condition faces different challenges and may require different treatments. The best way to manage Spina Bifida is with a team approach. Members of the team may include family members, neurosurgeons, urologists, nurses, orthopedists, physical and occupational therapists, orthotists, psychologists, and medical social workers.

## SPINA BIFIDA AND ADOLESCENCE

Many physical, mental, emotional, and social changes are associated with the adolescent and teen years. Teens and adolescents develop their own personalities and interests and want to become more independent.

This transition period can be challenging, especially for people affected by Spina Bifida. It is important for the parents and caregivers of adolescents and teens with Spina Bifida to take active steps toward making them independent starting in childhood, so that by the time they are older they can develop the necessary skills to help them reach their full potential.

**Physical Health:** As people with Spina Bifida mature, they will perform more and more activities themselves. Most teens will dress and bathe themselves, manage their bathroom plans, and move about independently in their homes and communities. They might begin to make their own doctor appointments and continue to participate in updating their own Individualized Education Plan (IEP) or 504 Plan, if they have one. They also should participate in a seating or wheelchair evaluation at least once each year if they use a wheelchair. This evaluation will make sure the wheelchair fits correctly and makes moving as easy as possible.

**Mobility and Physical Activity:** People with Spina Bifida higher on the spine (near the head) might have paralyzed legs and use wheelchairs. Those with Spina Bifida lower on the spine (near the hips) might have more use of their legs and use crutches, braces, or walkers, or they might be able to walk without these devices.

A physical therapist can work with adolescents and teens to teach them how to exercise their legs to increase strength, flexibility, and movement.

Regular physical activity is important for all teens and adolescents, but especially for those with conditions that affect movement, such as Spina Bifida. CDC recommends 60 minutes of physical activity a day. There are many ways for teens and adolescents with Spina Bifida to be active. For example, they can:

- *Engage in physical activities with friends.*
- *Roll or walk in the neighborhood.*
- *Lift weights.*
- *Participate in sports activities (for example, swimming) and on teams for people with and those without disabilities.*
- *Attend summer camps and recreational facilities that are accessible for those with disabilities.*

See the resources below to learn more about Spina Bifida and its treatment.

*EP Magazine thanks the Spina Bifida Association and the CDC for providing the above information.*

### NO BACKING DOWN : MORE ABOUT SPINA BIFIDA

**SPINA BIFIDA ASSOCIATION**
www.spinabifidaassociation.org

**CDC: SPINA BIFIDA**
www.cdc.gov/ncbddd/spinabifida

IMAGE COURTESY CDC.GOV

ORGANIZATION SPOTLIGHT

**FACING THE CHALLENGES:** The Spina Bifida Association advocates for programs, agencies and policies that help advance research, improve access to specialized, quality care of people with Spina Bifida and raise awareness about the birth defect.

# THE SPINA BIFIDA ASSOCIATION

*The mission of the Spina Bifida Association (SBA) is to build a better and brighter future for all those impacted by Spina Bifida. Fueled by dedicated health care providers, parents, adults, caregivers, and others, SBA is committed to helping people live longer, healthier lives through research, education and support, clinical care, network building and advocacy.*

Through the Spina Bifida Collaborative Care Network, SBA spearheads efforts to improve clinical care. Efforts include ensuring SB guidelines are understood and implemented; using data from the National Spina Bifida Patient Registry (NSBPR) to understand differences in patient outcomes; improving the transition from pediatric to adult care; advancing access to adult care; and networking with other organizations to build on shared education and advocacy priorities.

Living with Spina Bifida has its challenges and SBA is ready with information, education, resources and – importantly – the support of an understanding and caring community. One such resource is SBA's National Resource Center. Offering help in English and Spanish, the National Resource can identify local support, agencies, and services; the closest SBA Chapter; information about learning and health challenges in the school environment; facilitate complex health-related questions to specialists in Spina Bifida care; and much more.

Whether you have Spina Bifida; recently learned that you are expecting a child with Spina Bifida; are a loved one or caregiver; or provide health care or community services to people with Spina Bifida, SBA is ready to help. SBA is dedicated to serving and supporting every person impacted by Spina Bifida. For more information about the Spina Bifida Association, visit their website at **www.spinabifidaassociation.org** •

## ABOUT THE SPINA BIFIDA ASSOCIATION

SPINA BIFIDA ASSOCIATION

The Spina Bifida Association has devoted itself to responding to the needs of those whose lives have been touched by Spina Bifida. SBA has done so by its persistent advocacy efforts; in-depth research and review of current scientific and medical investigations; creating regular opportunities for members of the community to learn from and interact with each other; and supplying health care providers with best-practices that will help them care for people with Spina Bifida throughout their lives. Learn more at **www.spinabifidaassociation.org**

> “These BMX riders would push themselves and pull off these huge tricks. For me, seeing that at a young age helped push me and let me know there really are no limitations.”

# THERE ARE NO LIMITATIONS

## My Interview with Aaron “Wheelz” Fotheringham

BY FAYE SIMON, EDITOR IN CHIEF

PHOTOS PROVIDED BY AARON FOTHERINGHAM

**Aaron "Wheelz" Fotheringham is an athlete from Las Vegas, Nevada who invented wheelchair motocross. Wheelchair motocross, or WCMX, is a sport in which wheelchair athletes perform tricks adapted from skateboarding.**

**Aaron was born with Spina Bifida, a birth defect of the spinal cord, which resulted in him having no use of his legs. He is the third of six children, all adopted. Aaron never lets anything stop him through the power of manifesting his incredible spirit. Even as a baby and small child, he did anything anyone else his age could do; he just had to figure out how to make it work for him.**

**Aaron rolled over, sat up, and even crawled (on hands and belly, no leg action) pretty much on schedule. Within days of receiving his first walker, he was off and running. Next came crutches, which he mastered quickly. He would put on a Superman cape and blast down the hall on crutches believing, as any other 4-year-old, that he could fly.**

**RAREFIED AIR:** Aaron has become one of the best wheelchair motocross athletes in the world, perfecting his form and his tricks. From carving and grinding to hand-planting and power-sliding, there's nothing the fearless Wheelz won't try. His attitude has propelled him to an international career as an premier extreme-sports stunt rider.

Aaron started riding at skateparks at the age of 8 when his older brother Brian, a BMXer, said he should drop in. He had been going to the park with Brian and their dad for weeks, but Aaron would just watch from behind the fence. The first time was scary, and he fell hard, but he was never one to give up just because it wasn't easy. So, he tried again and from then on, he was hooked.

**"There is always some kind of blessing you can look on and you can notice from each situation."**

At the beginning of his career, Aaron entered and won a few BMX Freestyle competitions, including the legendary 2005 Vegas AmJam BMX Finals, but for Aaron that was always secondary to the joy of riding and hanging out with friends at all the skateparks in Las Vegas.

Over the years, Aaron has challenged himself to pioneer even more difficult stunts. In 2005, he perfected a mid-air 180-degree turn. Then on July 13th, 2006, he landed the first wheelchair backflip. Four years later, on August 26, 2010 at a camp in Woodward, PA, he landed the first ever double backflip. Since then, he has gone on to perform live on tour with the Nitro Circus. As if this is not enough, on February 9th, 2011, he landed his very first front flip in New Zealand, and on August 25, 2012, he shocked Brazilians by jumping and successfully landing a 50-ft gap off of the Mega Ramp in his chair. He is a four-time winner of the WCMX World Championships and has recently executed the first wheelchair flair/backflip 180.

After posting that first ever backflip on the internet, life has changed for Aaron; he has had the opportunity to travel globally, both performing and speaking. He has attended summer camps for disabled children as a coach/mentor. He has been featured in magazines, newspapers, and sports television. He receives and responds to e-mails from all over the world.

Aaron enjoys showing young kids with disabilities that a wheelchair can be a tool, not a restriction. He loves helping younger children learn how to handle their chairs in new and different ways and teaching them a trick or two. Someday he hopes to design and build the most wicked chair in the world.

Aaron has a passion for what he does. Not only is it a lot of fun, but he wants to change the world's perception of people in wheelchairs and to help everyone see their own challenges in a new way. Aaron's appeal is universal. You certainly do not have to be handicapped to be inspired by what he is able to do.

Since we got the information from his website (www.aaronfotheringham.com) that Wheelz has given us permission to print, he has competed in *America's Got Talent: Extreme,* coming in second place in the AGT: Extreme Grand-Final. He has been in Guiness Book of World Records five times, including for the longest wheelchair ramp jump.

**DRIVEN:** "Some tricks I have spent up to ten years working on before I was able to land it. You first start dreaming about it and then you try it and try it and you keep failing. I just think that means that the ones that take forever to land are just that much better."

## WHEELZ: THE INTERVIEW

I saw Wheelz on *America's Got Talent: Extreme* and knew his story would be a wonderful addition to the May issue. I am thrilled to have had the opportunity, via zoom, to interview Wheelz who was personable, positive, open, humble, very inspiring, and had a good sense of humor,

**Faye Simon:** How did you get the name "Wheelz"?

**Aaron Fotheringham:** Friends in middle school called me Wheelies. Then they started calling me Wheels. It stuck but I added the Z.

**FS:** Do you prefer to be called Aaron or Wheelz?

**AF:** Wheelz for the most part – only my Mom calls me Aaron.

**FS:** What does your wife call you?

**AF:** She calls me "Babe" or "Honey."

**FS:** Who are the people in your life that have given you the most inspiration and support throughout your journey?

**AF:** I got a lot of inspiration from watching BMX riders and action sports in general. There was something about seeing pro BMX riders and pro skateboarders do these tricks that one would think would be impossible, but somehow, they would end up pulling them off. Some would get hurt, but they would push themselves and pull off these huge tricks. For me seeing that at a young age helped push me and let me know there really are no limitations.

And to marry my wife… super supportive and loving. She coaches me and pushes me to be my better self.

**FS:** What gave you the idea and courage to do these amazing tricks even though you were in a wheel chair?

**AF:** I didn't think "even though I am in a wheel chair." It was "I have this wheelchair." It wasn't like a ball and chain. It was an advantage almost. I saw it as I can go fast everywhere. Like going through an airport, no one is faster than me.

**FS:** Throughout your journey, what was your family's reaction? Were they supportive, terrified?

**AF:** My family is awesome. Early on they knew they needed to let me do what I loved to do. They did whatever they could to support me in that. For a while, it was pretty expensive to buy me wheel chair parts, and they still did that and everything they could to support me in the skatepark scene. A huge blessing.

**FS:** What kind of training do you do to keep your upper body in shape and to deal with this kind of punishment?

> **"Having a wheelchair was an advantage. Like going through an airport, no one is faster than me."**

**AF:** When I am back home, I go to the gym every day and go to the skatepark. When I ride the tall Nitro Circus ramp it has got stairs all up the side. So, when I am there, I carry myself up one stair at a time. It's quite a workout. But it is like I am working out and having fun. I sit on one stair and do like shrugs all the way up.

**FS:** What is the design process and who do you work with to design and build your performance wheelchairs?

From the time I was nine until right before Covid, I had a good friend of mine build my chairs. He is basically like a father, mentor to me. I met him when I was nine. His name is Mike, who owns a company called Box Wheelchairs. He has been teaching me all along how to build wheelchairs and metal fabrication that goes into it. So, for two or three years I have been building my own chairs. I am super grateful to him for teaching me everything. I am thinking of possibly having my own wheelchair business.

**FS:** Do you have any motorized wheelchairs?

**AF:** Not at this moment but I have looked into it, because speed is always good.

**FS:** Tell us about your journey to and on *America's Got Talent*, whatever highlights you would like to share.

**AF:** When it first happened that I would be able to have the big ramp on AGT, and have that opportunity, it was like “No way, this is awesome!” I worked with Nitro Circus (they are the only people that have the big ramp) and AGT to get that ramp there. It was up to me to make sure I pull off my tricks and land them.

Being able to do my audition in front of the judges, crashing my first one and being able to get up and landing the second try…. It was, I would have to say, the most stressful moment of my life. Just because, I was like, NOOOO, I have to land this trick. I was glad I was able to get back up and do it again. And even to be able to make it to the finals, it is more than I could have ever dreamed.

**FS:** When you are up on that extremely high, high ramp, are you terrified, excited? I was terrified watching from the safety of my living room!

**“There are obviously things a disability stops you from being able to do, like, I can’t walk, but life did give me a different set of wheels.”**

**AF:** Definitely excited, mostly terrified. No matter how comfortable you get, you get up there and think, “Man this is serious”.

**FS:** How long train do you train for each trick?

**AF:** Every trick is a different investment. Some come pretty easily, like you land it in a day. Those are beautiful, but rare. Some tricks I have spent up to ten years working on before I was able to land it. You first start dreaming about it and then you try it and try it and you keep failing. It feels like it’s this far away dream and then years later, you’re in the right situation, you tried it enough. Some are quicker than others, but I just think that means that the ones that take forever to land are just that much better.

**FS:** After *America's Got Talent*, what did you do?

**AF:** I was on a Nitro Circus tour in Australia. Got to do eight shows in a month. It was about two a week and it was a lot of fun. I love riding the big ramp and am excited anytime I get the opportunity.

**FS:** What’s next for you?

**AF:** A couple things. As far as the riding, there’s more tricks I am working on. There are always more tricks. I am working on getting the back flip 360 landed again, and getting more comfortable on that ramp. While I am home, I am actually working on building wheelchairs and making a better skatepark chair and another chair for the mega ramp.

I have built chairs for friends and for my wife, and I sold a chair. I am trying to decide exactly what I want to do. I got into it because I break a lot of stuff. I am not sure that is what I want to do full time. I still want to do the riding and jumping. It is something I am exploring.

**FS:** How do you feel about people asking if you need help?

**AF:** I would prefer they don’t, unless it is something they would ask anyone not in a wheelchair, like if I was trying to carry a heavy TV. They should just watch and let it be my responsibility to ask for help, if it is a regular activity. I have my way of doing things, even if it looks difficult or awkward.

**ROLLING WITH IT:** “Early on, my family knew they needed to let me do what I loved to do. They did whatever they could to support me in that. For a while, it was pretty expensive to buy me wheel chair parts, and they still did that and everything they could to support me in the skatepark scene. A huge blessing.”

**FS:** Do you have words of advice for people who are mobility challenged?

**AF:** I think a lot of the time people who are facing a mobility problem, such as myself, it is easy to see where you want to be and see the barriers that you feel are stopping you from getting there. It is not that there is not pains and hardship, it is not pretending they aren’t there, because it is true, but there is always some kind of blessing you can look on and you can notice from each situation. I think it may suck that I can’t walk, but I have a wheelchair.

I think sometimes looking at the whole picture and trying to figure out every little detail is kind of discouraging. I honestly think keeping a positive mind and just doing what you love is important. There are obviously things a disability stops you from being able to do, like, I can’t walk, but life did give me a different set of wheels. Sometimes it’s not how we first visualized it, but I think we can have a good quality of life regardless of our situation.

We are not encouraging our readers to go out and try the amazing and dangerous stunts that Wheelz performs. But we hope that we all can learn from his positive attitude, determination, not letting fear rule him, and his ability to get up and try again when something does not go as planned.•

*To learn more about Wheelz, visit his website at* **www.aaronfotheringham.com** *or his youtube channel at* **www.youtube.com/user/AaronFotheringham**

# LJS Fac/X

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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.

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

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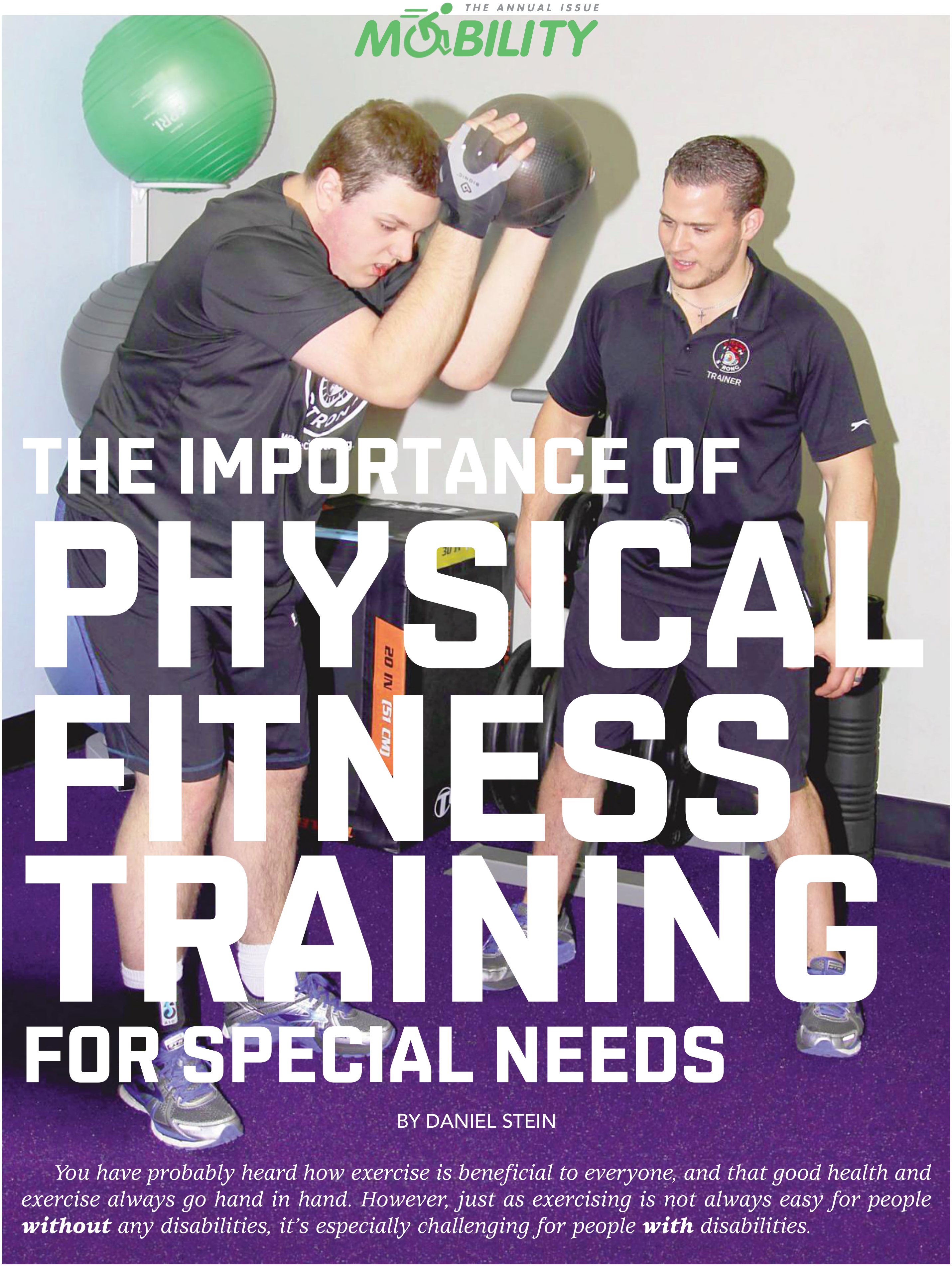

# THE IMPORTANCE OF PHYSICAL FITNESS TRAINING FOR SPECIAL NEEDS

BY DANIEL STEIN

*You have probably heard how exercise is beneficial to everyone, and that good health and exercise always go hand in hand. However, just as exercising is not always easy for people* ***without*** *any disabilities, it's especially challenging for people* ***with*** *disabilities.*

IMAGES COURTESY DANIEL STEIN

## WHY EXERCISE IS ESSENTIAL

According to the Centers for Disease Control and Prevention (CDC), less than half of American adults who suffer from mobility disability engage in any form of aerobic exercise even as simple as walking. In addition, the CDC notes that people with special needs and other disabilities are more likely to suffer from obesity and other chronic diseases like diabetes, heart disease, and stroke. People with disabilities who do not exercise are also prone to cancer. The good news is that regular physical exercise and fitness training lowers your risk of contracting any of these negative health conditions.

Despite the physical, mental or behavioral limitations, people with special needs can still greatly benefit from physical fitness training or any form of exercise.

As you know, exercise helps improve your physical, mental and overall well-being. Even a simple exercise such as brisk walking daily can help you maintain a healthy body weight, prevent chronic conditions like heart problems, strengthen your bones, and help improve your muscle endurance.

## WHY FITNESS IS A CHALLENGE FOR THE SPECIAL NEEDS POPULATION

There's a big reason why some parents do not encourage their child with special needs to exercise: The fear of getting hurt.

Parents or guardians of the special needs population think that exercise and physical fitness will hurt more than help their children. The fear of getting hurt is one of the biggest barriers to people with special needs to consider exercise as part of their daily routine. However, physical fitness training – when done right – can help someone with special needs to reap the many benefits that regular exercising has to bring not just for a month or two, but for a lifetime.

The good news is, exercise or physical fitness does not have to hurt. You don't have to engage in strenuous activities to achieve the health benefits that exercising can bring. Any form of physical activity, even as simple as brisk walking or taking the stairs instead of the elevator, can help improve your health in so many ways.

The key is to remain physically active doing the things that you enjoy even around the house. If you find it hard to stay physically active, here are some exercise tips that you can do and follow at home.

## BE PATIENT AND COMMUNICATE WELL

When it comes to people with special

### WORKING OUT FOR THE BEST : THE MANY BENEFITS OF EXERCISE

**Boost energy:** Exercising makes your heart pump more blood into your body. That means a surge of oxygen flow and a quick shot of energy to keep you moving and alert during the day.

**Lose weight:** One of the biggest problems of people with special needs is obesity. Unlike some form of diet that can be detrimental to your health, exercising helps you lose weight the healthy way. Even better, it helps you naturally fight obesity.

**Improve cognitive health:** When you exercise, your body releases good hormones that not only make you feel good but helps you to naturally combat stress, depression and anxiety. Regular exercise has also been known to help sharpen your memory and improve overall brain health together with prope sleep.

**Improve behavior:** For people with special needs, exercise helps improve behavior because of the same feel-good hormones that help you calm down thereby reducing the incidence of emotional outbursts or sudden meltdowns.

**Look good – or even better:** If you want that kind of glow that puts you in the pink of health, there's nothing better than exercise to do it for you. Exercise improves your muscle tone. It also strengthens and builds your body, making you look good and in turn feel good about yourself.

**Prevent muscular atrophy:** Muscular atrophy is a condition where the muscles decrease in size due to a lack of physical activity. Regular exercise is the key to preventing that from happening.

**Enhance rehabilitation and therapy:** Some people with special needs due to limited mobility caused by a severe injury or an accident can benefit from physical fitness training to help restore their range of motion. If that's not possible, exercise can help them manage their injury over time and still improve their range of motion in the best way possible.

**Live longer:** People who do regular exercise tend to live longer because of improved overall health. Special needs or not, all these benefits of physical fitness and exercise apply to everyone.

needs, explaining how an exercise routine is done may take more time than usual. With that, do your best to be patient when you communicate and make sure that they understand what you are saying before moving forward with the routine.

## PROVIDE A SUITABLE ENVIRONMENT

Some people with special needs can exercise at a traditional gym without any problem. But if that's not the case, providing a suitable environment at home with the necessary tools and equipment to do your exercise routines would be your best option. If possible, remove distractions so that you can focus on doing the exercise routine on time.

When it comes to exercise equipment, you can get tension bands, dumbbells, medicine balls or other similar tools to help you execute the exercise routines better.

## MAKE IT FUN!

Exercise routines do not have to be boring. This is why if you can make it, you can organize fun games or events that encourage physical fitness.

Go swimming, let them ride a bike, dance, or even play sports. If that seems a lot, a simple game of tag, hopscotch, tickle fights or even jumping rope will be good enough to keep that heart rate going.

These activities may need a few modifications to suit people with special needs, but it will surely make them more engaged in participating in a physical activity than just going with the usual routine.

## GOING STRONG : PRACTICAL EXERCISE TIPS THAT YOU CAN DO AT HOME FOR PEOPLE WITH SPECIAL NEEDS

**Know what they are capable of.** People with special needs are very much capable of doing exercise. However, they may not be familiar with a new routine which can become a problem. To avoid this, make sure that you match their skill level with a fitness routine and that they understand exactly what you want them to do to perform the exercise well.

**Modify the exercises if needed.** Running is good cardio to start with. But if someone is not yet fit to run or do brisk walking, you need to think of other exercise routines that would help them achieve the same benefit without forcing them to hurt their feet or leg muscles unnecessarily, such as swimming. You need to adapt each exercise to the individual needs and abilities of a person with special needs to make the fitness training work to their advantage. This is where adaptive fitness comes in.

**Use adaptive fitness.** There is a good reason why training people with special needs is called adaptive fitness. No two people are the same when it comes to their fitness goals. In the same way, no two people who both have special needs have the same goals and abilities when it comes to getting fit. With this in mind, you should know that every activity you can think of doing should be personalized according to the needs of the special needs person that you are dealing with. Most of the time, a regular workout routine consists of three segments: cardio, strength training and rest time. While it's true that people with special needs must participate in all segments, customization is still important because the exercises that will be placed in each segment will depend on their unique fitness level, skill set and fitness goals.

**Here are the top three exercises we recommend for wheelchair users:**

**KETTLEBELL DEADLIFTS**

Start with a 5lb kettlebell on the ground in front of the wheelchair. With a straight back, lift the kettlebell up to the top of your knees. Repeat this exercise for 10-15 repetitions for 3 sets. When the exercise is being done correctly, you will feel the exercise in your hamstrings and lower back.

**RESISTANCE BAND ROWS**

Attach a resistance band to the top of a door frame using a door anchor that comes from purchasing traditional resistance bands. Once the resistance bands are attached, position yourself facing the resistance band and move your wheelchair until there is no slack in the resistance band while holding the handles. Grab both handles of the resistance band and pull the bands until your elbows are in line with your hips. Squeeze the shoulder blades of the back together while pulling the bands.

**LEG EXTENSIONS**

Start with both feet on the ground. Slowly lift and extend both legs until the knees are locked. Hold the position for three seconds and lower the feet back to the ground. Repeat this 15 times for 3 sets. To increase the difficulty, add ankle weights.

**For equipment, you can purchase the following from Amazon:**

Yes4All Vinyl Coated Kettlebell Weights
**www.amazon.com/Yes4All-Coated-Kettlebell-Weights-Available/dp/B0093CMYRS**

VEICK Resistance Bands Set
**www.amazon.com/VEICK-Resistance-Exercise-Portable-Training/dp/B086X4PN48**

Gaiam Ankle Weights
**www.amazon.com/Gaiam-Weights-Strength-Training-Adjustable/dp/B01M65V335/**

## SET A GOOD EXAMPLE

Some people think that people with special needs want to isolate themselves from other people. The truth is, they are just like the rest of us. Social. Friendly. Wanting to belong. When people with special needs see their parents or any of their family members involved in physical fitness or any form of exercise, they will be interested to try it as well.

## CONGRATULATE THEM FOR A JOB WELL DONE

Physical fitness training for people with special needs will always be a challenge. That's why they deserve the applause for a job well done and for making it through their exercise routine, however simple or hard it may be. Simple words of encouragement can go a long way so next time your child or loved one is able to perform an exercise routine on their own, let them know that you are proud of them for doing a great job.

## HOW MUCH EXERCISE IS ENOUGH?

Any amount of exercise is better than no exercise at all. The rule of thumb is that any activity that makes your heart beat faster is ALWAYS good for your health.

If you want to achieve optimum results, you should exercise for at least 150 minutes every week. That's a total of 2.5 hours that can be broken down into smaller activities during the week that is equivalent to 25 to 30 minutes of physical exercise daily.

Take note that before you start any form of physical fitness training for people with special needs, make sure that you talk first to your doctor. Talking to a professional health care provider can help you find ways on how to plan an exercise routine that suits someone with special needs.

Starting an exercise routine for your kid or family member with special needs may seem daunting at the first. But the more you stick to your exercise routine, the more you find your efforts worth it with the many benefits that physical fitness training brings. •

### ABOUT THE AUTHOR:

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

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# UNDERSTANDING AUTISM

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- Partnering with leading research universities and autism centers
- Committing to research for the long term to advance understanding
- Inviting all individuals with a professional diagnosis of autism and their families to join

# SIT, FETCH, AND... IMPROVE BRAIN HEALTH

BY HENRY MAHNCKE, PHD

*As a scientist, I'm fascinated that I talk to my cats. They really don't speak English, and since they are cats, they never follow my instructions. And petting a cat is nice for the cat – but somehow feels nice to me as well! What's going on in our brains as we provide for and play with our pets? And is it possible that it's good for us – as well as good for our pets?*

In the past few decades, brain scientists have learned that many activities can contribute to better brain health and performance, because the brain is constantly reorganizing itself in response to what we ask our brains to do. This reorganization is called "brain plasticity" – the ability of the brain to change chemically, structurally, and functionally. Activities that demand attention, speed, and accuracy, and provide rewards for success, change our brains and permit learning, building skills, growing brain reserve and resilience, and protecting against cognitive decline.

Taking care of a pet – and building an emotional bond with a pet – is exactly that kind of activity.

Think, for example, of playing fetch with a dog – there's the brain speed and accuracy required to throw a ball, the attention required to make it interesting and different each time, and the reward when the dog brings the ball to you with its tail wagging in anticipation of more play.

Even if our cats, birds, and reptiles don't play fetch, when we play with them and take care of them, those activities stimulate our brains in important ways – and contribute to brain health.

## SOCIALIZATION AND BRAIN HEALTH

The companionship pets offer is important. Humans are social creatures, and our brains need social interaction to be healthy. Giving and receiving love from a pet – everything from belly rubs for your dog to when your cat curls up in your lap – stimulates social and emotional centers in the brain that are important for overall brain health.

Of course, many other activities – not involving pets – are brain healthy as well. Those may include, for example, getting together with friends for coffee, catching up on news and gossip, and playing a game together. What's important to brain healthy activities is that they involve brain speed, accuracy, focused attention, and reward. Some activities that people think are brain healthy – for example, doing crossword puzzles on your own – don't really require much speed or accuracy, and if our attention wanders a bit, it's okay. These activities can be fun and rewarding, but studies indicate that they don't do much for brain performance or brain health. If you asked me if you should go out for a walk with your dog, play fetch, and talk to some other dog owners, I'd say that's a more brain healthy activity than sitting by yourself and trying to figure out a four-letter word for a woody plant (it's "tree.").

## PETS AND BRAIN CHEMISTRY

Sometimes, people think of the brain as a cold information processing machine – storing memories or reacting to stimuli. However, the brain actually is a social and emotional system as well – we make friends, we interpret actions of other people, we work together, and we're happy when things go well. Those same systems come into play when we interact with pets.

Oxytocin is a brain chemical released in childbirth, mother/baby bonding, and social bonding in general. It turns out that oxytocin is involved in social bonding between people and

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**HAVING A BALL:** The brain is a social and emotional system – we make friends, we interpret actions of other people, we work together, and we're happy when things go well. Those same systems come into play when we interact with pets.

**ABOUT THE AUTHOR:**

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

their pets as well. When your dog puts her paws in your lap and gazes lovingly into your eyes – her levels of oxytocin go up, and so do yours. This builds the bond between you and your dog – and promotes brain plasticity in both of your brains, which helps your brain maintain its youthful ability to change and rewire itself.

Cortisol is a hormone involved in stress response. Interacting with other people might lower our stress and cortisol levels (if the interaction is with a friend or family member, and we're relaxing) – or might increase our stress and cortisol levels (if the interaction is with your boss, and we're on deadline). In general, interacting with a pet decreases stress and cortisol levels – it's like having a friend who always wants to relax and play together. Ongoing high stress and cortisol levels are not good for brain health – so playing with your pet for a while can help.

And finally, there is dopamine – a brain chemical released when you are rewarded – which reinforces learning and stimulates brain plasticity. It is the chemical that produces that "feel good" rush after you succeed at a task. Dopamine helps your brain rewire itself to build on your success. Playing with your pet – or just cuddling – releases dopamine in your brain, which makes you feel good about being with your pet – and also helps your brain stay healthy.

## BUILDING YOUR BEST BRAIN

In my family, we have two cats, a guinea pig, and a tortoise. It's a fair amount of work to take care of them all! But they're all wonderful members of our family. Having a pet helps with your brain health. If you want to ensure that you are at you best to take care of your pets, do everything you can to take care of your own brain.

In my professional life, I work on brain exercise programs – built on the principles of brain plasticity and shown effective in more than 100 studies – which helps people think faster, focus better, and remember more. We developed that brain training as an efficient way for people to exercise their brains to improve their brain performance and brain health. However, it's not the only thing we recommend. There are many ways to improve brain health including physical exercise and following the brain-healthy MIND Diet. As you now know, that list can include having a pet in your family.

What's most important is that you take steps to maintain and improve your brain health, so you can take care of furry, feathered, and scaly friends, and get the most out of life. •

**EP WANTS TO HEAR FROM YOU!**
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**ABOUT THE AUTHOR:**

Dr. Mahncke got his PhD in Neuroscience at the University of California, San Francisco in the Merzenich Lab, which discovered the brain remains "plastic" – capable of chemical, structural and functional change – at any age. Then, at the request of his academic mentor, Dr. Mahncke led a global team in harnessing that plasticity through the computerized brain exercises found in the BrainHQ app, which is produced by Posit Science, where he is the CEO. BrainHQ can be found at **brainhq.com**.

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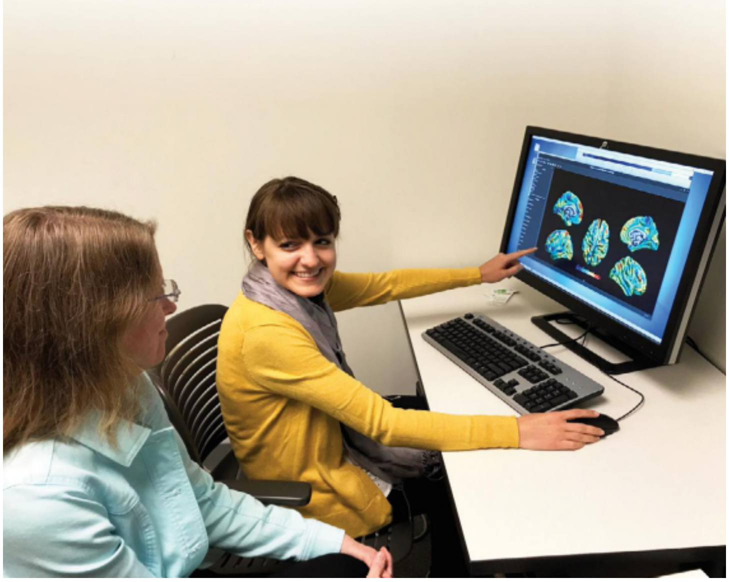

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During the initial consultation with an architect, you will get the chance to learn about the architect's design philosophy and style. It's a perfect opportunity to ask questions and talk about your ideas.

# ANATOMY OF AN ACCESSIBLE HOME:

## WORKING WITH A SPECIALIZED ARCHITECT

BY RAMESH GULATEE

*Planning for a new home, an addition to existing or remodeling of an existing home takes many careful considerations. This is particularly true for designing an accessible home.*

A household with a family member with an accessibility issue faces many considerations to make the home accessible for optimal independent living. The latest CDC data shows that almost every other American (1 out of 2) shall experience accessibility related issues in his/her lifespan, whether short- or long-term, including: cognitive, developmental, sports injuries accidental or combat related, age induced and/or lifestyle related.

### POINTS TO CONSIDER FOR ACCESSIBILITY AT HOME

***Make an accessibility checklist:*** A checklist allows you to prioritize options to make provisions for accessible living for current & future situations and brings cost considerations in focus.

***Consider flexibility in space layout:*** Design flexible spaces to accommodate changing situations and future needs.

***Accessibility products & resources:*** Integrate advances in design, marketplace and industry.

***Tax write-offs & other financial incentives:*** Investigate with a tax consultant, the medical deduction law & home accessibility upgrades relative to capital expenses.

**RECIPE FOR SUCCESS:** Once you've decided to hire a home accessibility specialized architect, ask him/her to prepare an American Institute of Architects (AIA) developed professional services contract for review and execution. This contract details both your responsibilities and the architect's responsibilities.

## WHERE TO BEGIN

1. ***Understand ADA:*** "The ADA'90 is a civil legislation with intent, goals and purpose that form the basis of broad-based accessibility in the American Society. **It does not apply to private homes.**"
2. ***Go beyond ADA:*** The concept of "accessibility for all" is called "universal design" (UD), meaning the principles of UD facilitate creating an enabling live/learn/work/play environment for all. Above all, with every situation being unique, consider an additional layer of accessibility i.e., evidence-based design, to customize what works for you.
3. ***Engage a home accessibility specialist:*** A licensed architect with know-how and experience in home accessibility from design and construction viewpoints. It is important to remember that every situation is different, yet accessibility design solutions should include family members irrespective of age/abilities. *Note: A general practice architect is familiar with ADA accessibility compliance issues applicable to various building other than private homes.*

> An architect experienced in home accessibility can be just the right resource to help you and your family live comfortably in the home of your dreams.

4. ***Information Sharing:*** Working with a home accessibility "architect" means openly sharing information about disability issues in the family. Your discussion within family may include the following: preference for pocket doors, lever faucets, toggle light switches, clear knee space under the counter tops, motion/occupancy sensors, keyless entry, intelligent thermostats and more.

   This helps the architect to better understand your situation in terms of concerns/priorities, preferences, and aesthetics for designing accessibility solutions.

## WHAT TO CONSIDER WHEN HIRING AN ARCHITECT

During the initial consultation with an architect, you will get the chance to learn about the architect's design philosophy and style. It's a perfect opportunity to ask questions and talk about your ideas. You'll need to discuss fees, timelines, and expectations etc.

## ASK AWAY : SOME QUESTIONS FOR THE ARCHITECT

You will get the chance to learn about the architect's design philosophy and style during the initial consultation with an architect. It's a perfect opportunity to ask questions and talk about your ideas as well as fees, timelines, and expectations.

**A. Why did you decide to specialize in accessibility focused architecture?** This is a great question to open with, as it gets the architect talking about his/her passion and motivation to work with people with accessibility issues. It sets the mood, allowing you to share your concerns, hopes and dreams for your home.

**B. Availability?** How will the architect address your concerns and requests? An architect may have a great design philosophy and a stellar portfolio, but if he/she's unreachable most of the time, or insensitive to your needs, he/she may not be the right person for the job.

**C. Projects on budget and schedule?** There are many issues related to construction that may affect finishing a project on schedule and within budget i.e., permit delays, unexpected conditions, builder/vendor, product availability etc. A good architect should be confident in his/her ability to design a project within the allocated budget and schedule, ensuring there are few surprises or delays.

**D. Involvement during the construction phase?** Depending on your project, you may hire an architect to draw up plans that your contractor will implement independently, or you may want the architect to work with the contractor from the project's inception through to completion.

**E. Can I see project samples?** This is a great opportunity to see an architect's overall style. The work portfolio may include photos/drawings and may include testimonials from past clients. Review everything carefully and ask questions about the projects that look similar to your own. Contact the architect's previous clients for more insight.

**F. Contract:** Once you've decided to hire a home accessibility specialized architect, ask him/her to prepare an American Institute of Architects (AIA) developed professional services contract for review and execution. This contract details both your responsibilities and the architect's responsibilities.

Be sure to have an attorney review the contract for modifications of conditions, if any, pertinent to the scope of professional services. Here are some key conditions that should be addressed:

- *The scope of work is defined in sufficient detail.*
- *A project development phase schedule is included.*
- *The fee payment schedule is tied to project phases and completion*
- *Project delivery & architect involvement (Design, Design/Build, Construction Management etc.) is clearly spelled out.*

## GENERAL INFORMATION

Planning for a new home or a remodeling project can be both exciting and daunting. An architect experienced in home accessibility can be just the right resource to help you and your family live comfortably in the home of your dreams. The scope of design services varies slightly depending on new construction or remodeling. However, they include generally the following stages.

***Design/Development (hourly basis until sign off):*** An order of magnitude cost estimate can be prepared at the completion of this stage.

***Documents Preparation (permitting and bidding)*** Fee basis on estimated/projected cost of construction.

***Construction:*** The Architect's involvement can be limited to observation and/or full oversight including project administration and management, for an hourly or fee percentage.

## PROJECT DELIVERY

There are several delivery methodologies to choose from depending on the scope of work, i.e. new construction or remodeling an existing home.

*Design/Build*
*Lump Sum (General Contractor)*
*Construction Management*
*Time and Material*

The optimal choice may depend on the level of your knowhow, involvement, input, availability, and ability to manage the process.

Experience has shown that sometimes a construction management delivery methodology may offer benefits of cost savings and greater project control. This allows a construction manager to engage in negotiations and manage the various trades with the understanding that savings in cost and time schedule are shared based on agreement between you and the manager. This agreement can be based on phased completion or on a monthly basis. •

### ABOUT THE AUTHOR:

Ramesh Gulatee, LifeCare Design Studio, LLC is an Illinois based architect with focus on home accessibility. Ramesh has practice licensures in USA and Canada where he has worked on numerous residential and housing projects. His knowhow is recognized by the regulatory, and professional bodies where he is either appointed as accessibility specialist and/or serve on various advisory boards at state and national levels. Contact him at **rgulatee@lifecaredesignstudio.com** or visit his website at **www.lifecaredesignstudio.com**

# END OF THE SCHOOL YEAR TIPS FOR TEACHERS AND PARENTS

BY JENN ADAMS

*As the end of the school year comes closer it is easy to forget that we can still help our students, families, and ourselves before summer comes. It is overwhelming with all the end-of-school-year activities and celebrations to think about things for the summer or even the next year. Let's face it as educators and providers we have a lot to do! Don't worry though, I have done that thinking for you! Here are some tips for things should be doing to end the school year on a positive note!*

## END OF SCHOOL YEAR PAPERWORK IS DONE!

Special educators are constantly working on documents for their students. There are IEPs (Individualized Education Plans), FBAs (Functional Behavior Assessments), BIPs (Behavior Intervention Plan), NOREPs (Notice of Recommended Educational Placement), re-evaluations, and so much more! Each of these are educational documents that are written for students in special education to determine their needs, outline goals and objectives for instruction, and provide information about interventions and supports the student needs to be successful in the classroom. The last thing that you want to do at the end of the year is forget to complete a document. Another thing not to forget is to revise an IEP for the upcoming school year or for extended school year if your students attend. It can cause stress on you next year, the new teachers the student may work with, the family, and the student also.

Sometimes, we have last-minute conversations with families who want to make a change to an IEP for the upcoming year. This could be based on moving to a new school, building, or program. Make sure that you have those documents ready to work for students to meet their needs before you pack your classroom up for the year. Then anyone that picks up that IEP document can have a great start to providing the services that student needs!

## REFLECTING ON THE END OF THE SCHOOL YEAR

First, think about what worked and didn't work in your classroom this past year. Perhaps a center you had dreamed up just didn't keep the students engaged like you hoped. Maybe you used a great morning activity that you would love to continue into the next year. You may have learned about a great way to communicate with parents during the year but didn't have the time or materials to start it up. But now, that you have some time off you want to implement it for the upcoming year. I love taking all these types of ideas and putting them in a list or simple chart to evaluate and figure out ways to get better.

All of this is perfect to start thinking about at the end of the year. Even if you don't know where you will be teaching there are some strategies and ideas that lend themselves well to tons of types of teaching roles. I've moved to different positions in my career but, I still have core values and routines that have stuck with me along the way.

## HELPING FAMILIES PREPARE FOR THE SUMMER

As teachers, we should also have a goal of communication and providing support to families no matter what time of year it is. When it's the end of the year we often think that we just need to say goodbye but there is so much more we could do to help!

As a parent myself, I know I am always looking for something to provide my children structure during the summer. It makes things run better when everyone knows the schedule and routine. As a teacher, I like to provide families that support with ideas of things they can do with their children in the summer. Many parents are concerned that their child will lose skills over the summer and look to me as their teacher to have information that can help. Some things I like to provide or help with are:

- *Create example summer schedules as a checklist or provide the visuals to make them!*
- *Provide a list of fun activities in your town to do (field trip ideas, public library events, volunteering, camps, etc.)*
- *Make a list of educational websites used in the classroom during the school year to practice skills.*
- *Provide materials to work on over the summer (worksheets, books, etc.)*
- *Compile a list of life skills activities families can work on over the summer with step-by-step instructions (washing the dishes, getting dressed, putting away laundry, etc.)*

"I LOVE TAKING ALL OF MY IDEAS FOR IMPROVING NEXT YEAR AND PUTTING THEM IN A LIST OR SIMPLE CHART TO EVALUATE AND FIGURE OUT WAYS TO GET BETTER."

Each of the items listed can be simply shared with families or if you have the time you can provide some of the materials needed. This could be printing the visuals for the schedule, providing printed worksheets, or a list of life skills activities as suggestions. Most of the families I have worked with in the past loved if I could give them easy actionable ideas with little preparation on their part. I'd save these lists and use them year after year.

## USE YOUR RESOURCES CAREFULLY

Do you get reimbursed for the materials that you buy for your classroom? All the lamination, Velcro, and dry-erase markers that you might have spent your own money on. If so, it's time to make sure that you have compiled all the receipts and you've been compensated. Not every district will do this, or they may only do it for a certain amount, but if you are lucky you should be sure to use it.

Do you get reimbursed for college classes or training you paid to attend earlier in the school year? Make sure you are getting that information into your school's business department. They will get you back the money you invested to grow professionally that you are owed. Many schools do this because they want to support their teachers in learning new skills and techniques to benefit those students in the district. Check your teacher contract (if you have one) to see if this is something you can take advantage of.

Another great idea is if you get a budget for your classroom spend all that money. Don't let the dollars you receive go to waste. Even if you use an idea you have for the next year to get supplies now. Remember the reflection I told you to do? And that new idea you wanted to try in your classroom? Use those extra dollars to buy the folders, book shelf, or flexible seating options you've always wanted!

Did you get gift cards from parents that showed you appreciation during the holidays or teacher appreciation week? You can look for ways to spend this money to better your classroom for next year. Whether it's getting a new carpet for your morning meetings or buying new caddies for your supply stations. At the end of the year we often may notice some items are worn out and need replacing. That money our families provided us with can come in handy to support future classes.

## TAKING CARE OF YOUR STAFF

It's crucial to make sure you are showing the people that help you run your classroom some appreciation. I try to make a habit of this several times a year and not just at the end but sometimes things get busy. Instead of looking then for what you need have it in the back of your mind all year. Every time you go to a store check out the clearance, gift, or school supply sections. You can find some great deals on items that come in handy as gifts for paraprofessionals, co-teachers, or even student teachers!

Once I have those items I have a bin of gifts I keep in my teacher closet. It's a milk crate with sticky notes, fun pens, thank you cards, word search books, small candles, and other stuff! I'm sure you can think of more things than I could, especially if you know what those people like. I often will have my staff complete a survey at the beginning of the year. It gives me an idea of what they like so I know what to look for as gifts!

Just remember this quote from Francis Flinn: “A person who feels appreciated will always do more than what is expected.”

Sometimes, it’s the little things after a long stressful school year that can make a person feel appreciated. I try to always take the time to show the people that devote so many hours of their day supporting my classroom the respect they deserve. I find that a positive note, and gift can go a long way.

## PACK UP WITH NEXT YEAR IN MIND

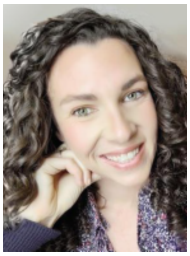
The daunting task of packing the classroom up can be so overwhelming for teachers. You spent all year getting the room to work for you, your staff, and your students. I think of the classroom library, the bulletin boards, the anchor charts, and so much more that needs to be safely put away. Many teachers have to pack up but also remember where you put them when you come back in the fall.

In my first few years of teaching, I made a mistake. I would just throw anything in a box close by with no rhyme or reason. Then I would come back during the summer to unpack and hate myself. Yes, are we all on the struggle bus at the end of the year and just want to get things packed up quickly? Of course! But, the problem with that is you are setting yourself up for failure when you come back in the fall.

My suggestion is to try to keep like items together that you know are going to be used together in the next year. So I try to have tubs that either are based on like items OR that are for certain times of the school year. For example, I have a "back to school" tub where I keep copies of welcome letters, information cards, bulletin board pieces, read-aloud books, and easy tasks for my students. It’s everything I use in the first month of school in one place that is easy to get to. Anything related to the things I might teach in that first month such as classroom rules, building classroom community, and teaching classroom routines. This saves me hours of spinning in circles trying to find the things I need.

In conclusion, there is no perfect way to end the school year. I’m sure every teacher could give you different ideas and points of view on what is the best thing to do. But, these ideas have always been ones that have given me positive outcomes when ending the year, and going into the fall to start a new one. I hope these can help you feel less stressed about the end of another school year and let you look forward to a summer break that you deserve! •

## 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.

# NAVIGATING SOCIAL OUTINGS WITH BUILT-IN LIFE SKILLS

BY STEPHANIE DELUSSEY

*Social outings are an almost everyday experience for many families, like going to the grocery store, the local library, or a department store. For families with special needs, there often needs to be a little more preparation to make the outing smooth and potentially less stressful.*

Experiencing life together as a family has so many benefits, like promoting family bonding and creating memories, social awareness and experiencing the outside world, improving one's sense of self, and encouraging independence, self-advocacy, and responsibilities.

"The best memories are the ones we make together." But every family and individual's needs are different. There are so many variables that come into play when planning a social outing or trip with your child with special needs. And even though a social outing is very different logistically than a planned trip or vacation, there are some commonalities.

One huge piece of planning a social outing is the pre-planning, but another piece of the planning is the answer to this question: "How will my disabled child be independent and self-advocate for him- or herself during this outing?"

Here are a few accommodations and modifications to keep in mind that may be very helpful in not only navigating any social outing, but also in assisting your child in increased independence and self-advocacy:

- *Visual schedules*
- *Offering multiple choices*
- *First, Then boards*
- *Social narratives/stories*

Once you have one or two of the above supplies prepped and ready to go for your next outing and adventure, it's time to start thinking about and planning for all of the other details. Here are four ways to prepare your family for a social outing:

## 1. CALL AHEAD OF TIME

If it's a big vacation or a big pre-planned trip, call the place where you are going or staying ahead of time to ask about disability accommodations and modifications they provide. Large theme parks also provide exemptions for individuals with disabilities.

Markeisha from **@funtherapytravel** suggests asking the five following questions to prepare your family for traveling:

- *What accommodations do you offer?*
- *What does the check-in process look like?*
- *Are there days/times that are less crowded?*
- *What dietary accommodations can be made?*
- *Is the kids' club trained to work with my child?*

**AWAY WE GO:** No matter where your next adventure takes you, a little bit of pre-planning can go a long way.

If you're going to be flying when traveling, reach out to the airport or airline prior to your travel to ask about supports they may be able to provide to make your air travels more comfortable. Most times TSA will provide assistance through security checkpoints, and most airlines will assist with equipment and provide an individual to assist you and your family throughout the airport.

## 2. PRACTICE AND ROLE-PLAY

If there are certain situations or unfamiliar moments that are new to your child with special needs, will require new or an extensive use of skills, or are not a part of the regular routine, role playing or practicing the upcoming social outing may be very beneficial.

If you have not yet tried Social Stories, they are a great way to learn about and practice a new routine or skill beforehand. According to Carol Gray, the creator of Social Stories, "Social Stories are a social learning tool that supports the safe and meaningful exchange of information…" For more information on Social Stories and for access to Carol's free library of Social Stories, visit **www.carolgraysocialstories.com**.

Visual schedules are also a great way to help your child see what is coming next in the day. They help individuals manage the day or outing in a discrete way that is specific to them. What's great about visual schedules is that each piece or part of the day has its own icon or schedule square, which visually allows students to see their day and each of its parts.

## 3. PACK EXTRA ITEMS

Luggage gets lost, clothes get dirty and wet, snacks get left behind or eaten… it is never a bad idea to pack an extra set of clothes or an extra snack in a bag that is with you at all times during the social outing.

## 4. GIVE YOURSELF EXTRA TIME

Whether it's a social outing or big vacation, add extra time into your schedule. Plan for the unexpected, like parking farther away from a store, a delayed flight, or waiting for a ramp to be set up.

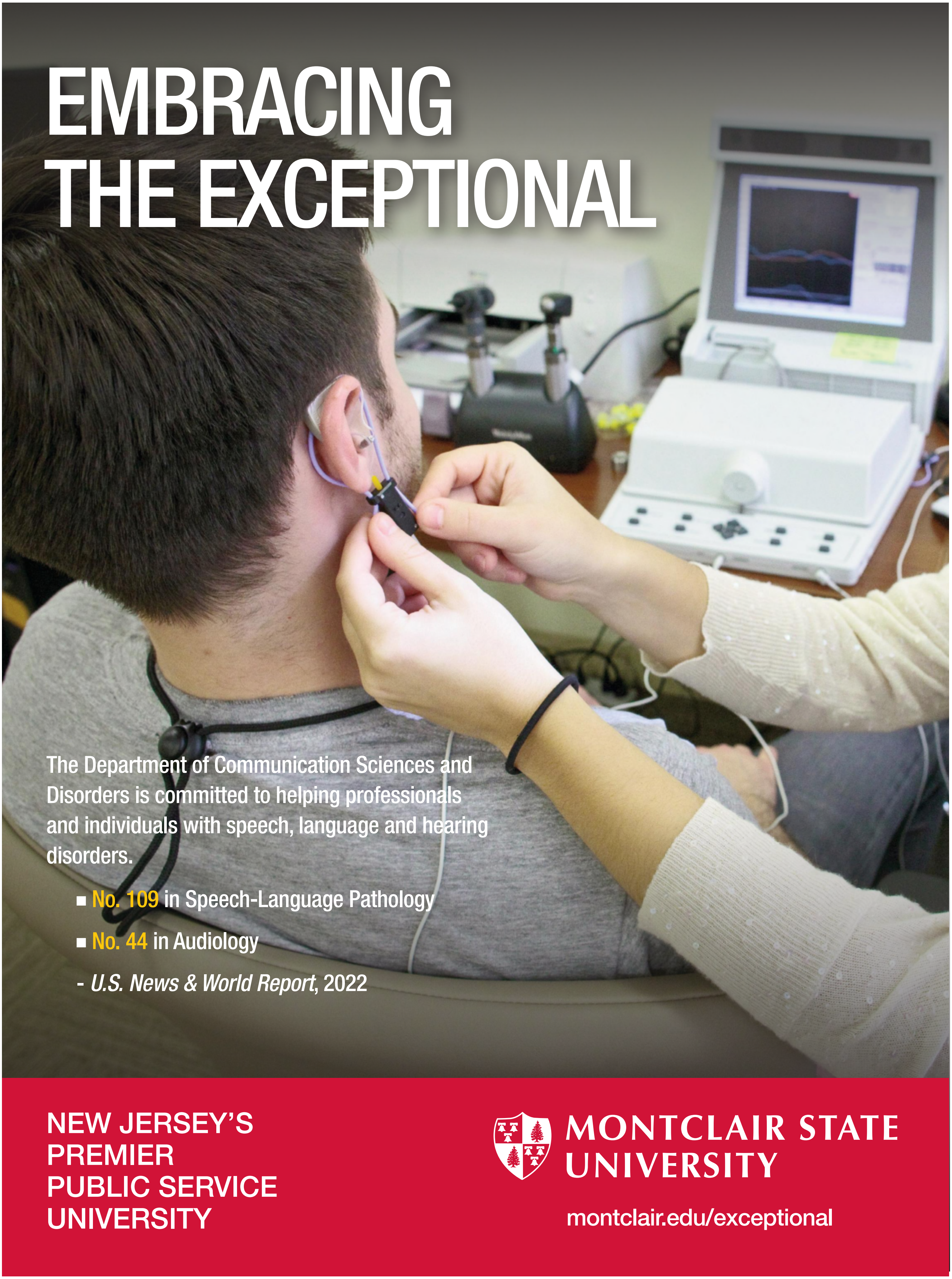
With any social outing also comes the opportunity to practice important life skills. Here are ten life skills you can practice on any social outing:

1. *Wait time*
2. *Ordering food at a restaurant*
3. *Paying for a service*
4. *Making sure you have enough money to buy something*
5. *Locating the restroom*
6. *Using public transportation*
7. *Making sure you have enough time*
8. *Following a schedule*
9. *Scheduling a reservation at a specific date and time*
10. *Wearing the correct clothes for the weather/season or event*

Once you have one or two of the above supplies prepped and no matter where you are traveling to and no matter where your next adventure takes you, a little bit of pre-planning can go a long way.•

### ABOUT THE AUTHOR:

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



**"In-person evaluation and care are excellent options, but telepractice and visual biofeedback methods have proven to be successful as well."**

# A HOLISTIC APPROACH TO SPEECH THERAPY

BY ANDREW MEES

*Professor Elaine Hitchcock and a team of volunteer researchers at Montclair State University are overseeing critical research to advance patient care for individuals with long-standing speech problems.*

The pandemic has changed parts of our way of life forever – including the ways in which patients are treated across the healthcare industry. Out of necessity, innovative new methods of treatment currently under investigation at Montclair State University have been adapted for online use over the past two years: And Associate Professor of Communication Sciences and Disorders Elaine Hitchcock and a team of speech-language pathologists and graduate research clinicians in the institution's Clinical Biofeedback Lab (https://sites.google.com/view/msu-cbl/home) are overseeing this critical research to allow speech therapy to effectively evolve for the greater good.

In collaboration with colleagues Tara McAllister of New York University and Jonathon Preston of Syracuse University, Hitchcock is currently overseeing a pair of federally funded research grants totaling more than $1.8 million, with each allowing for the study of telehealth and in-person speech therapy using visual biofeedback methods.

The grants – a $1.375 million sub-award as part of a study led by NYU that evaluates biofeedback-enhanced treatment for Speech Sound Disorder (SSD) in children, and a $430,000 award to study the efficacy of virtual speech therapy practices – have yielded findings that will improve future patient care.

"The pandemic has necessitated ongoing shifts towards telepractice delivery, and the need for research to validate the efficacy of this type of treatment," said Hitchcock. "But it's also provided the opportunity to reexamine in-person therapy, and see how it can be even further enhanced to provide the best possible care. These studies have yielded findings that will be able to help things change for the better, and which will also be publicly available, so that anyone can benefit."

## Innovative Approaches Yield New Treatment Options

As part of the studies, Hitchcock and the research team tested not only visual biofeedback treatment of SSD, but also converted two tasks typically administered in an in-person setting to a virtual application to assess the efficacy of telehealth treatment.

In the first study, the team utilized visual biofeedback treatment – which uses instrumentation to create a real-time visual display of different parts of speech that may be subtle or difficult to perceive – to study its success against traditional methods. Participants were presented a visual target and asked to alter speech patterns to match the target. The goal of the process was to provide new insights into the unconscious processes behind speech production so that they may be brought under conscious control.

Preliminary results of the study show that respondents showed a stronger response to the visual biofeedback than traditional methods, setting the stage for increased use of the approach in standard practice.

In the telehealth study, 80 typically developing children, ranging in age from 9-15, were given two tasks – identification of items along a synthetic continuum from "rake" to "wake", and category goodness judgment of /r/ sounds spoken by various talkers with and without SSD – in an in-per- son setting. Fifty children in the same age group were mailed a standard headset and given the same tasks in a telehealth format. Findings revealed that children performed in similarly both in-person and online.

**VIRTUAL ACCESS:** In a pilot telehealth treatment study including 7 participants, preliminary findings show participants made strong progress over the course of 20 sessions of virtual treatment for SSD, indicating the potential for permanent adoption of telepractice treatment for residual/r/misarticulation.

These findings and methods are all publicly available, allowing for easy implementation by licensed therapists around the world.

"Our research shows that telepractice delivery of visual biofeedback in speech therapy can work, and that positive results can be achieved," said Hitchcock. "But, perhaps more importantly, they serve as the foundation for continued research and refinement to make therapy delivered in this medium even stronger. They are proof that this is something we should continue to study, and that with continued research, even greater progress to improve treatment options can be made."

## Recommendations for Parents

For parents of children with persisting speech sound distortions, Hitchcock encourages them to explore these new methods of treatment – because they offer new possibilities and are likely to become more widespread.

"The growing successes of the children in our research and clinical programs demonstrate that there is hope for children who have struggled with their speech for long periods of time, some spending as long as 8-10 years in therapy," she said. "In our continuously advancing technological world, it is clear that visual biofeedback feedback and telepractice care options are only going to become more widely used, so it will be increasingly important for parents to learn about and understand these styles of treatment because they could mean all the difference in the long-term care and results for their child."

> **"The pandemic has provided the opportunity to reexamine in-person therapy, and see how it can be even further enhanced to provide the best possible care."**

Additionally, Hitchcock has the following tips for parents and families:

- **Don't wait:** If you are concerned about your child's speech or the impact SSD may be having on their emotional or academic wellbeing, you should schedule an appointment with a speech-language pathologist immediately.
- **Consider new treatment methods:** In-person evaluation and care are excellent options, but telepractice and visual biofeedback methods have proven to be successful as well. Considering these options could improve the long-term outcomes for children who have previously been unsuccessful in overcoming speech-related challenges. Importantly, such options can be used as effective alternatives to overcome geographic, transportation or other barriers to in-person care.
- **It's never too late:** Smaller-scale studies have shown that adults can successfully change long-standing speech patterns using visual biofeedback. No matter a person's age, there are treatment options available that can help you overcome Speech Sound Disorder. •

# COULD YOUR CHILD HAVE DYSLEXIA?

BY RICHARD SELZNICK, PH.D

*Parents frequently consult with me asking whether or not I think their child has dyslexia. When I ask the parents if they know what dyslexia is, a vast majority will say something like: "Isn't that when you read upside down and backwards?"*

Most parents are surprised when I explain to them that of the vast number of children that I have assessed over the years, virtually none of them has read upside down and backwards, yet a significant number of them were seen to be "dyslexic."

## MYTHS

There are pervasive inaccuracies and myths about dyslexia that interfere with parents seeking appropriate assessments and treatment. Among the more common myths are:

- *Dyslexia involves reading upside-down or backwards.*
- *"No one knows what dyslexia is."*
- *"Only neurologist can test for dyslexia," (which is often told to them by the school).*
- *Parents need to wait until a child is in third grade before a determination can be made.*

There are many more myths, but these are the most pervasive. Dispelling such myths is a first step toward understanding dyslexia and doing what you need for your child.

## RECOGNIZING AND UNDERSTANDING DYSLEXIA

Dyslexia is defined as a specific learning disability that is neurobiological in origin, which means it is likely to have been passed down from one or the other parent. It is characterized by difficulties with accurate and/or fluent word recognition and by poor spelling and writing abilities. Such difficulties typically are the result of weaknesses in the phonological (i.e., sound) system of the language.

As an example, let's take Sarah, an 8-year-old child who I recently evaluated and determined to have dyslexia. For Sarah, reading had been a laborious chore since kindergarten, something that she avoids at all costs. Each night around homework time, tensions run high.

The assessment that was done with Sarah showed that she had great trouble with "decoding" (i.e., the ability to sound out or break down words into their component parts) and that she frequently substitutes words while she reads.

The substitutions often are nonsense words that mean nothing within the context (e.g., reading *"pricpinny"* for *"porcupine"*). Such substitutions interrupt the flow of the meaning, resulting in very poor comprehension. As it was explained to Sarah's parents, the combination of her history (her father was a poor reader) and the evaluation results, noted that she did show dyslexia, although, there were no signs of the reversals or backward reading that most people believe need to be present.

Helping Sarah's parents understand that she had a legitimate learning problem was essential. Such understanding helped to reduce the tension, as the parents were guided to lighten up on

**ASSESSMENT LEVELS:** There are different levels of assessment ranging from a brief screening to a more comprehensive assessment that may be appropriate. Such assessments are typically conducted by a psychologist who specializes in dyslexia/learning disabilities.

homework-time and to try and turn down the heat. They needed to understand that Sarah's difficulties were not the result of her not trying hard enough.

## FIRST STEP: ASSESSMENT

Many children with a mild-to-moderate reading/writing disability are clearly struggling, but they are not seen as eligible for services based on the special education code in the school system.

This can result in parents feeling perplexed about what they can do, since the child will not be receiving services from the school. For many states, it is important to understand that "dyslexia" is not a category that exist in special education code, such as in the state of New Jersey, where I practice.

There are different levels of assessment ranging from a brief screening to a more comprehensive assessment that may be appropriate. Such assessments are typically conducted by a psychologist who specializes in dyslexia/learning disabilities. Seeking an outside evaluation is an alternative that should be considered by parents. Outside assessments are not covered by state special education code, and the focus of the assessment is not on special education eligibility, but a more fundamental basic question: Does the child have a problem? If so, how mild, moderate or severe is it?

Such an assessment provides a snapshot as to where the child is in his/her stage of reading, writing and spelling development. Once that stage is known, then a remedial plan targeting specific areas should follow.

> "The process of helping a child with a learning disability such as dyslexia is rarely a rapid process.
>
> Parents and teachers need to be extremely patient and celebrate small successes that occur along the way."

A good example is Timothy, age 10. For example, while reading a third grade selection within the evaluation, the text read, *"She hid her boat in seaweed."* Timothy read the sentence as, *"She hit her boat in Sweden."* When asked comprehension questions about where the boat was hidden, Timothy confidently answered, "She hit in Sweden." Often mislabeled a comprehension problem," his answer represented a clear misread of the text.

When such issues are identified within an assessment, this helps orient the parents as to what they can target and focus upon as a next-step. The assessment provides a roadmap to follow for the near future. Along with identifying deficits and providing a roadmap, assessments can also be energizing to struggling children, as it helps them realize that they are not "dumb" or "stupid" as they might have come to believe.

## NEXT STEP: REMEDIATION

Learning to read is not that different from learning how to play music. For some people, learning to play music is fairly effortless; they are musically inclined and have a great ear and a natural facility for playing music. For others, it is a much tougher road. They need more explicit instruction and guided practice over time. Repetition to mastery is essential in such situations.

It is the same with reading and reading disabilities.

When a child has an identified reading disability (dyslexia) she/he require specialized approaches to help overcome the areas of deficiency. Such children require direct, individualized instruction delivered in a manner that is highly explicit, structured and multisensory.

It is essential that the instruction be provided in a supportive and encouraging manner. The remediation cannot be rushed, as it is crucial that skill mastery at each step is achieved before moving onto the next step.

The remedial programs that are related to the "Orton-Gillinham" methods represent gold standard. There are a number of Orton-based methods on the market, (e.g., Wilson, Project Read, Sonday System), but they are very similar in their emphasis and delivery. The Orton-based approaches are not new and have remained fundamentally unchanged since the 1940s.

## LATER STAGE CONSIDERATIONS

Once a child gains greater confidence from the remediation, the remediation can shift to reading less controlled material, to practicing reading fluency. Within this later stage, there can be a greater emphasis on developing vocabulary and learning how to comprehend the text more effectively. It is, however, essential that the fundamental word identification and decoding skills are mastered as first stage.

## GETTING AROUND THE PROBLEM

Along with the specialized, explicit instruction that is essential, there are different ways of "getting around the problem" of having such a learning disability. These would represent the various accommodations that can be implemented.

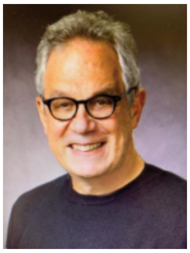
One of the best examples is the use of assistive technology. Helping children use technology that can help them manage the more challenging waters, particularly as they reach higher grades, is essential. There are numerous computer-based technologies that can be helpful to explore. Such technologies may give the child access to text material that they can understand, but not have the facility to independently read.

## PATIENCE, PATIENCE, PATIENCE

It is essential to understand that the process of helping a child with a learning disability such as dyslexia is rarely a rapid process. It takes a great deal of time to make incremental progress. Parents and teachers need to be extremely patient and celebrate small successes that occur along the way. Even with the best remediation, it is a long process to help a child overcome his/her difficulties and to gain greater confidence along with skill development.

In summary, finding the right type of assessment and follow-up remediation are the essential steps to helping a child achieve success. •

**ABOUT THE AUTHOR:**



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

# TEACH YOUR CHILDREN HOW TO OWN THEIR STORY

BY VICKIE STOLLE

*When you become a parent there is so much to take in and try to figure out no matter how prepared you felt before your little one arrived.*

When you become a parent to a child that has additional challenges, such as my parents did when I was born in 1977 with a bilateral cleft lip and palate that they were not aware of beforehand, the number of issues they felt unprepared for doubled overnight.

I know that my parents felt overwhelmed and isolated at times because so much of my early years was taken up with countless appointments, numerous medical procedures and surgeries, long recovery times, feeding struggles - the list was endless. As the years went on and I got closer to beginning school, they were tasked with the added concern of how I would be accepted and if I would be able to be understood due to issues with my speech. Thinking of how best to prepare me for interacting with the outside world was heavy on their minds.

Thankfully, my cleft team included a speech therapist. I'm not sure if the term "early intervention" was used back then as it is now, but early intervention was exactly what it was. Having access to that service was a vital part of my treatment to improve my communication before I began school and carried on for a few more years as I went through my early elementary grades. Although it added yet another appointment to my parents' to-do list, they knew that making the time for this therapy and doing the work before I got into school would pay off greatly as I learned how to work with my cleft to speak as clearly as possible.

These days there are so many types of early intervention services out there and available for all children – from speech therapy like I had, to occupational therapy, social and emotional therapy, the list goes on and on. However, one aspect of the early development of a child with additional challenges many parents aren't aware of is the way in which they talk about their child's difference.

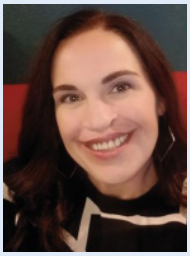
As a parent myself, I can attest to the fact that those little ears are always listening. Especially when I said an unfortunate word out loud and my daughter repeated it back to me with similar gusto. As parents we try to watch what we say around our kids, but have you ever paid much mind to how you talk about your child's difference with them and with others when they are around? Do you find that you tend to avoid talking about it with your child? Do you react defensively when asked something by a stranger? Do you tend to overshare and give all kinds of details to someone when approached? Your child is always listening, and they will take their cues from you. If you get nervous and anxious when going into social situations with your child because you are nervous about how you and your child may be received, that nervousness and anxiousness can be felt by your child. On the other hand, do you hold your head up high and make eye contact with others and be open but respectful of your child's feelings when people make comments or ask questions? Your child will see that too.

My parents didn't shy away from talking about my cleft with others and would do their best to answer questions when asked about my facial difference. While I generally look upon that as a positive, one aspect of their openness that trickled down to me was the feeling that I had to be that open too. I always felt that no matter what I had to answer the questions from people whenever I was asked, even when I was uncomfortable doing so. It wasn't until around middle school that I learned I did in fact have the power to say "no". "No, I do not want to talk about this right now." "No, I do not want to talk about this with you." I believe that my parents wanted to show by example to not be afraid of talking openly about my cleft, but I do not recall a time where they said that it was also ok not to share if I didn't want to.

**OPEN BOOK:**
Some kids are very open and comfortable talking a lot about their difference, but others may not be, and that is okay.

Learning to own my story and be comfortable sharing, or choosing not to, is a tool that I wished I learned at an earlier age than I did. As your child begins venturing out into the world, going to playgroups, and their first days of school, have conversations with them about how they want to talk about their difference. Some kids are very open and comfortable talking a lot about their difference, but others may not be, and that is okay. Help them come up with things they are comfortable saying when the questions and comments happen. Giving your child that little bit of empowerment will go a long way in helping them to realize they can share as much or as little as they want, and that you will support them no matter which option they choose. •

### ABOUT THE AUTHOR:



Vickie Stolle is a wife, mother, music lover, writer, and founder of the company Dragonfly Paradigm. She is also a woman born with a bilateral cleft lip and palate. Vickie knows from firsthand experience the emotional challenges one goes through when living with a facial difference. As a result, she has developed tools and strategies to support emotional resilience that she shares with the facial difference community through Dragonfly Paradigm. In addition to launching a digital course for parents of cleft affected children in the spring of 2022, Vickie currently sits on Smile Train's Cleft Community Advisory Counsel.

# WHAT FAMILIES NEED TO KNOW ABOUT OUT-OF-DISTRICT PLACEMENTS

**THE RIGHT PLACE:** Most children can be accommodated in their home school districts. Parental participation in decisions about what the child needs should be fully considered and respected in the placement decision.

BY LAUREN AGORATUS, M.A.

*Parents sometimes have to weigh the pros and cons when deciding on having their child with a disability in a school different from their home district.*

## WHAT DOES THE LAW SAY?

The Individuals with Disabilities Education Act (IDEA) states that “Each public agency must ensure that a continuum of alternative placements is available to meet the needs of children with disabilities for special education and related services.”[1] Further, IDEA states that the child’s placement “is as close as possible to the child’s home.”[2] It is important to note that parents are part of the IEP (Individualized Education Program) Team that makes the placement decision.[3] Families should not be walking into an IEP meeting and be told to sign the document; parents are a key part of the team that drafts and shapes the IEP.

## LEAST RESTRICTIVE ENVIRONMENT

IDEA also emphasizes that children with disabilities are entitled to a free, appropriate public education (FAPE) in the least restrictive environment. The least restrictive environment means that the first choice should be the school and classroom the child would have attended, if they didn’t have a disability. Alternate placement only occurs if FAPE cannot be achieved even with the provision of appropriate supports and services This is what the IEP team needs to decide collaboratively together, based on what the child needs.

## STUDENT IMPACT

Research in early intervention (EI) shows that children who are segregated even as early as birth to age 3, tend to remain so throughout their adult lives. Parents may be transitioning from EI and not be aware of their options or their child's rights. Data also shows that both children with and without disabilities benefit academically from inclusion.[4] Isolating based on disability, sometimes exacerbates the situation. For example, one wonders how a child with communication impairment (CI) will learn to communicate if the entire class has CI. Inclusion also allows for exposure to typically developing peers. Inclusion advocates also note that supports and services are portable so the team, including parents, have to look at what the child needs and not automatically assume it has to be provided somewhere else.

## THE INCLUSION DILEMMA

Most parents want their child to attend their home school and make friends in the neighborhood. The IEP team, including families, need to look at how to make this happen. For example:

- ❒ *If behaviors are the issue, was a Functional Behavioral Assessment (FBA) performed?*
- ❒ *Are there Positive Behavioral Interventions and Supports (PBIS) in the IEP?*
- ❒ *Was a Manifestation Determination done to decide if the behavior was due to the disability, prior to change in placement?*
- ❒ *Would a sensory diet, provided by a specially certified occupational therapist, using sensory breaks throughout the day, help with self-regulation?*
- ❒ *Could in class support/resource address areas of weakness?*
- ❒ *Would having a classroom, or even one-to-one, aide mitigate the need to go out of district with more support?*

Most children can be accommodated in their home school districts. According to the National Center for Educational Statistics, 95% of students with disabilities "ages 6–21 served under IDEA in fall 2019 were enrolled in regular schools."[5] The law however, does allow for a range of placement options. In the end, parental participation in decisions about what the child needs should be fully considered and respected in the placement decision. Families can get free help on this from the Parent Training and Information Center in their state. •

### IT'S NOT ABOUT THE FOOD

A sensory diet an individually tailored plan that outlines a set of specific activities designed to meet a child's sensory needs. Would a sensory diet, using sensory breaks throughout the day, help with self-regulation? Learn more at **www.andnextcomesl.com/2021/08/what-is-a-sensory-diet.html**

### 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**).

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3. https://sites.ed.gov/idea/regs/b/d/300.321
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## NEAR AND FAR : LEARNING MORE ABOUT OUT-OF-DISTRICT PLACEMENTS

allmeansall

**ALL MEANS ALL-INCLUSIVE EDUCATION**
**https://allmeansall.org.au/research**

disabilityscoop

**DISABILITY SCOOP**
"Inclusion Increasingly The Norm For Students With Disabilities"
**www.disabilityscoop.com/2019/02/19/inclusion-increasingly-norm/26067/**

Understood

**UNDERSTOOD.ORG**
"Out-of-District Placement: How it Works"
**www.understood.org/articles/en/out-of-district-placement-how-it-works**

IES NCES National Center for Education Statistics

**NATIONAL CENTER FOR EDUCATIONAL STATISTICS: INCLUSION OF STUDENTS WITH DISABILITIES**
**https://nces.ed.gov/fastfacts/display.asp?id=59**

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

# 5 WAYS TO SUPPORT THE DISABILITY COMMUNITY DURING STRESSFUL TIMES

BY JOSHUA FIELDS AND LISA BUTLER

*Society continues to be a more and more chaotic place… with conditions worldwide changing daily. From a pandemic that plagued our homes to a war abroad raging havoc on so many families. The conflict in Ukraine is a human issue. It is an issue that should reach the hearts of every American. Especially for children and young adults, the issues abroad can be overwhelming, confusing and scary. Helping kids navigate these thoughts and emotions become increasingly more important during this time.*

*Personally, in our line of work, many of our clients who have intellectual disabilities have started to ask questions about the conflict abroad. Conflicts on a global scale often tend to hit close to home. People want to know what they are hearing about on the news, and are looking for answers to remain calm and collected.*

*The following page contains some words of advice to help people with disabilities remain calm in stressful situations:*

## STRESS TEST : FIVE WAYS TO SUPPORT THE DISABILITY COMMUNITY DURING ANXIOUS TIMES

*For children and young adults, the issues abroad can be overwhelming, confusing and scary. Helping kids navigate these thoughts and emotions become increasingly more important during this time. Here are some words of advice to help people with disabilities remain calm in stressful situations:*

### 1.

First thing first, people with disabilities are just like you and me. They should be treated with respect and dignity, and we must acknowledge their individual voices.

### 2.

Being overwhelmed and anxious is a human condition. We all experience these emotions in various ways. Remember to remind your child with a disability that their emotions are valid, and that many people experience the same emotions and stressors.

### 3.

Human instinct is to want to help or solve conflicts. We all often have a "fix it" mentality. Channel this need to want to repair the world, and connect people with disabilities with opportunities to serve their local communities. This act of giving yourself to a cause often helps to relax and bring purpose to an individual. Some of the ways our community members with disabilities serve their local communities include: volunteering at local animal shelters, collecting items and letters for soldiers overseas, and supporting the food pantry with item collections.

### 4.

We all need time to breathe! Take time to teach and practice mindfulness tactics to help relieve stress and anxiety during difficult times. Mindfulness is the way we acknowledge our feelings and the way we process these feelings. Some mindfulness tactics that have worked well for our community include: deep and slow breathing exercises, color-feeling associations, physical exercise, and guided meditation.

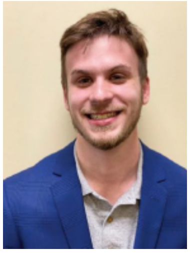
### 5.

Talk to someone you trust or a mental health expert! There is a stigma associated with talking to an expert about issues or negative feelings you may have. It is important to remind people with disabilities (and people without disabilities) that there is nothing wrong with pursuing professional support.

Whether the conflict is here at home or far away, people want to know how changing conditions in the world affect them. People with disabilities are no different. They should be given the access and opportunity to understand major conflicts, and also have the tools to process these complicated feelings.

Our list is in no way an exhaustive list of ways to support people with disabilities during conflict, but we hope it gives you a foundation to start! As the world continues to climb out of the chaos, we must all continue to prioritize equity and inclusion for all people, including those with disabilities.•

**ABOUT THE AUTHOR:**



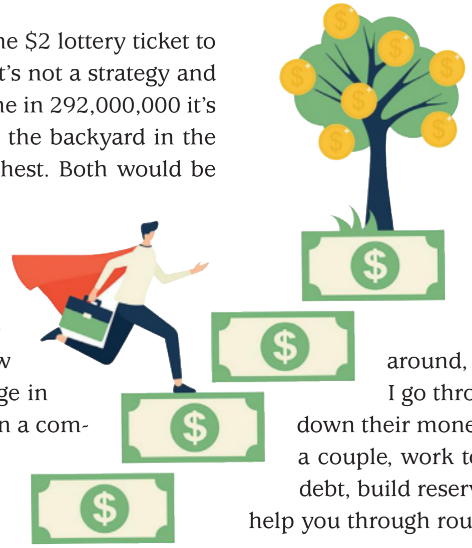
Joshua Fields is the co-founder and CEO of The Next Steps Programs (TNS), a non-profit that aims to break down the barriers that prevent people with disabilities from finding educational and employment opportunities after high school. He co-founded TNS at 16 years old and has been involved in the disability rights movement since.

# KEYS TO ACCELERATING PLANNING FOR YOUR FUTURE

BY ROB WRUBEL, CFP®

*Is there a "secret" to planning for your future? A special sauce that few know that everyone desires? A key to unlock the treasure chest? One tip or technique that makes special needs planning simple, lucrative and done?*

If so, let me know. I can tell you it's not the $2 lottery ticket to win hundreds of millions of dollars. That's not a strategy and with Powerball odds at something like one in 292,000,000 it's barely even a fantasy. It's not digging in the backyard in the hopes of finding a long-lost pirate treasure chest. Both would be nice, though.



Last year, I participated in a research project with the National Leadership on Developmental Disabilities Consortium's future planning efforts (I know, it's a mouthful). The research team wanted to dig into how to help self-advocates and their families engage in future planning. Great work, important work in a complex area of life and the researchers sought to find the top ideas to help propel people into planning. See here for more information: NLCDD Publications (**natleadership.org**).

The researchers asked what helped to make it easier for someone to have an account to fund future needs. This simple question tries to get to the heart of the "secret sauce" that leads some families to plan and others to fall behind.

At events, parties and kids' soccer games, people ask me what "hot stock" to buy. They ask about the economy, the global crisis of the moment and when will gas prices go lower. And while all of the matters to the health of the stock market and the values of our 401(k)s, none of those showed up as one of the top three factors for those in the poll.

What were those tips? The top three factors indicating success were the following:

*I have a clear vision for my family member with disabilities.*

*I went to a class about future financial planning.*

*I have strong family support/involvement.*

The good news from this survey is that two of the three top reasons why people have moved forward are under your control, even if they don't always seem easy.

A vision for the future comes from an important step – taking the time to sit quietly to dream and then to take what comes from those dreams and write those thoughts down. Crafting a vision takes time and it starts with this initial step (then repeated as needed). Some people get caught in the emotions that arise from thinking about the future and stop themselves. Others have not given themselves the permission to ask for what they want. Those issues need to be addressed as you go along though they do not have to stop you from taking the time to try.

Classes on financial planning pop up as you look for them. Many local nonprofits host special needs planning workshops and there are online ones as well. You don't have to start with a special needs workshop – any general financial planning workshop should cover the basics that can get you started. Next time at therapy, ask other parents if they know of classes. Or fire up the search engines and see what you can find.

The third item is a gift when it comes but not one you can always receive. Many families just don't talk about money or the messages passed down are ones of mistakes and failure. These messages can be turned around, once you are conscious of them. One exercise I go through in my workshops is to have people write down their money messages – good and bad. If you are part of a couple, work together to support each other as you pay off debt, build reserves and invest for the future. The support will help you through rough times in building your financial health.

At least once a year, I review my vision of the future. Life changes as my children and I grow, learn and develop. The secret sauce is the process of thinking ahead and having something to go back to when making decisions. The vision gives structure to decision making and a blueprint for success in all aspects of life. It's never too late to start and the benefits are immense – less stress, more finances and a plan for your loved one with a disability can all be in your future. •

## ABOUT THE AUTHOR:

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

FROM OUR FAMILIES... TO YOUR FAMILIES

# MILITARY SECTION

MILITARY LIFE

PTSD SERIES PART III

PUZZLES AND CAMO

**LIVE AND LEARN:** Incidental learning can happen when we grasp something new from reading a novel, watching a movie, going shopping, chatting with a friend, playing a video game, doing household chores, playing sports, taking a hike, or traveling somewhere near or far.

# EMBEDDING INCIDENTAL LEARNING OPPORTUNITIES WITHIN YOUR PERMANENT CHANGE OF STATION

BY ANGELA SHAW

*Mindful focus upon incidental learning can ease the stress of PCS occurrences. Families who are military-connected are greatly similar to their civilian counterparts, however, those in the family of the service member have unique perspectives, adventures and challenges.*

Due to the practice of regularly scheduled duty transfers across the map or around the globe, military connected kids are a highly mobile group, experiencing frequent moves across our nation or worldwide. These recurrent duty transfers from one post or base to the next, termed a permanent change of station (PCS), may occur every two to four years, relative to assignment. The PCSing of families in the military is linked to increased incidence of school transitions and numerous changes in hometowns that may differ intensely rel-

**SKILL BUILDING:** Engaging in games or activities and performing tasks involving balance or motor coordination like standing or jumping on one foot, touching right ear with left hand and so on, can maximize time with family and provide for growth in areas like listening, imitation, motor planning, and fine/gross motor skills.

ative to culture or climate, as well as possible separation from extended family and friends. Even still, despite these daunting circumstances, many military families build and sustain connectedness and resiliency, along with robust and inspired family traditions. One thing for certain, transition and relocation are consistent military-connected inevitabilities, so why not make the most of it. Mindfully embedding incidental learning opportunities along your PCS journey may serve as a helpful step toward creating positive engagement and adaptability within your family's new PCS and beyond.

Incidental learning is informal, naturally occurring learning that does not have to be deliberate or intentional. It happens outside of formal classroom instruction. Incidental learning may be referred to as a "teachable moment". It encourages curiosity, learning and long-lasting memories in a setting tailored to personal interest, or during everyday activities. Using natural experiences promotes learning through enjoyment and participation. It can happen when we learn something new from reading a novel, watching a movie, going shopping, chatting with a friend, playing a video game, doing household chores, playing sports, taking a hike, or traveling somewhere near or far. The side-benefit provided can be increased soft skills, otherwise known as social skills, within valuable and hard-to-teach social areas like communication, teamwork, problem-solving and other interpersonal skills. Increasing these soft skills may serve to benefit positive peer acceptance, interaction within the classroom, as well as during play or other casual moments in your child's day. Additionally, incidental learning may promote increased academic learning within the classroom because of amplified practice, real-life application, cross-learning and most of all, pure enjoyment. Fine and gross motor skills, motor-planning and stamina are often strengthened through play or leisure-time activities, as well. As individuals continue to grow and learn throughout life, incidental learning continues to be important and beneficial, across their lifespan, beginning at infancy and throughout adulthood. The wonderful thing is that these opportunities abound within your home and community wherever your PCS path may lead.

Although incidental learning is a vital component for all, it is particularly beneficial for youth who are identified with special needs. Today's parents and educators are discovering that students identified with specific learning disabilities (SLD), attention deficit disorders (ADD) and a variety of other learning differences, benefit from a mindful approach that includes incidental learning. The beneficial opportunities for incidental learning occurring within natural settings for students identified with a learning difference, can be nurtured and, in fact, are often formally used within the classroom or therapy-based instruction. This specialized methodology is based upon student interest and takes advantage of naturally occurring incidents to teach skills and support generalization.

Parents are the most important teachers in their child's life. Therefore, parents may consider discussing with the IEP (Individualized Education Program) team the possibility of adapting and tailoring the formalized teaching methods currently utilized within the learning environment include incidental learning opportunities at home. The IEP process and specialized teaching practices are often a launchpad in which to start the thinking, planning and customizing, in order to expand engagement, and support diverse learners across a variety of environments. An IEP team may suggest:

- **Nurture and support incidental learning through reading engagement.** Asking questions about the story can foster language, play, comprehension and social skills.
  *"How do you think the boy feels?"*
  *"Why do you think the girl feels happy?"*
  *"What is the horse doing with his head that makes him look sad?"*
  *"What do you think will happen next?"*
- **Involve your child in cooking.** Incidental skills in math, planning, and self-help skills, as well as strengthening fine and gross motor skills can be cultivated through cooking tasks. Beginning with safe no-heat recipes or tasks and progressing toward increasingly complex culinary adventures may be appropriate. Through measuring and stirring

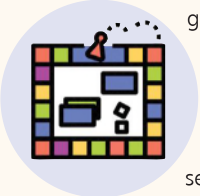
ingredients, frosting cupcakes, calculating times and setting timers, children enjoy time with family, relish the cooking and tasting experience, while being provided valuable life and motor skills and incidental side-benefits.

Much incidental learning is already occurring at home. The tone and manner in which parents, grandparents, other grown-ups in the home as well as neighbors and the community at large, interact with one another, provide many incidental learning scenarios that influence the children. Authentic praise and appreciation are key in support of internalizing positive growth and effort.

In summary, mindful exploration and customization of your child's strength's and needs through natural incidental opportunities can in many ways mitigate the stress and challenges of PCS events. Imbedding incidental learning techniques can unlock a wealth of perspectives and understandings. Many everyday incidental learning occa-

## WHILE WE'RE AT IT : INCREASING OPPORTUNITIES FOR GROWTH THROUGH INCIDENTAL LEARNING

Authentic praise and appreciation are key in support of internalizing positive growth and effort. Offered here are a few ideas to support and inspire families embarking upon a path of mindful engagement of incidental learning:



- **Engaging in games or activities on family night** that involve turn-taking, potentiates the learning of social and play skills, all-the-while increasing connection and bonding. Playing imitation games, such as Simon Says or similar games, while performing tasks involving balance or motor coordination like standing or jumping on one foot, touching right ear with left hand and so on, can maximize time with family and provide for growth in areas like listening, imitation, motor planning, and fine/gross motor skills.

- **Family-time within the local community or on the road** provides a range of embedded learning possibilities. Building language and critical thinking skills through a fun family adventure can be discovered via authentic reflection and discussion of family trips and outings. Expanding knowledge about one's physical and social world and follow-up discussions through the shared eyes and thoughts of others promotes empathy, navigational skills, listening and turn-taking. Try building in supports for talking and turn-taking, such as setting a visual timer, passing a concrete object to the talker or drawing names from a bowl.
- **Hobbies have the power to ease feelings of boredom** and cultivate feelings of connection and positivity. Engagement in chosen activities during leisure time for fun, enjoyment and relaxation is a general description of a hobby. Helping your child grow in their hobby offers a range of benefits. Based upon your child's interest and skill, hobbies may include physical, creative or academic pursuits. Many hobbies inspire a healthy curiosity, as well as generalization and growth across a broad expanse of life, academic and motor skills. Interestingly, studies reveal that individuals identified with dyslexia often persevere through intense reading materials when geared to their specialized interests or hobbies. Parent and child discussion of interests and motivations, observation of strengths and staying open and positive are helpful tips in guiding your child toward discovering a meaningful hobby. Shared interests within the family can further serve as a connecting line through interesting discussion, fun activities, as well as learning and playing together.

The sky is the limit when considering the benefits of hobbies:

✓ *Identity and connection: The likelihood for kids who are military-connected to broaden their social scope through engaging in a hobby, can easily be potentiated when they find meaning and enjoyment in their chosen activity. Hobbies are portable and offer opportunities to connect with others with similar interests within their current, past and future PCS.*

✓ *Skill building: Engagement within a chosen hobby often allows for opportunity to tap into an inherent strength, which allows opportunities for social, academic, physical skills, vocational growth and skill building. Through a favored hobby, children and teens may boost a wide range of positives:*

- Relaxation
- Self-confidence
- Self-control
- Patience
- Goal-setting and accomplishment
- Decision making
- Problem solving
- Physical activity
- Fine/gross motor
- Bilateral coordination
- Critical thinking
- Creativity
- Exploration of new ideas

✓ *Boost well-being: Children and teens are afforded a wealth of activities and experiences that encourage social, emotional and physical well-being through a myriad of possible hobbies. Taking care of others, understanding other's perspectives, and turn-taking are all essential components of playing, making friends and positive engagement within the community. Hobbies involving caring for animals, volunteering, recycling and birdwatching are but a few activities children and teens may be inclined toward. A few hobbies to spark the imagination include:*

- **Organized sports:** Movement and strength-building are encouraged through organized sports. Playing as a team, increasing confidence and problem-solving are potential side-benefits. Mindfulness of your child's interests, strengths and preferences relative to proximity and movement patterns are proactive considerations when considering organized sports as a hobby.

sions have the potential to connect you and your children to the bounty of your new hometown and hold the capacity for creating a substantial network of inspiration and application to be drawn upon today and stored for use in tomorrow's endeavors. This practice can often turn challenging situations into confidence building teachable moments, causing transitions to be positive events replete with learning opportunities. •

## ABOUT THE AUTHOR:

Angela Shaw is a retired special educator with dual Master's degrees in special education and school counseling. Her son-in-law is active-duty military. Angela and her husband spend their time enjoying their military family and exploring the scenery along the way. With a writing focus upon special education topics, Angela synthesizes her teaching experiences and education to support and encourage families and educators navigating the diverse learning needs of the children in their care across a changing educational landscape.

- **Yoga:** For kids who seek a physical activity without the competitive component, yoga might be an option of interest. Reanna Shaw, certified yoga instructor and military spouse, shares that some kids may enjoy practicing yoga as a physical outlet on their own, rather than coordinating with a team or a group after a long day of socializing at school. In a recent interview, Reanna shared a wide range of valuable incidental opportunities:

o ***Increased balance to support daily living*** *is a physical and emotional need that benefits people of all ages. The balance of mind/body connections is realized through yoga practice. Through poses that require balance strength and stability are gained, affording safety and improved physical movement. As an outcome of performing balancing poses that require different parts of the body working together, improved concentration, focus and memory are nurtured.*

o ***Body awareness*** *which generalizes increased conceptual awareness of where one's body is in space, in order to better control movement is supported through yoga. In many aspects of life, knowing where your body is located in space can be helpful for safety, socialization and daily tasks of living. Body awareness serves to create more efficient movement patterns. Reanna, suggests initially providing the visual support of a mirror along with auditory cues, as your child practices their yoga poses. Eventually fading the mirror support and suggesting to your child to visualize what their body looks like while they are in the pose will begin to increase body awareness. This visualization exercise can be done with eyes closed, if your child has the balance to support that practice. Otherwise, just have them keep their eyes open and visualize in their mind's eye what the pose looks and feels like. You can also try a seated pose with this exercise, if your child is working toward balance. Through modifications and practice your child potentiates their ability to feel what their body is doing. For example, with arms extended outwards to either side of their body, your child may be able to picture in their mind's eye the distance of their hand from the trunk of their own body and the distance from their hand to the wall next to them. They can imagine how far their arm would reach from the wall. This awareness is vital to children, in order to increase motor planning, understand how their bodies move and coordinate their body through space and around objects in their environment.*

o ***Self-soothing, mindfulness, and relaxation*** *can be potentiated. Through yoga practice one is encouraged to slow down enough to observe their mind in a way that is gentle and without judgement, comparison or expectation. For example, when feeling frustrated for a moment during the day, one may internalize the ability to pause without reacting emotionally; then reflect and realize the meaning behind whatever is causing that thought or feeling minus a big emotional reaction, which supports getting through the day without emotional blow-ups.*

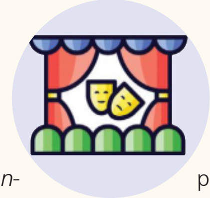
Parents can help kids grow in their yoga practice while supporting learning and development through yoga games and yoga stories. Reanna pointed out that yoga instructors focus upon positive intentions and positive words. She left me with what she considers a vital social/emotional piece of what yoga incidentally provides children through instructional guidance, "Yoga focuses upon positivity and gratitude, which fosters optimistic outlooks through gratitude and noticing the positiveness of the world around them."

- **Gardening:** Digging in the soil, feeling the sun and fresh air and caring for nature's bounty is a relaxing pastime for many kids. In addition to lowering stress, kids are exposed to and navigate plant life cycles, soil types and insects or worms. Many enjoy increased strength and physical mobility, small motor control and motor skills, as well as incorporation of sensory play through gardening.
- **Performing Arts:** For youth who find joy in music, dance and theater, a wealth of side-benefits is extended. Performance-based hobbies offer exciting activities for the family to enjoy through active or passive interaction, in addition to enhancing physical remuneration.

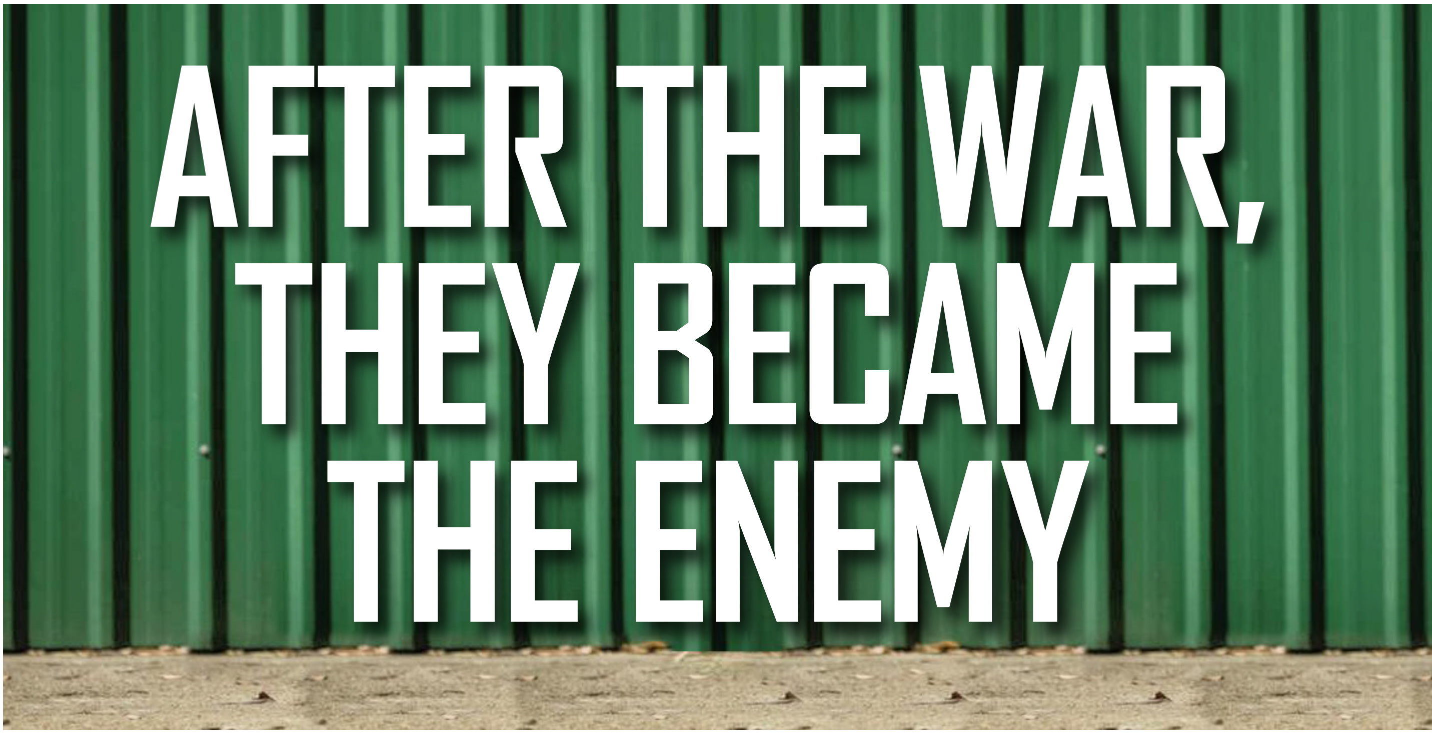
o **Singing** has the potential to enhance respiratory and cardiac function.

o **Dancing** can nurture joy in spirit and maintain physical health.

o **Theater and acting** may hone your child's expressive and/or receptive communication skills, perspective-taking and problem-solving skills. Actors are provided a channel for self-expression and emotional exploration.



o **Playing a musical instrument** derives multiple brain benefits. This includes regions that process fine and gross motor skills, executive functions of planning and decision making, and regions that process vision, sound, movement and memory.



# AFTER THE WAR, THEY BECAME THE ENEMY

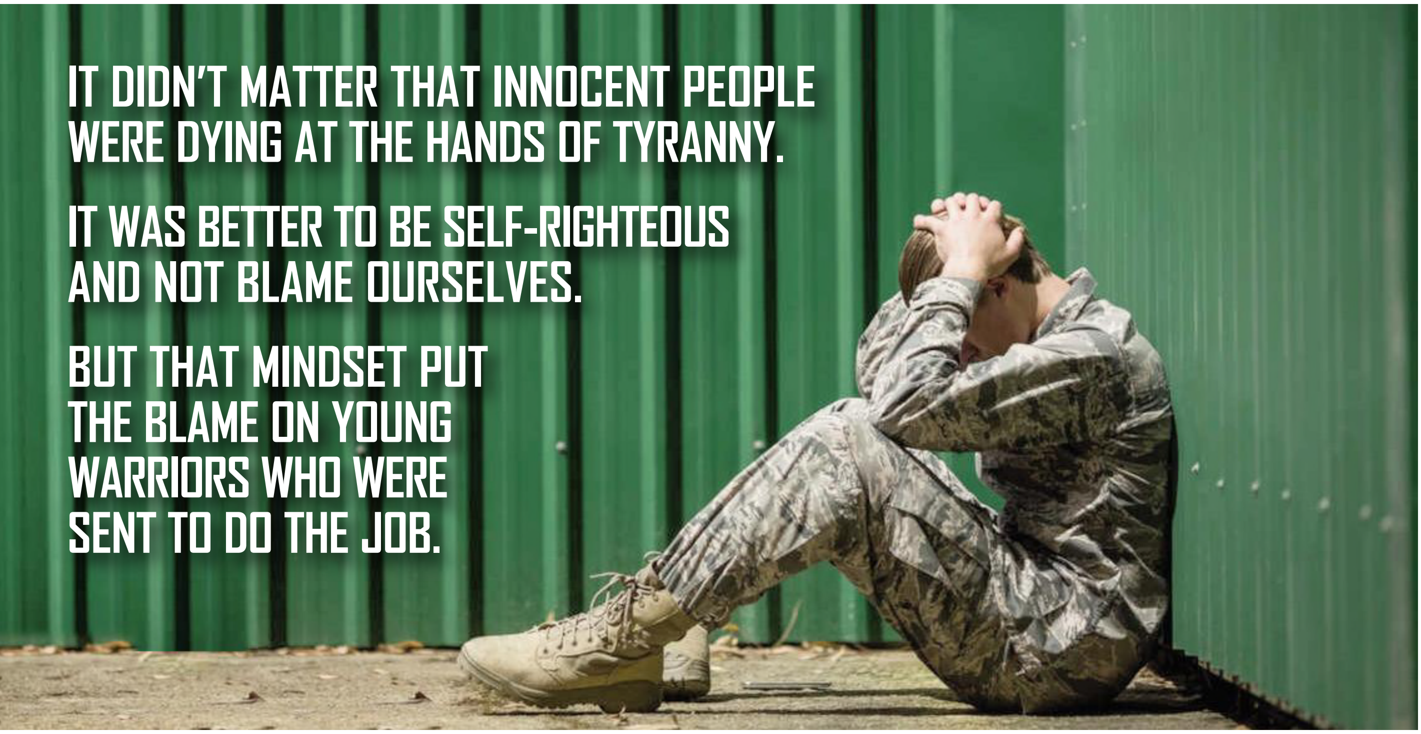
BY DOMINIC CERTO

*"Pow" is the sound of a muffler blast from a past-its-prime car. Suddenly, you're face down on the sidewalk, biting gritty cement, with one arm outstretched and the other bent firmly against your side. As you lay on the cold winter concrete reaching for a weapon that doesn't exist, you look up to see two somewhat familiar men in business attire. They are looking down at you with questioning eyes, wondering if you are mentally challenged or uptight – alarmingly so. Your new job as a trainee broker for an investment banking firm is already in jeopardy as you struggle to calm and compose yourself, offering apologies.*

This is how you now recall those years, post-Vietnam 1970s. The Wounded Warrior Project, designed to honor and empower wounded soldiers returning home, had yet to be invented. Homecoming receptions for combat warriors, if they took place at all, were notable for what they lacked. There was no "Thank for your service." No smiles or support. If the folks back home displayed concern, it was fear for their own safety. The American boy trained to fight and kill in foreign wars was returning to civilian life as a grown man – possibly dangerous, addicted to drugs and violently deranged. **This is the first phase of your post-combat life: "The social readjustment process for returning Vietnam combat veterans."**

"Oh, my God" is the sound of your wife, holding up her arms in fear and self-defense, anticipating your bursts of violence. Her beloved husband is now transformed into a stranger who suffers from chronic nightmares. You struggle to shake yourself free from dreams of hellish landscapes where you find yourself – and almost lose yourself. Shocked and wide awake, she asks what's happening and if you're all right. You have no idea what kind of screams she heard or what actions you may have executed, but you are thankful that upon awakening, you were no longer there, trapped in a hellish nightmare. The woman you care about looks at you in shock, fear and a touch of sympathy as you beg her to relax. You tell her it's OK, but she's not so sure. She's afraid, concerned and unsure about the future. **This is Phase Two: "The family readjustment process for returning Vietnam combat veterans."**

Silence is the deafening sound that envelopes you, as you stare at a wall and remember the worst parts of war. The choppers bellowing from above, carrying dead or wounded friends. Blood-splattered children crying for the loss of murdered parents. Explosions, smoke and rounds of fire. It all reminds you that hell exists beyond the world of the dead. You look for a cigarette, a drink, a joint – anything to stop the thoughts. This is life in the 1970s – the TV paints you as a war criminal, not a returning hero. It doesn't matter if you served to defend or you tried to save lives – you were part of an atrocity, no matter what ideals you nurtured. Who are you and what have you become?



IT DIDN'T MATTER THAT INNOCENT PEOPLE WERE DYING AT THE HANDS OF TYRANNY.

IT WAS BETTER TO BE SELF-RIGHTEOUS AND NOT BLAME OURSELVES.

BUT THAT MINDSET PUT THE BLAME ON YOUNG WARRIORS WHO WERE SENT TO DO THE JOB.

Wake up, Marine. **This Phase Three: "The personal readjustment for returning Vietnam combat veterans."**

Each war had a message for returning combat vets. After World War II, Americans held out open arms to tell them: We all struggled together, let's rebuild. The iconic photo of a sailor kissing a young nurse on the cover of *Life* magazine, the parades in the streets, the patriotic movies – all these symbols of appreciation gave the combat warrior a sense of pride, welcome and understanding.

Then Korea made its mark. Vets were seen as faithful heroes who did their jobs, contained the enemy and established a perimeter that exists to this very day. They were treated with a cosmetic-like measure of compassion. It was not the "Big One," but it was another battle that called American soldiers to active duty, and our heroes answered the call. Yes, they faced their own inner struggles, but the country's arms were open and proud.

Fast-forward to the 1970s and Vietnam. Americans shared a day-to-day disdain for not only the conflict of war, but also the political aspects of it. As a country, we had graduated and succumbed to our own uninformed political opinions. TV war dramas, drugs, free love and spoiled kids of the '60s dominated the news and opinions. The country was rich and powerful, and couldn't be bothered by the messy, dirty, bloody aspects of war. It didn't matter that in one far-eastern land, a government fueled by cruelty and greed was trying to overtake and dominate another. It didn't matter that innocent people were dying at the hands of tyranny. It was better to be self-righteous and not blame ourselves. But that mindset put the blame on young warriors who were sent to do the job. Vietnam was too far away to understand. The Russians and ballistic missiles were easier to fear. It was a nuclear era, considered to be more modern then it really was. The world was still a place of aggression and barbarism. But the comfortable, spoiled youth – many in academia and falsely led – labeled themselves heroes. They were able to turn the country against the soldiers, especially the Marines, who did the dirty work.

There are too many suicides every day, committed by maladjusted combat vets from all wars. But the trauma of combat and war is magnified by immeasurable exponents when the warrior is scorned, ignored, labeled and forgotten. This is the case of the Vietnam vet. While "Thank you for your service" finally includes them, they still suffer the effects of a nationwide rejection that persisted for too many years. For those veterans who did return home, the scars will not go away. Fifty years later, they deserve a salute to their service, their sacrifice, and their brave response to the call of duty. •

*This article was first published in the Washington Times in 2015.*

### ABOUT THE AUTHOR:

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

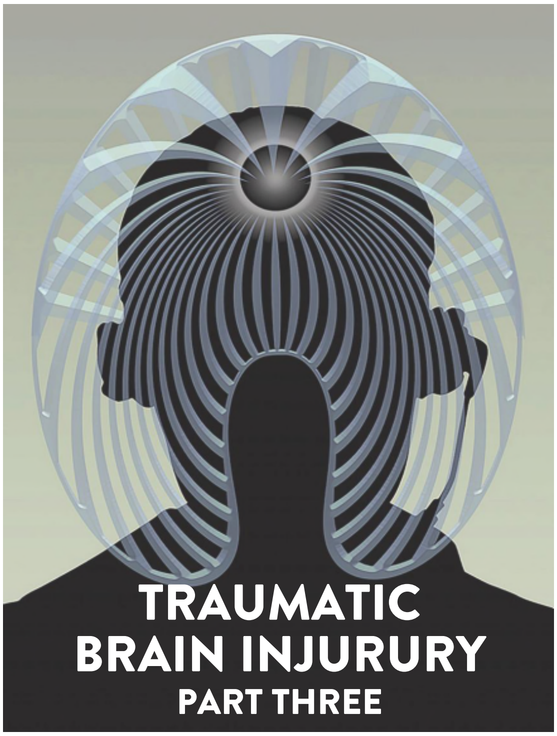
U.S. MILITARY ★ PTSD SERIES PART III

# Substance Abuse: A Crisis of Hope

BY LORRAINE SILVETZ, MSW

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

*The world is not an easy place, and when you have endured a traumatic experience in combat, a servicemember can be left with a scar on the psyche. There is no way to escape the fact that an experience of heightened fear and violence casts a shadow upon its recipient. We may avoid the memories in a number of ways, through repression, denial, and forms of escape. This does not negate that the experience of pain and fear occurred.*



To avoid something does not mean it does not exist. It means that the one who went through the traumatic event is not willing to re-experience the memory. Unfortunately, what we try to avoid only builds momentum, becoming stronger, wielding demons in its wake.

These demons come in small sizes at first, such as inconsistent sleep, irritability, lack of concentration, and the inability to get along with others at work or at home, and then they grow into more insidious demons, taking shape in the form of self-destructive activities, such as binge drinking, drug abuse, and sometimes even violence. Trying so hard to run from the painful experiences of the past, the person is unconsciously attracted to creating destructive experiences in the present.

Avoiding pain through self-destructive behavior is not the answer. Many veterans are coming back to the United States addicted to painkillers as well as illicit drugs. They experience a lot of shame after they have taken them. For example, one veteran shared with me that he did things he was not proud of while on them, and another shared that he disappointed a family member by driving drunk and by acting irrationally. There was a theme of heavy, even if irrational, guilt that remained consistent among all of the veterans in their anecdotes about taking drugs or drinking excessively. To get past the guilt, the servicemember needs to see what drove him or her to making these potentially lethal choices in the first place. If one can get past the shame to look at how one was feeling shortly before taking drugs or drinking excessively, one may find that the feelings are the same. Some shared with me their feelings of hopelessness, general malaise, despair, and anger, which led to their desire to escape by numbing themselves or desiring to achieve that brief feeling of euphoria and elation that might come from a stimulant. They expressed that they were looking to ease the dull ache, the insidious pain, with which they were wrestling, in most cases unconsciously.

## LEARNING FROM MY MISTAKES : A NARRATIVE FROM AN ANONYMOUS MARINE

*Editor's Note: This narrative was written by the same concerned U.S. Marine Corps Noncommissioned Officer (NCO) veteran who contributed to the first installment in the series about traumatic brain injury, post-traumatic stress disorder, and related health issues, which appeared in the March 2022 issue of EP. The piece describes the experiences of this Marine veteran attempting to cope with traumatic experiences undergone during his time in combat, his subsequent struggle with substance abuse, and his road to recovery.*

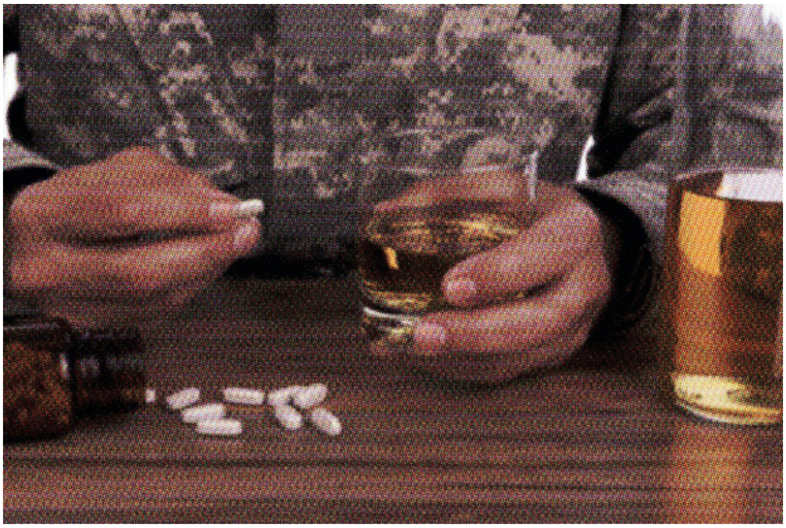
The first time I ever used a substance, it was a 10mg Valium. I was at my old job. My boss was a Vietnam veteran, and he had a prescription. I was extremely stressed out one day, and my boss said, "Try one of these." He gave me the Valium, and I felt like a million dollars. After I experienced that, I went to my doctor and told him, "I've been feeling great stress, and is there any way you can help me relieve it?" She wrote me a prescription for 10mg of Valium, and I didn't take it every day. I would take it once a month and increased the dosage anywhere from 20mg to 30mg and finally got up to 100mg in one sitting, but once a month. When I was on Valium, I would lie on my couch and listen to music by Pink Floyd. I would try to do this before my wife came home from work so that she wouldn't see that I was altered. But still, I wasn't using it every day. Then I would go back to the doctor and get another prescription. I went infrequently so that I would not be red flagged. This went on for six months. I switched doctors, and he was even more willing to write me prescriptions. He prescribed 10mg of Valium. This went on for a few years. Two years ago, I started getting sick a lot and had a few physical problems that required painkillers. First, I was prescribed Percocet, then OxyContin, and finally Vicodin. Then I started mixing drugs. I wouldn't be taking the prescribed amounts. I would be taking much more.

At that point, my wife started to notice that I was out of it. She warned me that I shouldn't be taking too many medications. As my health worsened, I finally got to a point where I was out of it for a month. My wife left me at this time, since I had become uncontrollable. At that point, I went to rehabilitation, stopped taking these drugs, and went to a new psychiatrist who prescribed antidepressants and antianxiety medications. I was prescribed a large dosage of Ativan, and I went through a month's supply in a week. I was drinking and taking antianxiety medications. I was on a real binge. While I was abusing drugs, my judgment was very impaired. Finally, I ran out of my antianxiety medication and my psychiatrist would not refill my prescriptions due to his understanding that I was abusing them. For three weeks, I was living in hell, going through withdrawal. I was circling around my dining room table in a panic, feeling like I was going to die. It was through prayer that I made it through the experience. Humans have free will. I asked God for the strength to turn away from drugs, but I had to be willing to do the work. I prayed for help and wisdom. I had hit rock bottom, and it was a real eye opener. I went to my psychiatrist, and I confessed that I couldn't be trusted with large amounts of drugs. I asked for a lower dose of a medication that instead of providing instant relief would provide long-term relief. This was Klonopin. I could not abuse drugs anymore. I have to take medications as they are prescribed. I bought seven-day pill holders, designating morning, afternoon, evening, etc. It structured the taking of the medication for me.

I've been a balanced individual ever since. I now am thinking clearly. I'm happy instead of being totally emotionless; I now feel joy. I started going out and doing things that I've always wanted to do, like taking singing lessons. And I feel more productive at work. Also, I don't lose my temper the way that I used to. This new regimen, in tandem with therapy, has really helped me change my life for the better. I can have a conversation that gets to a point of disagreement and can now express myself calmly instead of becoming angry. This was not easy for me before. I also stopped drinking, since I understood that drinking was a catalyst to craving the other substances. They go hand in hand. I am clean and sober, although taking medication as prescribed by my psychiatrist. What I would strongly recommend is instead of taking pills out of the bottle, get one of those weekly pill containers, since when I was abusing them I would take a few out of the bottle, not realizing how quickly I was consuming them. Now, I have stopped abusing drugs and feel great. I've improved communication with my family and friends. Again, taking medication as prescribed, I am feeling stable and at peace. If conflicts arise, I can handle them in a spirit of equanimity as opposed to angry confrontation. The only time that I do express my rage is in therapy, which is a safe holding environment and is within reason. In other words, I don't get up and punch my therapist!!

Therapy and psychopharmacologic agents have made a huge difference in my recovery. And, again, I really recommend that weekly medicine container, since it has made a huge difference for me, since it kept me on the straight and narrow in taking my prescriptions in a correct fashion. What I went through, I don't want anyone else to go through. Get help before you lose your family, job, and all that is important to you. We are military men and women, and we know what self-discipline is. We should remember our training and practice that self-discipline that was instilled in us to get us out of this mire. I would also recommend speaking to a professional about your problems and what you've been through. When I did so, it opened the pressure cooker and all that rage which had built up inside of me started to release in a positive way as opposed to a destructive one. When you are doing drugs or drinking to excess, you are only masking the pain and anger that you are feeling. You are hurting yourself. It is simple: If you were feeling good and happy, you would not be taking drugs or drinking excessively since you wouldn't feel the need. As a Marine veteran NCO (Noncommissioned Officer) who cares about his brothers at arms, learn from my experience. I am not fully recovered from all that I've been through, but this problem will not defeat me.

Some veterans shared that they feel as if they are bad in some way, and that is why they are taking drugs and alcohol. They seem resigned to the notion that they are not worthy of feeling good about themselves. Face it, waking up after a night of bingeing and/or drug use is not a good feeling. One is not going to wake up singing, “Oh, what a beautiful morning!” Many have said to me that to attempt to allay the urge for drugs, they imagine what they will feel like about 12 hours from the beginning of taking them, in hopes of being deterred. Generally, they will succumb to the urge, because the pull for that feeling of relief is stronger than the deterrent of a hangover the next day. It’s those 12 hours that the servicemember is after, a way to relieve the pain. What do I mean by relief? Feeling better. A way to escape feeling depressed, anxious, or half alive, as one military member described. The problem is that this relief is so very temporary and, even worse, can prove fatal. Where can a servicemember find a form of healthy relief? Therapy is a good start. Unfortunately, some express their fear of opening up with anyone, afraid that their history would not remain confidential. There is a feeling of loss of safety after having been through some very scary, life-and-death events. Feeling trust in anyone or anything in a world that no longer feels safe is a very difficult hurdle to overcome. There is a loss of faith not only in themselves but in the world at large.



If you can relate to this, do not give up on finding a practitioner or friend that you can trust to share your experiences with, since this is not a problem that is conquerable alone. The desire for relief from the pain born out of traumatic experiences is a very strong one. One veteran said that he grapples with the desire to turn to drugs or alcohol. What occurred to me as he said this is that one needs to get in touch with what is driving the actions toward this destructive behavior. Before healing can occur, he or she will have to take a long, hard look at the traumatic event and its aftermath.

Fear is a mighty foe. There is fear of facing the past, fear of remembering the acts from combat, and fear of facing a personal sense of guilt for these acts. Self-medication is a way of escaping from fear and shame. The problem is that this form of escape not only creates more shame, but can put a person’s life in jeopardy. In speaking with veterans, I found that several of them were not moved by the idea of losing their lives while taking drugs. They had seen close friends, comrades, the enemy, and innocent civilians die, and they were numb to the desire to live as a result. They seemed to be living in and out of their bodies. In therapeutic terms, they were dissociating.

> **“No matter how low you think you have sunk into an abyss, there is hope. At the root of all of this pain is a crisis of faith. I do not mean faith born only of religion, but faith whose root lives in a person’s innermost, private being – the faith that produces the momentum to believe that life can be meaningful again.”**

Dissociation is a very self-protective act, a form of defense, to dissociate oneself from feelings that were generated by a traumatic event. Unfortunately, war is a source of traumatic events. Dissociating is a way for one’s psyche to protect itself from experiencing feelings of sorrow and pain. The double-edged quality of this defense is that it leaves a person unable to experience real joy as well.

In an attempt to survive, the ability to thrive has been thwarted. One becomes like a vessel floating emptily, aimlessly, uncertain of the past and very disconnected from the future. The present is what one is attempting to endure. And the quest for the high, the quest for numbness, is a way to avoid feeling pain, an attempt to experience a synthetic form of joy or elation. It is not the kind of joy one feels when he or she sees a loved one accomplish a milestone in their lives (e.g., seeing a son or daughter graduate from college, or an elder parent reach age 80, or the feeling of joy one feels when he or she falls in love). It is a very temporary feeling of elation. As I’ve heard it described, “I felt amazing, although it was short-lived.” Where is the future in that shortlived feeling? There is none. It is hollow. So how does one shed the pain, be alive again in a real way? How does one learn how to create and experience real joy? How can one avoid being paralyzed by the pain of the past? No matter how low you think you have sunk into an abyss, there is hope. At the root of all of this pain is a crisis of faith. I do not mean faith born only of religion, but faith whose root lives in a person’s innermost, private being – the faith that produces the momentum to believe that life can be meaningful again. To do this, one must investigate the pain born out of past traumatic experiences that led to this place. One must face it, look it in the eyes, and make peace with it, and more often than not, a person needs to seek self-forgiveness.

Mankind carries his own jury and executioner within, which when fully engaged is waiting to criticize its owner. The louder this voice is within, the harder one binges, the more one desires to escape or numb feelings and emotions, creating a vicious cycle in which one feels less and less alive.

Finding hope in the midst of so many contradictory feelings is not easy. Ideally, part of this path needs to be traversed with a trusted professional who can help a patient wade through the traumatic experiences that led to destructive behavior. This requires a person to let down his or her guard enough to let someone in. A practitioner or friend has to care enough to avoid judgment while they help the person cultivate the best of themselves, heal the hurt and anger, and plant the fragile seeds of self-esteem. As healing occurs, the seeds of success, instead of failure, are nurtured and lead to seeing the world in a very different way.

But often, one needs support to redefine personal faith in life. Man is not an island. Much of our pain and sorrow in life is sown with others— and healing will not occur without a band of brothers holding our hand along the way.•

*Recovery from substance abuse related to post-traumatic stress disorder can be gained through programs like Alcoholics Anonymous (AA) and Narcotics Anonymous (NA), where people find the safety to share their feelings and experiences with others. AA and NA along with individual therapy and medication prescribed by a professional are among the best forms of treatment for addictions.*

## ABOUT THE AUTHOR:

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

# Different Perspective at Sixteen

## As I watch Broden grow, he knows. He knows what is happening around him. He knows there are things Hayden is doing that are things he will not get the chance to do.

Broden turned sixteen years old this past month. This was a tough one. Broden should be getting his driver's license and walking out of the house to see the car he would soon be driving to school. As parents, Mark and I should be excited for him, but still feel the pit in our stomachs, knowing that he will not be experiencing a different level of freedom similar to his older brother, Hayden. Broden should be looking forward to prom this Saturday like his older brother. I should be helping both of my boys try on their tuxes and I should be purchasing two corsages, one for Hayden's date and one for Broden's date, but I'm not. Broden's milestone birthday, in a way, cemented the fact that his life is very different than a typical kid his age. I'm not sure if Broden will truly understand what freedom feels like. It hurts and I realize that this is the reality I will face.

This is the dark side of severe autism. This is the side that no one likes to hear about because it makes people uncomfortable. People do not know what to say because there isn't really anything anyone can say. I don't want to hear an apology, it just is. It's part of our lives if we like it or not. I keep telling myself that I need to focus on where Broden is at now and celebrate the little things. Something as small as Broden reaching out to connect with his brother is a glimmer of light in my eyes. Hayden was gone for a ten day school trip to Costa Rica. Broden never asked about him, but Mark and I would watch Broden walk into his room each day to check if he was there. When Hayden came home, he walked into Broden's room to say hello and give him a turtle necklace he had bought him. Broden looked at Hayden and reached out his hand so Hayden could hold it. Hayden smiled and squeezed his hand, "Hey there Buddy. I missed you." Broden stood up and hugged him, then ushered Hayden out of his room.

Hayden looked at me sort of defeated, "Broden doesn't even want me in his room. I've been gone for a week and a half". I told him that I understood that it hurts, but he needed to focus on the fact that Broden reached out to hold his hand. I assured him that Broden missed him while he was gone. I've learned over the years that Broden shows that he cares in his own way. Something as small as witnessing the simple shifts in his requests or reaching out for a hand squeeze, is really important for Broden.

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**PULLING TOGETHER:** "I assured Hayden *(above, right)* that Broden missed him while he was gone. I've learned over the years that Broden shows that he cares in his own way."

One thing I've noticed is a change is in how he likes his hair. About a month ago, Hayden was running late for school and he was putting hair product in his hair while Broden was waiting to jump in the shower. I'll never forget how intensely Broden was watching Hayden. After Broden got dressed after his shower, he came to me and said, "Hair." I had noticed that there were clumps of hair product in his hair. Broden had tried to mimic his brother by doing his hair like his big brother. As I pulled the clumps of product out of his hair I asked, "Broden, do you want your hair like Hayden's?" After blurting out, "Yea," I told him that in the morning, if he tells me to do his hair, I can do it for him so it can look like Hayden's hair. Ever since that day, Broden will come to me and say, "Hair product" to remind me to do his hair. I like to think that this is his way of coming of age in his eyes. He knows he's getting older and he notices that if he has his hair like his brother, then maybe he'll start to feel like he's being seen as getting older.

> "We'll remind ourselves that Broden is on his own journey and he will be the one to show us where that journey will take us."

It's the little things that I need to celebrate, little things that the parent with a typical child may not notice. A few weeks ago, Broden's behavioral therapist texted me and was so excited. Broden had cussed appropriately, "I'm going to use my own damn hands!" Normally, a parent would be frustrated with receiving a text such as this one, but I was ecstatic. I remember telling her, "Please let me know if he cusses again and uses other cuss words, because I know I say enough of them!" With cussing appropriately and then texting his behavioral therapist that he was bored in therapy, one might think that there are several aspects about Broden that are quite typical. This is what makes autism so mysterious and complex. As I watch Broden grow, he knows. He knows what is happening around him. He knows there are things Hayden is doing that are things he will not get the chance to do. This is what makes being sixteen, not so sweet.

Broden at sixteen will not be testing for his driver's license. Broden didn't go to prom last night with his brother, but we'll continue to celebrate what Broden can do. We'll remind ourselves that Broden is on his own journey and he will be the one to show us where that journey will take us. He just needs to know that where ever that journey leads, we'll be there supporting him every step of the way. •

### 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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