PLUS: UNITED STATES MILITARY SECTION

EXCEPTIONAL PARENT
MAGAZINE
FEBRUARY 2024
$14.95

CLINICAL REASEARCH TRIALS:

WHY ARE PEOPLE WITH DISABILITIES LEFT OUT

PLUS • ENCOURAGING PHYSICAL FITNESS:

FIRST STEPS *to* HEALTHY HABITS

FAMILY TRIPS:

WORTH *the* WORK

EP's ANNUAL HEALTH CARE ISSUE:

Parenting Takes A Village

EP MAGAZINE
1971 2024
53
YEARS
CELEBRATES

Corie and Scarlett Weber

CONTENTS

FEBRUARY 2024 VOLUME 54 ISSUE 2

ANNUAL HEALTHCARE ISSUE

FEATURES

ON OUR COVER

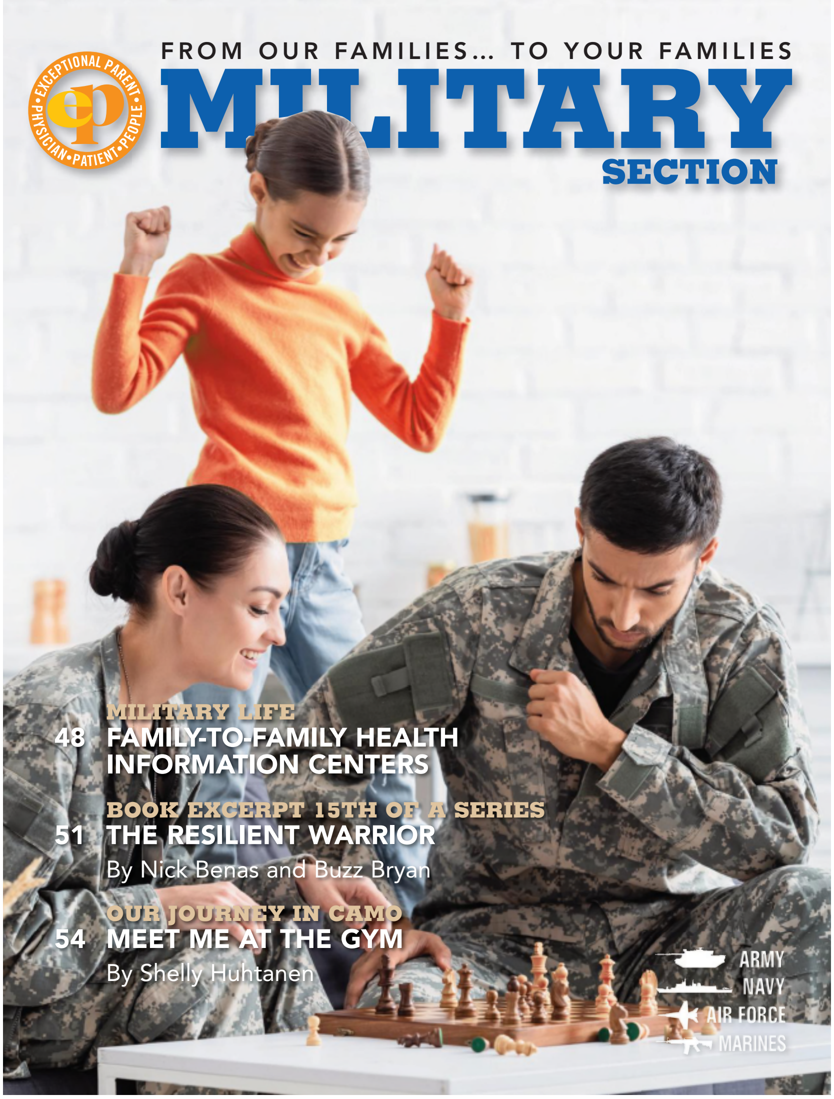
EP Magazine's Annual Healthcare Issue contains a wide selection of articles for parents and caretakers who are raising children and youth with special healthcare needs, including families who have multiple children with disabilities. Further topics include early intervention, oral care, medical bills and physical fitness – concerns faced by most families, but especially challenging to those with special needs. *Coverage begins on page 12.*

CONTENTS

FEBRUARY 2024 VOLUME 54 ISSUE 2

DEPARTMENTS

MILITARY SECTION



GET SOCIAL WITH EP MAGAZINE

Stay current with Exceptional Parent Magazine. New issue updates, exclusive article excerpts, and inspiring and helpful content for the special needs community.

FOLLOW US TODAY ▪ SHARE OUR POSTS ▪ RETWEET

FOLLOW EP ON TWITTER

[NEW TWITTER ADDRESS]

twitter.com/epmzine

FACEBOOK

facebook.com/
exceptionalparentmag

INSTAGRAM

instagram.com/epmzine

SUBSCRIBE FOR FREE AT EPMAGAZINE.COM

To Your Health

According to the National Institutes of Health, approximately 1/5 of all kids in the U.S. have a special health care need.[1]

Our focus in the February issue of EP Magazine is healthcare, and particularly as it pertains to individuals with special health care needs. For individuals with disabilities and special health care needs, these needs may be medically-complex, meaning many areas of life are impacted, possibly over the individual's lifetime, or, they may have a single diagnosis that temporarily impacts the individual and the family.

As Cindy Weber and Tara Szymanek point out in our cover story, "the more people with disabilities in a home, the more support they will require. This means that supporting the needs of multiple children with disabilities can require additional support for both the children and caregivers throughout their lifetime." Their article is an excellent summary of how parents can locate and utilize specialized support systems on the local, state and federal level, as well as create a support network of family and friends.

> "The needs of children with disabilities can require additional support for both the children and caregivers throughout their lifetime."

The issue also contains articles on various other challenges families face while caring for people with physical, developmental or intellectual disabilities, such as: obtaining adequate oral care; navigating medical bills; and encouraging physical fitness. Other highlights include an informative overview on newborn screening, and an especially poignant piece by Kim McCafferty on the tradition of her yearly family vacation.

Lorene Reagan, MS, RN addresses the question "Why Are People with Intellectual and Developmental Disabilities Left Out of Clinical Research Trials?" and Lauren Agoratus, M.A. offers "How People with Disabilities and Their Families Can Be Involved In, Lead, and Change Systems of Care."

We would like to remind our readers that comments, suggestions and questions are appreciated at fsimon@epmagazine.com or epmagazinevp@gmail.com. Your feedback helps us in our goal to constantly provide relevant and helpful information to as many families and professionals as possible, on a wide variety of topics. We also request that you share our magazine with friends, family, coworkers and colleagues who might benefit from our substantial content, and let them know that they can sign up for EP for Free at www.epmagazine.com to read both the digital magazine and newsletter for free. Be sure to join our community by following us on Facebook at facebook.com/exceptionalparentmag, on Instagram @epmzine and on twitter.com/epmzine and share our posts.

Faye Simon

Editor In Chief

---

1. www.cdc.gov/childrenindisasters/children-with-special-health-care-needs.html

THE EDITOR IN CHIEF'S DESK

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

Information and Support for the Special Needs Community

VOLUME 54 ISSUE 2
ESTABLISHED 1971

Publisher
Len Harac
lharac@epmagazine.com

Editor In Chief
Faye Simon
fsimon@epmagazine.com

Art Direction & Design
Leverett Cooper
lev@foxprintdesign.com

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

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

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

EXCEPTIONAL PARENT MEDIA

Exceptional Parent (ISSN 0046-9157) is published monthly 12 times per year including the special January EP Guide - Navigating Special Needs Resources by Exceptional Parent Magazine, 1360 Clifton Avenue, Ste. 327, Clifton, NJ 07012 Internet address: www.epmagazine.com. Postmaster: Please send address changes to: Exceptional Parent,1360 Clifton Avenue, Ste. 327, Clifton, NJ 07012. Any applicable periodical postage paid at Clifton, NJ and additional mailing offices (USPS 557-810). Basic annual subscription for EP Digital is free. Limited edition print subscription $199.00. Subscriber Service: Direct all inquiries & address changes to: Exceptional Parent, 1360 Clifton Avenue, Ste. 327, Clifton, NJ 07012 08758. Customer Service/New Orders: E-mail: fsimon@epmagazine.com or call (973) 726-6218. Back issues incur a charge of $17 each with shipping, (January issue $20 when requested) and depend upon availability. Call (973) 726-6218. Agreement #1420542

A QUARTER OF TEENS WITH AUTISM GO UNDIAGNOSED, RUTGERS RESEARCHERS FIND

About a quarter of 16-year-olds with autism spectrum disorder (ASD) have yet to receive a formal diagnosis, according to research from Rutgers

DIAGNOSIS ZERO: "The finding that many individuals go undiagnosed – and that many adolescents who could benefit from support never receive it – suggests that schools and health care providers could improve their tools for detecting ASD."

The study, which appears in the *Journal of Autism and Developmental Disorders,* used a method called active multiple-source surveillance to produce what its authors believe to be the best-ever data on ASD prevalence among adolescents in our region.

"We think this is the largest ever study of ASD in this age group, and we hope it helps schools, health care providers and others with information that leads to better understanding and services," said Walter Zahorodny, an associate professor at Rutgers New Jersey Medical School and lead author of the study.

The researchers found that, overall, 1.77 percent of 16-year-olds in northeastern New Jersey have ASD, but the condition affects males more than females, whites more than Blacks or Hispanics, and high-income adolescents more than low-income peers.

Researchers also found that one in four adolescents with ASD has not been diagnosed and that three in five ASD adolescents have one or more neuro-psychiatric conditions – most commonly attention deficient hyperactivity disorder (ADHD).

> ***"ASD was twice as common among adolescents from high-income households compared to low-income families, and was 50 percent more prevalent in white adolescents than in Black and Hispanic peers."***

Researchers reviewed school and health records for 4,875 of the 31,581 16-year-olds who lived in four northern New Jersey counties in 2014. That initial review identified 1,365 records that merited comprehensive evaluation and analysis, which, in turn, confirmed 560. Of those, 384 had been previously identified by monitoring when the cohort was 8 years old, and an additional 176 individuals satisfied ASD diagnostic criteria at age 16.

ASD was identified more frequently in adolescent males, 2.89 percent, compared to females, 0.62 percent. ASD was twice as common among adolescents from high-income households compared to low-income families. ASD diagnosis also varied significantly by race and socioeconomic status. ASD was 50 percent more prevalent in white adolescents than in Black and Hispanic peers. (There weren't enough Asian teens in the cohort to compare rates.)

"This confirms what other studies have found about the relative occurrence of autism by sex, race and socioeconomic status in childhood, and it almost certainly reflects true incidence patterns rather than better diagnosis rates among groups that get more frequent and better medical care," Zahorodny said. "Our study didn't examine why prevalence rates vary, but other studies suggest a complex interaction of genes and environment."

The study's most important findings may be the identification of a significant number of undiagnosed autism cases, particularly among adolescents with mild forms of impairment and the high percentage of adolescents with ASD who also have other neuropsychiatric disorders.

The finding that many individuals go undiagnosed – and that many adolescents who could benefit from support never receive it – suggests that schools and health care providers could improve their tools for detecting ASD. The finding that most people with ASD have another neuro-psychiatric disorder suggests that this group will have more complex and possibly require more intensive interventions and planning.

The latest study was the second by this research group to examine the same group of people, but Zahorodny hopes it won't be the last. "We would love to continue studying this same cohort going forward because we know so much less about autism in adulthood," Zahorodny said. "Continuing to follow this group of more than 500 people could greatly add to what is known about ASD and how it is characterized in adulthood, which will, ultimately, lead to the identification of interventions which maximize well-being."

Read the study at **https://link.springer.com/article/10.1007/s10803-023-06058-8**

BRAIN RESEARCH
IES
FOUNDATION
Since 2004

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

THE IRENE AND ERIC SIMON BRAIN RESEARCH FOUNDATION

We are back in 2024!

FIRST EVENT SINCE COVID

Endorphin Golf
Outing & Dinner
June 3rd, 2024
at Lake Mohawk Golf Club
in Sparta, NJ

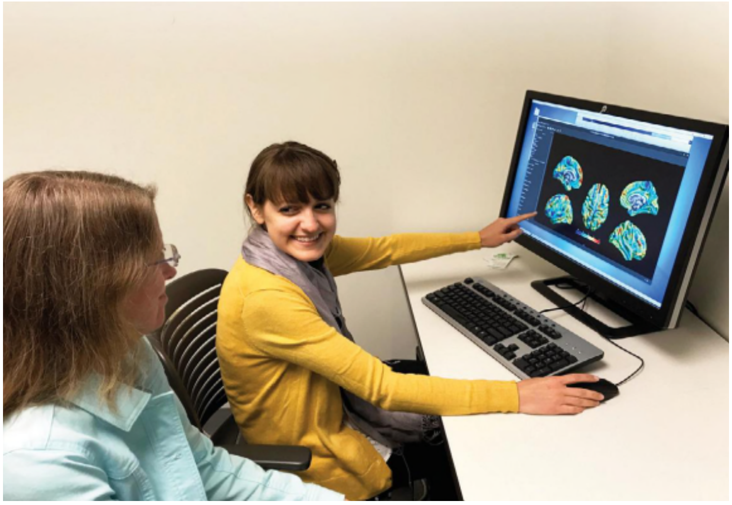
SUMMER FELLOWSHIPS

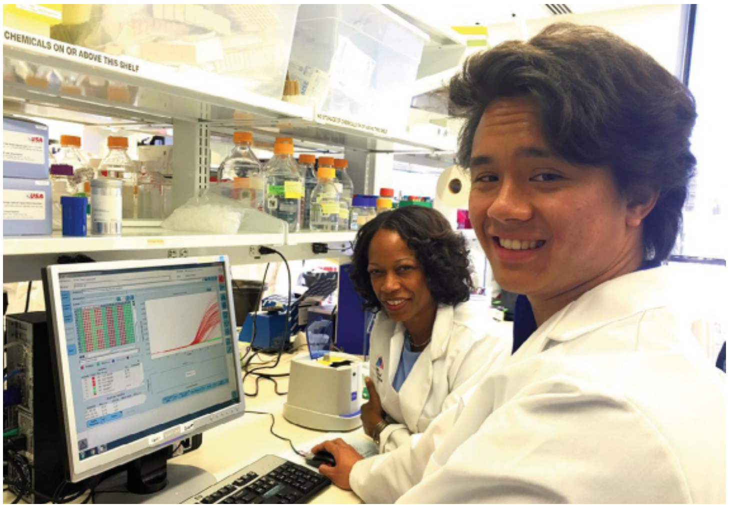
will resume

SPECIAL CELEBRATIONS IN 2024

The inspiration for our Foundation, Eric Simon would have been 100, as well as his wife and Foundation co-namesake, Irene.

2024 is also the 20th anniversary of Irene and Eric Simon Brain Research Foundation being announced.





www.iesBrainResearch.org

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

www.facebook.com/IESBrain | www.twitter.com/IESBrain | www.instagram.com/iesbrainresearch

WHAT'S HAPPENING

WALMART INTRODUCES SENSORY-FRIENDLY SHOPPING HOURS FOR INDIVIDUALS WITH AUTISM

To support shoppers with sensory disabilities, Walmart is adding sensory-friendly hours between 8 a.m. and 10 a.m. local time every day at all of its stores in the U.S. and Puerto Rico, the retail giant announced recently.

SERENE SHOPPING: The retailer aims to provide a less stimulating shopping experience for individuals with sensory sensitivities such as autism.

The stores will turn off the radio, lower the lights where possible and change the TV walls to a static image during those hours. The company does not have an end date for these changes, according to the announcement.

Walmart decided to add sensory-friendly hours to all of its stores after receiving positive feedback from a pilot initiative earlier this year.

Walmart tested out sensory-friendly hours during the back-to-school season last fall but previously limited the hours to Saturday mornings. Initially, the retailer offered this accomodation in July and August.

“These changes may have seemed small to some, but for others, they transformed the shopping experience,” the company wrote in its announcement. “During these hours, we hope our customers and associates will find the stores to be a little easier on the eyes and ears. These changes are thanks to those who shared their feedback on how their stores could help them feel like they belong.”

Walmart has previously made other changes to its operations to serve customers with concerns. Beyond changing its operations for customers with sensory disabilities, the company early on in the COVID-19 pandemic set aside 7 a.m. to 8 a.m. as the grocery pickup hour for shoppers aged 60 and older, first responders, customers with disabilities and other high-risk shoppers.

Sensory-friendly hours were spearheaded more than a decade ago by museums and other cultural institutions that cater to children, and have been moving into the mainstream ever since.

- *The Smithsonian Institution says it was one of the first when its "Morning at the Museum" program began in 2011, offering early entry and sensory-friendly activities to people on the autism spectrum.*
- *Other pioneers included the Museum of Modern Art and the Metropolitan Museum of Art in New York City.*
- *AMC Theatres offers a regular schedule of sensory-friendly films in partnership with the Autism Society: "We turn the lights up and the sound down, so you can feel free to be you at these unique showings for people living with autism or other special needs."*
- *Chuck E. Cheese holds “Sensory Sensitive Sundays” with early openings plus “a quieter environment, dimmed lighting, and a trained and caring staff to ensure each guest has a safe, fun-filled visit.”*

In addition to making its stores more inclusive, Walmart has invested in revamping its stores nationwide. Last month, the retailer said it is investing more than $9 billion over two years to upgrade over 1,400 U.S. locations with new features, including improved layouts, broader product selections, QR codes with helpful product information and nursing rooms for families.

WHAT'S HAPPENING

WYDEN, SMITH ANNOUNCE AGREEMENT ON FRAMEWORK TO REESTABLISH CHILD TAX CREDIT

Senate Finance Committee Chairman Ron Wyden (D-Ore.) and House Ways and Means Committee Chairman Jason Smith (R-Mo.) announced a commonsense, bipartisan, bicameral tax framework that promotes the financial security of working families, boosts growth and American competitiveness, and strengthens communities and Main Street businesses.

WHERE CREDIT IS DUE: A rally for the child tax credit in December 2022 in Washington, DC; A proposed $80 billion package would temporarily expand the benefit, lifting 400,000 out of poverty entirely and make another 3 million less poor in its first year.

Senate Finance Committee Chairman Wyden said: "Fifteen million kids from low-income families will be better off as a result of this plan, and given today's political climate, it's a big deal to have this opportunity to pass pro-family policy that helps so many kids get ahead. At a time when so many people in Oregon and all across America are getting clobbered by rising rents and home prices, the improvements this plan makes to the Low-Income Housing Tax Credit will build more than 200,000 new affordable housing units. By incentivizing R&D, this plan is also going to promote innovation and help sharpen our economic competitiveness with China and the rest of the world. My goal remains to get this passed in time for families and businesses to benefit in this upcoming tax filing season, and I'm going to pull out all the stops to get that done."

The deal would enhance refundable child tax credits in an attempt to provide relief to families that are struggling financially and those with multiple children. It would also lift the tax credit's $1,600 refundable cap and adjust it for inflation.

"American families will benefit from this bipartisan agreement that provides greater tax relief, strengthens Main Street businesses, boosts our competitiveness with China, and creates jobs." Ways and Means Chairman Smith said. "We even provide disaster relief and cut red tape for small businesses, while ending a COVID-era program that's costing taxpayers billions in fraud. This legislation locks in over $600 billion in proven pro-growth, pro-America tax policies with key provisions that support over 21 million jobs. I look forward to working with my colleagues to pass this legislation."

Learn more at https://waysandmeans.house.gov/category/press-releases

THE TAX RELIEF FOR AMERICAN FAMILIES AND WORKERS ACT OF 2024 : A BIPARTISAN BOOST TO FAMILIES

The plan, which will be introduced as The Tax Relief for American Families and Workers Act of 2024, supports working families with an enhanced Child Tax Credit:

- *Expands access to child tax credit: phased increase to the refundable portion of the child tax credit for 2023, 2024, and 2025.*
- *Eliminates penalty for larger families: ensures the child tax credit phase-in is applied fairly to families with multiple children.*
- *One-year income lookback: creates flexibility for taxpayers to use either current- or prior-year income to calculate the child tax credit in 2024 or 2025, similar to bipartisan action taken six times in the past 15 years.*
- *Inflation relief: adjusts the tax credit for inflation starting in 2024.*
- *Helps families get back on their feet with disaster tax relief covering recent hurricanes, flooding, wildfires, and the Ohio rail disaster.*
- *Increases supply of low-income housing by enhancing the Low-Income Housing Tax Credit, a public-private partnership with a proven track record, with increased state allocations and a reduced tax-exempt bond financing requirement.*
- *Eliminates Fraud and Waste by Ending the Employee Retention Tax Credit Program*
- *Saves over $70 billion in taxpayer dollars by accelerating the deadline for filing backdated claims to January 31, 2024 under the COVID-era employee retention tax credit – a program hit by major cost overruns and fraud.*

PHOTO COURTESY TASOS KATOPODIS/GETTY IMAGES

WHAT'S HAPPENING

HHS AND THE ROCKEFELLER FOUNDATION PARTNER TO PROMOTE FOOD IS MEDICINE IN HEALTH SYSTEMS

The U.S. Department of Health and Human Services (HHS) and The Rockefeller Foundation announced a new partnership to accelerate the adoption of Food is Medicine in health systems.

MEAL TICKET: “We know good food is the foundation of good health.”

Through this partnership, HHS and The Rockefeller Foundation aim to improve health outcomes and health equity by engaging a broader public audience in understanding nutrition, accelerating collective understanding of Food is Medicine interventions and their impacts, and exploring strategies to scale successful Food Is Medicine programs to more eligible Americans.

“We know good food is the foundation of good health, and study after study has found Food is Medicine interventions can make people healthier while reducing health care costs,” said Dr. Rajiv J. Shah, President of The Rockefeller Foundation.

While Food is Medicine programs are widely recognized as powerful interventions, they only reach a fraction of those who could benefit. Through a public-private partnership, HHS and The Rockefeller Foundation will exchange information and ideas to:

- *Advance and leverage research design and findings through knowledge to produce definitive evidence on clinical health outcomes, cost effectiveness, and optimal program design.*
- *Engage a broader public audience in the meaning and value of FIM interventions and resources.*
- *Support Food is Medicine adoption by identifying opportunities and barriers to support greater uptake and scaling.*
- *Ensure Food is Medicine supports diverse individuals and communities with a focus on health equity.*

“HHS and The Rockefeller Foundation are working together to accelerate food as medicine adoption in various health systems and communities. We are eager to build on this dynamic opportunity and we anticipate powerful outcomes through collaborative action,” said HHS Secretary Xavier Becerra. “One of our shared priorities is to engage the public in understanding food is medicine. We seek to help accelerate interventions, and build strategies to expand successful programs to more eligible Americans. The Biden-Harris Administration is using every lever available to drive new innovations in policy, and deliver durable solutions that improve our health.”

The Rockefeller Foundation also announced that it is increasing its total commitment to advancing Food is Medicine programs to more than $100 million, which includes up to $51 million to the American Heart Association to increase understanding about the health and economic outcomes of Food is Medicine programs in diverse populations across the United States.

This partnership with HHS also marks The Rockefeller Foundation’s second with the U.S. government to expand domestic Food is Medicine programs. In April 2023, the U.S. Department of Veterans Affairs (VA) and the philanthropic organization announced a new collaboration to support two Produce Prescription pilot projects and associated research pilot programs at VA health care systems in Salt Lake City, Utah, and Houston, Texas. •

ABOUT THE ROCKEFELLER FOUNDATION:

The Rockefeller Foundation

The Rockefeller Foundation is a pioneering philanthropy built on collaborative partnerships at the frontiers of science, technology, and innovation that enable individuals, families, and communities to flourish. The Foundation is focused on advancing human opportunity and reversing the climate crisis by transforming systems in food, health, energy, and finance. For more information, visit **rockefellerfoundation.org** and follow **@RockefellerFdn** on X.

WHAT'S NEW WINTER WARMUP

MAGNETIC WORM GAME

The Woodpecker Magnetic Worm Game features a wooden bird with a magnetic beak and a set of colorful worms that can be fed to the baby bird. The worms are made from high-quality wood and are painted with vibrant colors that are sure to catch your child's eye. The game is easy to play – simply use the magnetic beak to pick up the worms and feed them to the hungry bird. This colorful game will help with counting skills, fine motor skills, hand-eye coordination and developing hand, wrist and finger control. It will encourage purposeful play with zero screen time and develop patience, attention span and self-discipline.

TOPBRIGHT
www.topbrighttoys.com

WEIGHTED HOODIE

Enhance your child's sensory wardrobe with the cozy and calming weighted hoodie that offers both comfort and style. This plush zip-up sweatshirt is designed for maximum relaxation and sensory support. It features removable weights that fit discreetly into inner pockets, allowing your child to enjoy the calming effects without compromising style. One remarkable feature is the specially sewn seams on the weights' lining, ensuring even weight distribution for a non-bulky appearance and a comfortable feel. Grounding weight provides proprioceptive input to the trunk, promoting focus, anxiety reduction, and calm in sensory-loaded situations. Whether at home, school, or on the go, this sweatshirt provides grounding proprioceptive input that promotes calmness and enhances focus.

SENSORY KIDS STORE
www.sensorykidstore.com

BREATHING BUDDHA

The Breathing Buddha creates a gentle daily reminder to pause and focus on mindful breathing during your busy day. For adults and kids who might benefit from a gentle daily reminder to "pause and reset," visual learners who might prefer guided open-eyed meditation, or beginning to advanced meditation practitioners; Easy to follow fade-in, fade-out color prompts that simulate the popular 4/7/8 or 5/5 "calming breath." Fits perfectly on desk or nightstand or wherever you might benefit from a reminder.

MINDSIGHT
www.mindsightnow.com

OUT OF THIS WORLD FIDGET BOARD

Take kids on an intergalactic journey of sight, sound and touch! This rocket-shaped board is packed with tons of irresistible features that children can't wait to explore! From a calming astronaut slider to a rotating satellite that delights with every spin – each permanently attached accessory gives kids an engaging way to calm themselves, improve their focus and more. Durable plastic board measures 10 1/4" x 14".

LAKESHORE LEARNING
www.lakeshorelearning.com

Are You Ready to...

- Increase your income?
- Explore your work options?
- Keep your Medicaid/Medicare while you work?
- Gain greater personal fulfillment through work?

Social Security's Ticket to Work program and Work Incentives can help you find meaningful work. If you're age 18 through 64 and you receive Social Security disability benefits, you can take advantage of these free services.

Choose a Ticket to Work employment services provider.
Work with your provider to plan a better future.

Are You Ready to Choose Work?

Information/Resources
Call 1-866-968-7842 or
1-866-833-2967 (TTY)
Visit www.socialsecurity.gov/work
www.facebook.com/choosework

SOCIAL SECURITY ADMINISTRATION
TICKET *to* **Work**

DEVELOPMENTAL DISABILITIES AND ORAL HEALTH

COURTESY THE NATIONAL INSTITUTE
OF DENTAL AND CRANIOFACIAL RESEARCH

NIDCR supports research to find ways to make dental visits more comfortable for children with ASD. Spanish language captions available in YouTube player settings.

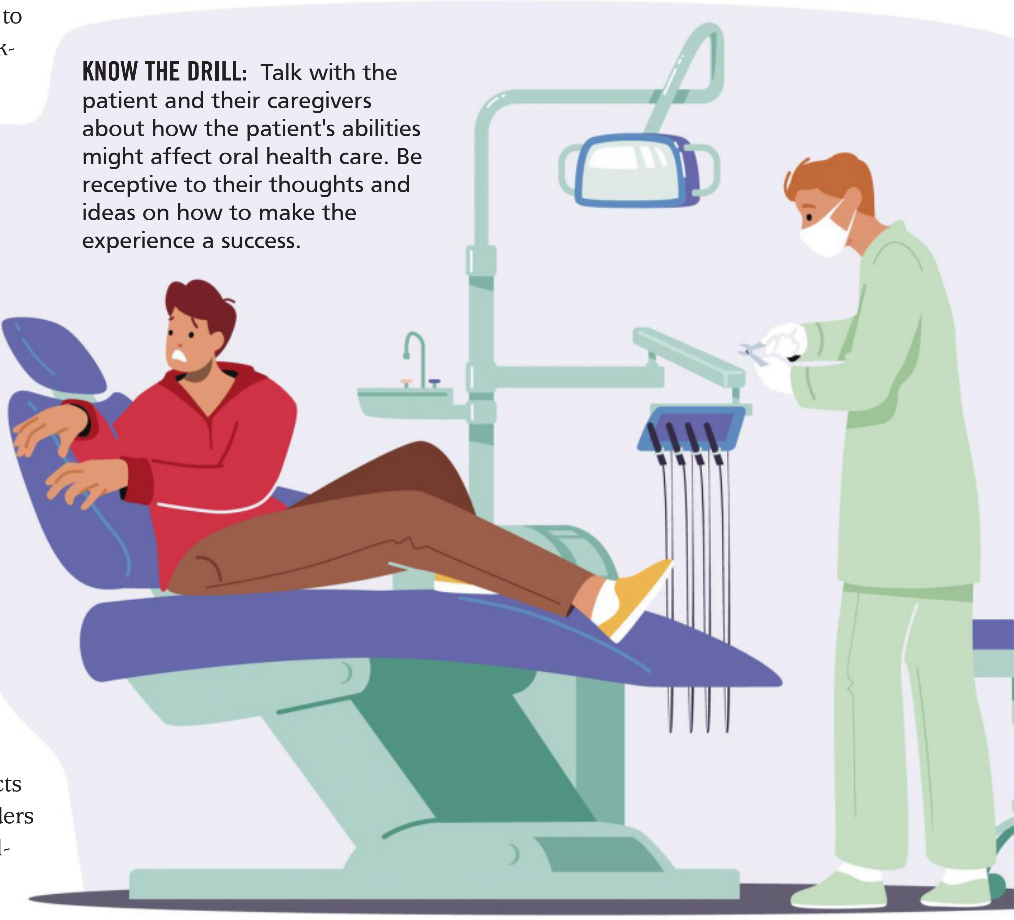
Developmental disabilities such as autism, cerebral palsy, Down syndrome, or others create challenges in accomplishing daily activities, especially self-care. People with these disabilities may need extra help to achieve and maintain good health, which includes oral health.

HEALTH CHALLENGES

- **Mental capabilities** will vary from person to person and may have an impact upon how well someone can remember and follow directions in a dental office and at home.
- **Behavior problems** can complicate oral health care. For example, anxiety caused by a developmental disability may make someone uncomfortable during treatment.
- **Mobility problems** may require a person to use a wheelchair, mobility scooter, or a walker to move around. Mobility issues can also make lifting and manipulating objects more challenging, impacting self-care. Access to the dental operatory and chair may require special arrangements and assistance with patient transfer. Longer appointment times may be needed.
- **Neuromuscular problems** can affect the mouth. Some people with disabilities have persistently rigid or loose chewing muscles, or have drooling, gagging, or swallowing problems that complicate oral care.
- **Uncontrolled body movements** can jeopardize safety and the ability to deliver oral care.
- **Cardiac disorders** are common in people with developmental disabilities such as Down syndrome. Consult a cardiologist to determine the need for pre-treatment antibiotics.
- **Gastroesophageal reflux** sometimes affects people with central nervous system disorders such as cerebral palsy. It may cause difficulty lying on their back, and teeth may be sensitive or display signs of erosion.
- **Seizures** accompany many developmental disabilities. Patients may chip teeth or bite the tongue or cheeks during a seizure.
- **Visual impairments** and **hearing loss or deafness** may also be present in people with developmental disabilities, leading to communication difficulties while being treated.
- **Latex allergies** may be more likely in people with developmental disabilities.

ORAL HEALTH PROBLEMS

- **Tooth decay** is common in people with developmental disabilities. This may be due to poor oral hygiene, and teeth may be crowded or malformed, making them more difficult to keep clean. Dental sealants are effective in children and adults to prevent decay.
- **Periodontal (gum) disease** occurs more often and at a younger age in people with developmental disabilities. Difficulty performing effective brushing and flossing may be an obstacle to successful treatment and outcomes.



KNOW THE DRILL: Talk with the patient and their caregivers about how the patient's abilities might affect oral health care. Be receptive to their thoughts and ideas on how to make the experience a success.

- **Malocclusion** occurs in many people with developmental disabilities, which can make chewing and speaking difficult and increase the risk of periodontal (gum) disease, dental caries, and oral trauma.
- **Damaging oral habits** such as teeth grinding and clenching, food pouching, mouth breathing, and tongue thrusting can be a problem for people with developmental disabilities.
- **Oral malformations** may cause enamel defects, high lip lines with dry gums, and variations in the number, size, and shape of teeth.
- **Delayed tooth eruption** may occur in children with developmental disabilities such as Down Syndrome. Children may not get their first baby tooth until they are 2 years old.
- **Trauma and injury** to the mouth from falls or accidents may occur in people with seizure disorders or cerebral palsy.
- **Prescription drugs** may cause dry mouth, swelling of the gums, or other changes that make it more difficult to achieve and maintain oral health.

HELPFUL TIPS FOR CAREGIVERS

Taking care of someone with a developmental disability requires patience and skill. As a caregiver, you know this as well as anyone does. You also know how challenging it is to help that person with oral care. It takes planning, time, and the ability to manage physical, mental, and behavioral concerns. Oral care isn't always easy, but you can make it work for you and the person you help.

- **Brush every day.** Depending on whether the person you care for is able to brush their teeth, you may need to take on the job of brushing their teeth yourself. Or, modify the toothbrush to accommodate physical limitations to allow the person to continue brushing his or her own teeth.
- **Floss regularly.** Some people with developmental disabilities may find flossing a real challenge. You may need to do the flossing for them or obtain aids such as floss holders or floss picks.
- **Visit a dentist regularly.** Disease prevention, early detection, and treatment are important for maintaining good oral health. It may take time for the person you care for to become comfortable at the dental office. Contact your dentist to plan a "get-acquainted" visit with no treatment provided. This might help to familiarize the person you care for with the office and the exam routine before a real visit.

BUILDING A BRIDGE : ORAL HEALTH AND DD

MEDLINEPLUS

The National Library of Medicine's collection of links to government, professional and non-profit/voluntary organizations with information on developmental disabilities and oral health.

https://vsearch.nlm.nih.gov/vivisimo/cgi-bin

SPECIAL CARE DENTISTRY ASSOCIATION

An organization of oral health professionals and other individuals who are dedicated to promoting oral health and well-being for people with special needs.

www.scdaonline.org

DEVELOPMENTAL DISABILITIES NURSES ASSOCIATION

A specialty organization that provides education and support for nurses who care for people with intellectual and developmental disabilities.

https://ddna.org

DENTAL EDUCATION IN THE CARE OF PERSONS WITH DISABILITIES (DECOD)

This clinic at the University of Washington School of Dentistry provides dental care for people with developmental and acquired disabilities

https://dental.washington.edu/decod

HELPFUL TIPS FOR DENTAL PROFESSIONALS

Providing oral care to patients with developmental disabilities requires adaptation of the skills you use every day. Most people with mild or moderate developmental disabilities can be treated successfully in the general practice setting.

As a dental professional you also need to be aware of the different needs – behavioral, physical, emotional and cognitive – that a patient with developmental disabilities may have. Learning appropriate skills and techniques to meet the unique oral health needs of people with developmental disabilities will help you be successful in delivering care to these patients. Below are some general tips to help you adjust to the special oral care needs of people with developmental disabilities.

- **Create a person-centered environment.** It is up to you to ensure all patients are treated with respect, dignity, and empathy.
- **Determine your patient's mental capabilities and communication skills**. Talk with the patient and their caregivers about how the patient's abilities might affect oral health care. Be receptive to their thoughts and ideas on how to make the experience a success.
- **Set the stage for a successful visit.** Involve the entire dental team – from the receptionist to the dental assistant.
- **Observe if physical manifestations of the disability(ies) are present.** How does the patient move? Look for challenges such as uncontrolled body movements or problems with sitting in a dental chair.
- **Ask if the patient has an allergy to latex before you begin treatment.** Latex allergies can be life threatening and may be more common among patients with developmental disabilities.

For more information, Visit **www.nidcr.nih.gov/health-info/developmental-disabilities**

ABOUT THE NATIONAL INSTITUTE OF DENTAL AND CRANIOFACIAL RESEARCH:

NIH National Institute of Dental and Craniofacial Research

The mission of the National Institute of Dental and Craniofacial Research (NIDCR) is to advance fundamental knowledge about dental, oral, and craniofacial (DOC) health and disease and translate these findings into prevention, early detection, and treatment strategies that improve overall health for all individuals and communities across the lifespan. Visit **www.nidcr.nih.gov**

Parenting Takes A Village When Caring for Multiple Children with Disabilities

BY CINDY WEBER
AND TARA SZYMANEK

CLOSE KNIT: Corie and Scarlett have a seven year age gap, but they're actually pretty close. Scarlett has been Corie's shadow since she could walk. Now that they're both older, they have figured out what they both enjoy, as well as what they should do separately.

PHOTOS PROVIDED BY CINDY WEBER AND TARA SZYMANEK

It's not unusual for families supporting multiple children with disabilities to need to look to the community for opportunities to have the help that they need.

These opportunities can help parents create and maintain an environment to provide strong outcomes for the individual with the disability. Being a parent of a child living with a disability is a long difficult road, but what happens to a family that is raising more than one child with disabilities?

The truth is, the more people with disabilities in a home, the more support they will require. This means that supporting the needs of multiple children with disabilities can require additional support for both the children and caregivers throughout their lifetime. The need for additional support is universal. Often families need to look outside of their immediate circle to the community for support for both themselves and the children in their care.

Navigating medical, school and community systems, all while having to meet the needs of multiple children with disabilities, is a very daunting task. An easy example for us to think of is getting ready for school in the morning. By the time a child is around eight years old, the average parent should be able to delegate some of the tasks to the student to complete each morning, such as picking the granola bar and drink they want in their snack, or putting on their own clothing. However, a child with disabilities, by and large, takes longer to learn these independent skills, and may require verbal and/or physical prompts in order to get ready for school. This requires more parental supervision, and for some children, that higher level of supervision may not change over time.

Teaching life skills, medication management, and an understanding of their disability appropriate to their developmental ability can help the child learn how to ask for his or her needs and accommodations to make a task more achievable. These skills are the foundation needed to teach the child or youth what they need to do to accomplish their life goals. A life skill often overlooked is the ability to go to and participate in dental cleanings. Simple procedures like a preventative tooth cleaning may require sedation or complete anesthesia, making it a procedure that requires much more planning, cost, and risk. These extra steps can make planning for routine care much more challenging.

WALK OF FAME: The Szymanek family enjoying a stroll on Disney's Hollywood Boulevard; *(left to right)* Connor, Michael, Tara, Garett, Sophia and Johanna.

FALL FUN: Cindy Weber with Corie and Scarlett attend a autum dinner hosted by Corie's youth group;“Ideally, every family would have a village of support that they could draw on, but that’s not always the case. Sometimes, we have to find and make our village.”

Neurotypical children are able to learn quickly that it is safe, and what they need to do to have their teeth cleaned. For children with disabilities, this learning process typically requires repetition and perhaps multiple visits per year before they are able to allow dental staff the trust to clean their teeth. You can talk to your dentist about letting your children come in for more than just cleanings. For example: you might bring them in to just sit in the chair and get comfortable with the environment and equipment. For those who can’t become comfortable, sedated dentistry may need to be an option to have their dental needs met. With multiple children with disabilities, dentist visits might need to be separate for each child, and that means a lot more time away from potential working hours for the parent.

Frequently, parents need to balance routines between children that have a wide variation in their skills and abilities. Perhaps, one child can dress themselves independently and pack their own lunch, and the other child requires a higher level of prompting and assistance to complete the same tasks. It can be especially difficult to navigate when the child who requires the higher level of support is older. This is just one example of why it is so important to talk to your children about their disability, and teach them self-advocacy skills. It can also be worth reviewing your child’s routine to see if an additional accommodation might provide them with a higher level of independence. A child that needs a higher level of prompting and support to dress themselves in the morning may be more successful if their clothes are laid out the night before. A small change like this can make the routine smoother, helping both the child complete their daily activities in a more independent way, and the caregiver, by perhaps giving them a moment to help the other child or sit down and tend to their own needs.

For those raising more than one child with a disability, it’s not unheard of for the children or youths’ support needs to be very different. For example, one child may thrive in busy social events, another may prefer to be in a quieter setting. How can parents meet the needs of both children when they conflict? Ideally, every family would have a village of support that they could draw on, but that’s not always the case. Sometimes, we have to find and make our village. Parent support groups can be a good place to start. If you’re wondering where to start, or want to learn more about parent groups and their benefits, check out the Center for Parent Information and Resources for more information. Obtaining emotional and logistical support from a peer who has lived experience, and understands the struggles of raising children with exceptional needs can have an enormous positive effect on the mental health and empowerment of caregivers. They are also a helpful resource for school, community and state level programs that serve families of children with disabilities.

Families raising multiple children with disabilities are much more likely to experience higher levels of stress without support from family or community. “Parents of children with special educational needs experience high levels of parental stress”. (Andrew W. Y. Cheng and Cynthia Y. Y. Lai, 2023) As the old saying goes, it takes a village to raise a child and the need for support is exponential for a parent with multiple children with disabilities. Parents need to coordinate doctor’s appointments, medical procedures, therapies, school, and social events. Everyday outings to the store for immediate needs requires careful planning. Knowing the support available in your area can make a big difference in the outcomes for the family and provide a small sense of normalcy.

BRANCHING OUT: The Szymanek family vists the Tree of Life at Disney's Animal Kingdom; "The care that children with disabilities receive can be complex and difficult to manage with one child. That difficulty increases when you're parenting multiple children in need of specialized care."

Medical case management can be a helpful tool for families providing care for multiple children with disabilities. Where possible, consider selecting providers at a single hospital system. This allows for simpler coordination of care and less overall paperwork for the caregiver to manage between offices. Medical Case management can be a much-needed resource for details surrounding what is covered by their insurance plan, as well as, helping to arrange for things like a personal care attendant. Utilizing Medical Case Management can also streamline assistance with appeals and coordinating complex care.

The care that children with disabilities receive can be complex and difficult to manage with one child. That difficulty increases when you're parenting multiple children in need of specialized care. Talk to your children about the medical professionals that support each child, the medications they take and why. Read social stories or better yet, create your own. Narrate and use checklists that explain what you are doing, as you complete various tasks to schedule appointments. Watch videos of people scheduling, planning, and attending medical appointments. This will support their experience and help them learn the skills they need to complete more complex planning and execution. For resources to help with these skills, check the National Center for Pyramid Model Innovations.

Parenting multiple children with disabilities is universally hard. Having support systems like family and friends to help can really make a positive difference. What happens if they have no experience with disabled children? Perhaps, they would love to have a connection with your child, but have no idea how to relate to them. If they want to learn, teach them. When you explain your child's disability, also include ways to connect and things to avoid.

"How can I learn to build a connection with my grandchildren so we can have a close relationship?" - Sandra Klinkhammer

It's entirely possible that you may have family or friends who would love to help you and build a relationship with your children, but they are unsure how to start. Teaching your child the language to explain their likes and dislikes can also help them explain their needs and connect with others on their own.

In addition, first responders can be overlooked when you're educating your child's community. It's important to consider whether they too might benefit from understanding how best to interact with your children in case of an emergency. Many counties and states have programs that keep registries of those with disabilities or special health care needs, as well as, how best to interact with them, in case of emergency. As this service is run slightly differently in each area, check with your local police and fire department for more information.

For families with more than one child with a disability, there are more factors that contribute to stress than for the average family. Due to the higher level of stress, and the unique needs of the disabled children/youth, parents are more likely to experience marital issues, need mental health services, and are more likely to experience health issues. “Overall, parents may experience grief, isolation, and considerable stress, leading to mental health issues such as, depression and anxiety. The available evidence suggests there are barriers for parents of children with disabilities to access mental health services. (Chen et al 2023)” That is why self-care and stress prevention, where possible, is critical for the survival of parents of multiple children with disabilities.

Parents that are quick to locate support and get informed on what they can use to ensure that they engage in regular self-care, have a head start on the majority of parents of children with disabilities. Self-care goes well beyond getting a manicure or a bubble bath. As an adult supporting children with high needs, you need to find ways to feel supported, rested, and empowered. As parents, we can ensure that we have opportunities for self-care if we build community connections that create what are known as, natural supports to support the family.

PILLARS OF SUPPORT : PARENTING RESOURCES

Here are some helpful federal programs for caregivers of children with disabilities.

CIPR PARENT GROUPS

www.parentcenterhub.org/parentgroups

Find my Parent Center

www.parentcenterhub.org/find-your-center

NATIONAL ASSOCIATION FOR MENTAL ILLNESS

www.nami.org/Home

TITLE V STATE PROGRAMS AMCHP

https://amchp.org/title-v-state-profiles

CHILDREN SYSTEM OF CARE

www.acf.hhs.gov/toolkit/resource-guides-populations-served-acf-programs

Programs funded by the Administration for Children and Families (ACF)

www.acf.hhs.gov/sites/default/files/documents/main/resource-guide-for-families-with-children-ages-0-12.pdf

NATIONAL CENTER FOR PYRAMID MODEL INNOVATIONS

https://challengingbehavior.org/resources

PARENT TO PARENT USA

www.p2pusa.org

The Children’s System of Care is a strong community support for youth and families with mental health, behavioral, and Intellectual/Developmental Disabilities (I/DD) health needs. A youth can be provided a broad range of services, including: short term mobile response therapeutic support, case management with Intensive in the Community (IIC) or Intensive in Home (IIH) therapeutic support. For parents with I/DD youth, there are additional services that vary state to state, but can include respite options, community engagement, and family support services. Also, depending on your school district, there may be a variety of after school support for students with disabilities, such as clubs, sports, and therapies. For more information, consider speaking with the school social worker or your child’s Case Manager.

While the school social worker and the child’s case manager can be helpful resources for navigating school related concerns, parents and caregivers can also contact their Parent Training and Information Center or PTI. Each state has at least one PTI. They are tasked with performing a variety of services for children and youth with disabilities, families, professionals, and other organizations that support them. While each PTI has different programs and services, they are a great resource to find out more about who to contact in your area for assistance. Topics covered might include things like: how to sign up for insurance, Individualized Education Plan (IEP) support, workshops, 504 plans and civil rights laws that support inclusion, both within the school system and in places like childcare settings. To learn more about PTIs and to locate the one nearest to your area, visit the Center for Parent Information and Resources and select “Find My Parent Center”.

It is worth stressing the value that these supports can provide the individual with disabilities. Supported social activities can reduce at home behaviors and overall stress in the home. Having typical children is stressful. When you add on some of the individualized needs of persons with disabilities, it can become quite overwhelming and difficult for parents to maintain relationships, work, and lifestyle, while balancing the needs of their children. We aren’t built equipped to cope with all of these added stressors.

Many parents of children with disabilities experience a process called grief cycling. Although this is not studied heavily, it is the shared experience of both authors, and a common experience for parents of children with disabilities where the parent grieves for the hopes and dreams that they imagined for their child, before realizing their disability would put limitations on those aspirations. There can be a sense of loss when parents realize their child(ren) may have a drastically different future than the one they imagined. As your child(ren) age, so do their peers, so it is completely understandable to grieve the things your child may not experience as a result of their disability. Life transitions like: starting school, riding a bike, learning to read etc. can be very difficult, as they are built in reminders that your children’s journey may be different than the future you imagined, when you realized you were having a baby. It’s natural to compare them to their peers of the same age, and it can be difficult to see the differences in their achievements. It is however, important to celebrate their achievements, no matter how small they may seem. Walking at three is still walking, speaking at 8 is still speaking, and they worked extremely hard to achieve it. Work to notice and celebrate these victories, as they can help defend against feelings of grief.

Parents should learn to be on the lookout for signs that they need support by utilizing mental health resources. Mental health professionals can teach and support in a variety of ways, including: how to be self-aware of your mental health needs, new coping skills, refresh skills, talking through situations, and they can be a sounding board for parents. Since the pandemic, virtual options are also more frequently available, which can address provider scarcity in more rural areas.

It's not unusual to experience stress in your marriage. In fact, many studies address a higher divorce rate when you're parenting a child with a disability. "When you have a child with special needs, your marriage is much more likely to be stressed. This is demonstrated by the numbers: Surveys show that the rate of divorce in families with a child with disabilities may be as high as 87% (Gold Buscho , 2023)." If you and your partner are feeling the strain on your relationship, a little marriage, family, or individual counseling can help talk through the issues at hand, and you can learn new ways to resolve the conflict and get back to living life together. Parenting multiple children with disabilities or special health care needs can put an unsustainable stress on a marriage. It's important that the couple work on communicating their needs in a healthy way, before resentment builds. It may not sound like an important need to a lot of people, but if you have multiple children with disabilities, it is crucial that you find time to recharge yourself and your relationship, whenever you can. Counseling can educate parents separately or together, on new communication tools that can help prevent future issues.

The care of children with disabilities or special health care needs is exceptional by nature. This means your self-care and relationship care must also be exceptional, in order to survive. Finding those moments where you can enjoy your favorite activities can make a big difference in your ability to stay calm during the tough times. In addition to finding alone time, consider working to build in time where you can connect with your partner. What do you enjoy doing together? How can you work on your marriage while parenting children with exceptional needs? It could be something as simple as a shared TV series after everyone is in bed, or an outing to a preferred place. Finding time to spend together as a couple, building and maintaining intimacy in your partnership are significant challenges when you're used to putting the needs of your children first. However, consider the fact that your energy and patience are not limitless, and a strong relationship can be a good source of strength on the hard days of parenting.

> **Your energy and patience are not limitless, and a strong relationship can be a good source of strength on the hard days of parenting.**

No one is going to tell you parenting is easy. Parenting multiple children with disabilities and/or special health care needs is infinitely harder. Consider educating whatever support system you have, as well as reaching out to community resources like parent support groups and your local PTI to fill in what is missing. Finding your community can really impact your parenting journey in a positive way. It's likely that over the years, parenting disabled children will come with waves of grief as you move through the rough patches. Take the moments available to you to rest and recharge, so you can problem solve at your best. Consider alternative ways for your children to complete a task that may allow them to be more successful. Working to develop self-advocacy skills can help children and young adults with disabilities develop the skills needed for appropriate levels of independence. Try and remember the positives, and take the time to really connect with your children over a preferred activity, and laugh with them. •

References

Gold Buscho , A. (2023, February 28). Divorce and special needs children. Psychology Today. https://www.psychologytoday.com/us/blog/a-better-divorce/202302/divorce-and-special-needs-children#:~:text=When%20you%20have%20a%20child,with%20autism%20is%20about%2080%25

Andrew W. Y. Cheng and Cynthia Y. Y. Lai (2023, August 10). Parental stress in families of children with special educational needs: a systematic review Front Psychiatry. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC10449392/

Chen, C., Bailey , C., Baikie, G., Dalziel, K., & Hua , X. (2023, July 6). Parents of children with disability: Mental Health Outcomes and utilization of Mental Health Services. Disability and Health Journal. https://www.sciencedirect.com/science/article/pii/S193665742300078X#:~:text=Overall%2C%20parents%20may%20experience%20grief,such%20as%20depression%20and%20anxiety.&text=The%20available%20evidence%20suggests%20there,to%20access%20mental%20health%20services

ABOUT THE AUTHORS:

Cindy Weber is the Early Childhood Training and TA Specialist for the New Jersey Inclusive Child Care Project and a Family Engagement Coordinator for the Genetic Alliance, both of which are projects that are part of SPAN, New Jersey's Parent Training and Information Center (PTI). In addition, Cindy is the Board President of the Cumberland Gloucester and Salem Family Support Organization. Cindy and both of her children share a diagnosis of PTEN Hamartoma Tumor Syndrome. Through their diagnostic journey and beyond, Cindy learned to adapt to a parenting journey full of unexpected specialists and last minute changes. Cindy is a member of various committees serving New Jersey families as well as serving families of children with disabilities nationally through her volunteer work with the Rare Disease Legislative Advocates and (NYMAC) New York Mid-Atlantic Caribbean Regional Genetics Network.

Tara Szymanek works as a Training Specialist on the (PTI) Parent, Training, and Information Center Training Team, a trainer on the (SEVA) Special Education Volunteer Advocates Project, and a Family Resource Specialist on the (WRAP) Wisdom, Resources, Advocacy, and Parent to Parent Support Project. Tara is a premutation carrier and her twin twelve-year-old children share a diagnosis of Fragile X Syndrome. Tara is a military family member with parenting experiences in military programs, special education, and health advocacy systems. Tara is a graduate of Partners in Policy Making through the Boggs Center of New Jersey and is a member of various committees serving New Jersey families as well as serving families of children with disabilities nationally through her volunteer work with the Rare Disease Legislative Advocates, (NYMAC) New York Mid-Atlantic Caribbean Regional Genetics Network, and the National Fragile X Foundation.

WHY ARE PEOPLE WITH INTELLECTUAL AND DEVELOPMENTAL DISABILITIES LEFT OUT OF CLINICAL RESEARCH TRIALS?

BY LORENE REAGAN, MS, RN

"Clinical trials should, to the extent possible, enroll a population that is representative of the diversity of the population that will use the medical product, if approved." [1] *That makes sense, right? Unfortunately, people with intellectual and developmental disabilities (IDD) are typically left out of clinical trials. They are not alone. Other historically underrepresented populations include people with physical disabilities and people with mental illness.*

WHAT IS A CLINICAL TRIAL?

Clinical trials provide critical evidence regarding whether a medical product, such as a medication or medical device, is safe and effective.

WHAT ARE THE BARRIERS TO PARTICIPATION IN CLINICAL TRIALS FOR PEOPLE WITH IDD?

According to an article published by the American Institutes for Research (AIR®) Center on Knowledge Translation for Disability and Rehabilitation Research,[2] approximately three-quarters of clinical trials funded by the National Institutes of Health, directly or indirectly exclude adults with intellectual disabilities. Some study exclusions specifically disallowed participation by those with cognitive challenges, reduced functional capacity, or the inability to read or write. Additionally, researchers may not have considered the need for accessible study materials, the support needed for people with IDD to participate meaningfully, or the importance of ensuring people with IDD, not proxies, provide direct input, as study participants.

WHY HAVE PEOPLE WITH IDD HISTORICALLY BEEN UNDERREPRESENTED IN CLINICAL TRIALS?

Concerns about informed consent and the capacity to understand the benefits and risks of clinical trial participation, and the potential for exploitation are often cited as reasons for excluding people with IDD from clinical studies. While important, these risks can and should be mitigated through careful attention to inclusive study design.

WHY IS THIS SUCH A PROBLEM?

Excluding people with IDD from clinical trials means the treatments used for a variety of conditions have not been evaluated to determine the benefits or the risks of use in people with specific developmental conditions. One example of this is research involving drugs used to treat Alzheimer's disease. Even though a high percentage of people with Down syndrome will eventually develop dementia by age fifty-five, very few clinical trials involving Alzheimer's disease have included people with Down syndrome.[3]

FAIR TRIAL: Excluding people with IDD from clinical trials means the treatments used for a variety of conditions have not been evaluated to determine the benefits or the risks of use in people with specific developmental conditions.

HOPE IS ON THE HORIZON

In September of 2023, the National Institutes of Health (NIH) formally designated people with disabilities as a population with health disparities, allowing greater opportunities to include people with disabilities in research efforts. "Research to understand the barriers and unmet needs faced by people with disabilities, and to develop effective interventions to address them, is needed. This designation will help to improve access to healthcare and health outcomes for all people." [4]

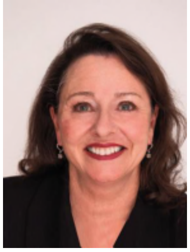
In addition, the US Food and Drug Administration (FDA), the entity responsible for approving drugs and medical devices, recently sought public input into a proposal to address inequities in study design, by requiring those who are conducting clinical trials to use disease prevalence and incidence data by demographic group, to inform clinical trial enrollment by those who are expected to use a particular drug or device. This means information about disability status must be considered in the study design, to ensure that people with disabilities are not unnecessarily excluded.

As advocates for people with IDD, we play a critical role in supporting full and meaningful participation in all activities, including clinical research trials. Understanding the history of exclusion and the efforts to promote inclusive study design and implementation will help ensure that people with IDD have the same opportunities as others to participate in research activities. •

References

1. Public Workshop to Enhance Clinical Study Diversity. 2023. US Food and Drug Administration & Clinical Trials Transformation Initiative. https://ctti-clinicaltrials.org/wp-content/uploads/2023/12/FDORA-Diversity-Primary-Slide-Deck-11.28.-23-FINAL.pdf
2. Inclusive Methods for Engaging People with Intellectual and Developmental Disabilities in Research Practices. 2023. American Institutes for Research® (AIR®) Center on Knowledge Translation for Disability and Rehabilitation Research. https://ktdrr.org/products/info-briefs/KTDRR-EngagingPeopleWithIDD-508.pdf
3. Excluding People With Disabilities From Clinical Research: Eligibility Criteria Lack Clarity And Justification. 2022. Health Affairs. https://www.healthaffairs.org/doi/10.1377/hlthaff.2022.00520
4. NIH designates people with disabilities as a population with health disparities. 2023. National Institutes of Health (NIH). https://www.nih.gov/news-events/news-releases/nih-designates-people-disabilities-population-health-disparities

ABOUT THE AUTHOR:



Lorene Reagan, RN, MS, has over 35 years of experience in the field of intellectual and developmental disabilities (IDD). Lorene is the former Bureau Chief for IDD services in New Hampshire, was Manager of Care Management for a Medicaid managed care organization, and a Principal in a consulting firm focusing on state Medicaid policy and operations. She is the former Director of Public Relations at IntellectAbility (https://replacingrisk.com/) which provides tools and training to agencies, governmental entities, and supporters of people with intellectual and developmental disabilities to foster early recognition and mitigation of health risks and promote health equity for people with IDD. Currently, Lorene provides strategic consulting services focusing on health risk management and health equity for people with IDD.

NAVIGATING CHILDREN'S MEDICAL BILLS

PROTECTING YOUR FAMILY FROM ERRORS & FRAUD

BY DAVID BURZYNSKI

Every parent's primary concern is the well-being of their children, especially when it comes to healthcare. Raising kids isn't cheap.

According to the Brookings Institution, an average two-child family will spend just over $310,000 to raise a child from birth to age 17 (**https://www.brookings.edu/wp-content/uploads/2022/08/Brookings_Cost-to-raise-a-child_inflation-adjusted-2.pdf**). When raising children with disabilities or special needs, it costs even more (**www.autismspeaks.org/financial-resources-autism-help**).

The world of medical billing is often a maze of complexity, with medical billing errors, and sometimes fraud hiding in plain sight. When these sneaky and surprisingly common issues crop up, parents may unknowingly cover incorrect bills for their children's medical care, ultimately creating a significant financial burden.

In today's economy, where costs continue to rise and many families are tightening their belts, it's important that parents are equipped with the right tools to navigate a complicated healthcare financial landscape with confidence.

UNDERSTANDING THE UNSEEN THREAT OF MEDICAL BILLING ERRORS & FRAUDULENT CLAIMS

Medical billing errors, while inevitable, are more common than many people realize. In fact, most bills contain inaccuracies (**www.beckershospitalreview.com/finance/medical-billing-errors-growing-says-medical-billing-advocates-of-america.html**). These errors can manifest in many ways, some of the most common of which include:

- *Double billing: This occurs when a singular medical service is billed more than once.*
- *Incorrect provider information: Attributing care to the wrong provider can cause claim denials.*
- *Unbundling: Some providers may mistakenly bill services separately, when they should be billed together.*

PROTECTING YOUR FAMILY'S HEALTH & FINANCES

To safeguard your family's financial and medical well-being, it's essential to remain vigilant. These five steps can help to establish a strong foundation and proactive process for managing family healthcare costs:

1. REGULAR REVIEW

Schedule regular times each month to review new medical bills and EOBs. Staying proactive can help you catch errors early. At the beginning of each new insurance cycle, thoroughly review your policy to understand its terms and coverage limitations, as well as any changes from the previous coverage year.

2. KEEP RECORDS

Maintain organized and secure records (both physical and digital) of all medical bills, receipts and healthcare-related paperwork. This makes it easier to spot mistakes or quickly address any issues arising from old claims.

3. QUESTION DISCREPANCIES

If you find any differences between the EOB and your healthcare provider's bill, contact your insurance company for clarification and next steps.

4. APPEAL CONCERNING CLAIMS

If you suspect your insurance provider has denied a claim due to an error, follow the appeals process. This is specific to each insurance carrier and may involve providing additional documentation and putting together a detailed case for approval. Parents can take this on themselves or use a service that negotiates appeals on their behalf, to save valuable time and avoid countless rounds of phone tag and hours on hold.

5. GET KIDS INVOLVED

Empower your children with medical literacy and involve them in healthcare decisions, especially their own. Teaching them how health insurance works and helping them implement wellness-fueling habits will show them how to advocate for themselves, and keep them healthy for years to come. This is particularly crucial for children with special needs, as they transition to adulthood.

While billing mistakes already pose a significant concern, an even more sinister issue lurks; medical fraud. Fraudulent medical claims can take on various forms, including billing schemes and identity theft, which can put your child's healthcare at risk while draining your financial resources. A few common examples of medical fraud include:

- *Phantom billing: Healthcare providers bill for services that were never performed or weren't medically necessary.*
- *Upcoding: This occurs when a provider submits a bill with codes that represent more expensive procedures than the ones performed.*
- *Identity theft: Criminals may steal your child's personal information to obtain medical services, which can lead to incorrect bills and compromised healthcare records.*

IDENTIFYING RED FLAGS ON MEDICAL BILLS & EXPLANATIONS OF BENEFITS

Understanding key indicators of common billing errors and being able to identify them early in an Explanation of Benefits (EOB), the document your insurer provides outlining medical claims prior to provider billing, is the first step in protecting your family. Here are some red flags to look out for on both bills and EOBs:

- *Unfamiliar charges: Review your medical bills and claims carefully. If you spot charges for services that you don't recognize or remember, investigate further. It may also be beneficial to use a free tool like Medical Dictionary Online* (**www.online-medical-dictionary.org**) *to look up unfamiliar terms, as well as, brush up on Current Procedural Terminology (CPT)* (**www.verywellhealth.com/what-are-cpt-codes-2614950**) *codes to ensure the correct service is being billed for the correct amount.*
- *Duplicated and unbundled services: Look for repeated entries of the same service on a single bill or claim. Be cautious of itemized services that should typically be billed together as a package.*
- *Incorrect dates or details: Ensure the dates of service listed on the bill and claim match the actual dates your child received medical care. Confirm that the billing provider's name and information match the one who treated your child. Finally, make certain insurance and identifying information on bills and claims is correct.*

At the end of the day, in the complex world of medical billing, knowledge is any parent's most powerful tool. By understanding the landscape, recognizing red flags and taking proactive measures, you can protect your most precious asset, your family, from billing mistakes and fraud. This ultimately ensures your children receive the quality care they deserve while still safeguarding your financial resources.•

ABOUT THE AUTHOR:

David Burzynski is a proud dad and the Chief Customer Officer for HealthLock – a leading digital solution that monitors members' healthcare claims and keeps them apprised of possible red flags putting their medical identity and finances at risk. In his role, David ensures HealthLock reaches and meets the needs of millions of everyday people who want more control over healthcare billing and privacy. More at **healthlock.com**.

PHOTO COURTESY HEALTHLOCK

EP FOR FREE!

RECEIVE A FREE SUBSCRIPTION TO THE DIGITAL VERSION OF EXCEPTIONAL PARENT MAGAZINE

Simply visit us at

www.epmagazine.com

and click

"EP FOR FREE"

you will receive an email each month when the magazine is published as well as a free newsletter.

Both will come from

news@EPmagazine.com

DO NOT REPLY TO THIS ADDRESS.
WE WELCOME YOUR QUESTIONS AND INPUT AT
FSIMON@EPMAGAZINE.COM

Print subscriptions: $199 a year;
Available at www.epmagazine.com
Questions: epmagazinevp@gmail.com

Subscribe Today at www.epmagazine.com

EP's ALL-NEW RESOURCE GUIDE FOR 2023

EXCEPTIONAL PARENT MAGAZINE • $15.95

Early Intervention: STANDARDS FOR EARLY CARE

GROSS MOTOR MILESTONES

Plus: ESTATE AND CARE PLANNING

2023 EP GUIDE
NAVIGATING SPECIAL NEEDS RESOURCES

AI Solutions: WHAT STUDENTS WITH DISABILITIES NEED TO SUCCEED IN COLLEGE

Special Olympics: NAVIGATING YOUR CHILD'S INTELLECTUAL DISABILITY DIAGNOSIS

THIS ISSUE COURTESY OF BLANKROME

AN AMAZING ADVERTISING OPPORTUNITY

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

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

For more advertising opportunities, email us at

fsimon@epmagazine.com

EP MAGAZINE: THE JOURNAL FOR SPECIAL NEEDS FAMILIES AND PROFESSIONALS

FACILITATING NEWBORN SCREENING AND EARLY INTERVENTION FOR INFANTS BORN WITH RARE DISEASES

BY CATHERINE NESTER, BSN

In the push for fast and accurate diagnoses that save lives, improved newborn screening capabilities offer hope for improved outcomes.

Few areas of infant healthcare are as important as newborn screening and early intervention. When it comes to diagnosing and treating babies born with rare diseases, whose symptoms might not be immediately apparent, current comprehensive screening technology has proven to be life-saving.

Consider these scenarios:

A baby is born prematurely and shows signs of respiratory distress. She is immediately admitted to the neonatal intensive care unit (NICU), where she undergoes a series of tests including an electrocardiogram, a computed tomography (CT) scan, and a panel of lab tests. She is seen by a cardiologist and an endocrinologist.

The parents endure what seems like an eternity of waiting. Finally, the cardiologist informs them that some of the tests suggested abnormalities in their baby's arteries, and encourages the parents to consent to a genetic test that could provide additional clarity. They agree to move forward with the test and the results show that their daughter was born with generalized arterial calcification of infancy (GACI), the infantile form of ENPP1 Deficiency, a rare disease characterized by abnormal mineralization and pathologic calcification of the arteries. It is a serious disease that requires early recognition and intervention.

Although the baby remains in the hospital for two months, her condition stabilizes to the point that she can go home with her parents and meet her siblings and other family members. Meanwhile, her parents learn of a clinical trial for what could be the first approved treatment for GACI. The baby meets the trial's eligibility criteria and is enrolled. Over the course of her participation in the trial, during which she receives the investigational therapy, she makes a series of visits to specialists, and undergoes close monitoring. The baby grows and thrives, despite the many challenges related to her disease.

In a different state in the U.S., another family welcomes a baby boy. He is also born prematurely and is admitted to the NICU. He is seen by a similar team of specialists and eventually is sent home, seemingly on his way to a healthy early life. But after a week at home, his parents become concerned and tell their pediatrician that their son is having trouble eating and sleeping. They are told to continue to monitor him and report back if the issues persist.

> **“THESE NEW INITIATIVES, SPURRED BY THE COOPERATION OF PATIENT COMMUNITIES, ADVOCACY GROUPS, MEDICAL EXPERTS, AND INDUSTRY LEADERS, ARE SIGNIFICANT STEPS FORWARD IN PROMOTING EARLY DIAGNOSIS AND INTERVENTION AROUND THE WORLD.”**

One night, their son has trouble breathing. The parents call 911 and ride in an ambulance with him to the hospital. Tragically, he suffers cardiac arrest the following morning in the NICU and passes away. It is only then that a test is performed that shows he, too, was born with GACI.

In rare disease, such a tragic outcome is too often the reality. While newborn screening has continually evolved since its inception in the 1960s, there is much work to be done to close the gap between the positive and negative scenarios described above.

Of nearly four million babies born in the U.S. each year, 98 percent undergo screening in the first days of life. **www.ncbi.nlm.nih.gov/pmc/articles/PMC5381153** But current screening programs vary and currently some states screen for only 31 to 76 of the hundreds of severe childhood genetic diseases that have available treatments. Adding a new genetic disease to a newborn screening protocol can be time-consuming (5 to 6 years per condition), laborious, and costly. While newborn screening is considered one of the most successful public health programs in the U.S., 100 percent of expert participants in a 2021 survey acknowledged the need for change to improve the process. **(https://everylifefoundation.org/wp-content/uploads/2023/09/ELF-NBS-WhitePaper_Final.pdf)**

The limitations of the current newborn screening system underscore the inherent challenges of diagnosing a rare disease. In a recent study, “The Cost of Delayed Diagnosis in Rare Disease,” the EveryLife Foundation estimated that the diagnostic odyssey takes an average of six years and 17 clinical encounters to obtain a definitive diagnosis. When a baby is born with a disease such as GACI, which has just a 50 percent rate of survival in the first six months of life, such an extended timeline is unacceptable. What’s more, the EveryLife Foundation study revealed that newborn screening and early diagnosis can yield significant economic benefits, as well as, improved long-term health outcomes. **(https://everylifefoundation.org/wp-content/uploads/2023/09/EveryLife-Cost-of-Delayed-Diagnosis-in-Rare-Disease_Final-Full-Study-Report_0914223.pdf)**

According to the National Institutes of Health (NIH), there are approximately 7,000 rare diseases affecting between 25 and 30 million Americans each year **(https://www.nih.gov/about-nih/what-we-do/nih-turning-discovery-into-health/promise-precision-medicine/rare-diseases)**. Advocates are currently lobbying to add many of these rare diseases, such as GACI, to newborn screening panels. Continuing to raise awareness of the impact of rare genetic diseases and the need for improvement in newborn screening programs is one of the best ways we can push for expansion of newborn screening panels and more widespread use of advanced screening technologies. Fortunately, a diverse group of advocates, physicians, biotech executives, and other interested parties have made it their mission to foster this evolution in newborn screening.

On the global stage, Genomics England recently announced its initial list of over 200 rare diseases (including GACI) as part of its Generation Study, which the United Kingdom’s National Health Service (NHS) will soon launch. Genomics England developed this initiative to advance early detection and treatment of rare genetic conditions, with the goal of setting a new standard in newborn screening. **www.genomicsengland.co.uk/news/genomics-england-announces-list-of-rare-conditions-to-be-included-in-world-leading-research-study**

Over time, the Generation Study is expected to identify suspected diagnoses for an estimated 500 to 1,000 out of the 100,000 participating babies. According to Genomics England, the study will play a pivotal role in advancing early diagnosis and intervention, potentially leading to the creation of more comprehensive newborn screening programs that save lives by giving families timely clarity on their babies’ conditions and informing next steps for appropriate care.

Initiatives like these exemplify why I am more optimistic than ever about the future of newborn screening. These efforts, spurred by the cooperation of patient communities, advocacy groups, medical experts, and industry leaders, are significant steps forward in promoting early diagnosis and intervention around the world.

Awareness continues to grow for the myriad of rare diseases that must still be incorporated into newborn screening panels. Through ongoing research and advocacy efforts, we can facilitate early diagnosis and timely treatment for greater numbers of babies born with rare diseases. The stakes are nothing less than the difference between life and death.

ABOUT THE AUTHOR:

Catherine Nester, BSN, is Senior Vice President of Health Care Professional (HCP) and Patient Engagement at Inozyme Pharma (**www.inozyme.com**) and is an accomplished leader in the biotech industry. With more than 25 years of clinical and pharmaceutical experience, Catherine works closely with patient communities, advocacy groups, and physicians to raise awareness of the needs of individuals living with rare diseases impacting the vasculature, soft tissue, and skeleton. She is proud to be part of a company that is a founding member of the BeginNGS™ consortium, an initiative developed by Rady Children’s Institute for Genomic Medicine to evaluate a diagnostic and precision medicine guidance tool to screen newborns for approximately 400 genetic diseases. Inozyme joined the consortium due to its conviction that the development and widespread adoption of advanced newborn screening technologies is essential to diagnosing rare diseases and quickly mapping out a treatment plan that facilitates better outcomes, while also enhancing understanding of the incidence and prevalence of rare diseases. Through the consortium’s work, Inozyme hopes to secure the inclusion of many more genetic diseases in standardized newborn screening panels in the near future.

Build wealth through Real Estate

Let us show you in three easy steps how you can change your life.

Unlike other investments, Real Estate is also a ‘lifestyle asset”.That means setting yourself up for the future by generating wealth now, while creating family memories along the way.

visit oxygenmortgage.net or scan here

OXYGEN
Mortgage

From helping choose the location, getting a mortgage and finding the best real estate agent, to managing the short term rental once you own it, let **Oxygen Mortgage** show you how you can build wealth from real estate, right now.

Oxygen Mortgage LLC NMLS#2247462 Illinois Residential Mortgage Licensee. AL,AZ,CO,IL,GA,FL,SC,NC,TN

An Equal Housing Lender

Call or text now to explore the possibilities
+1-720-308-0055

THREE TIPS FOR ENCOURAGING PHYSICAL FITNESS AND HEALTHY EATING IN CHILDREN AND TEENS WITH AUTISM, INSPIRED BY RESOURCES AND INSIGHTS FROM AUTISM SPEAKS

FIRST STEPS TO HEALTHY HABITS

BY MARTA CHMIELOWICZ

DIGGING IT OUT: Seth Morris runs the bases for his team in the Sunshine League baseball league for those with special needs.

Everyone has their own way of staying active and healthy. For some, a brisk walk around the block is enough to clear the mind and get the blood pumping. For others, a lap around a track, hike in the woods or a game of kickball might be a better fit. However, for children with autism, finding the right balance of physical activity and nutrition can be challenging.

For Seth Morris, a 16-year-old autistic boy from Atlanta, a healthy diet and exercise plan of baseball, walking and weightlifting were the answer. Thanks in large part to his mom, Muhsinah Morris, Seth lost a whopping 70 pounds in the first year of his fitness journey and continues to thrive through healthy eating, exercise and extracurricular activities. His wellness journey wasn't always smooth sailing, but with a bit of creativity, discipline and dedication, his family is helping him learn to eat healthy and take care of his body—two habits that will serve him well in the future.

THE BENEFITS OF AN ACTIVE LIFESTYLE

Regular physical activity is one of the most important things people can do for their health. According to the CDC, being physically active can improve brain health, manage weight, reduce the risk of disease, strengthen bones and muscles, and improve your ability to do everyday activities.[1] It's no secret that what's good for the body is good for the mind. Even small amounts of physical activity have been shown to reduce mental health conditions like depression and anxiety.

"Studies have shown that exercise helps with executive function, anxiety, stress management and mood. In general, people who have an active lifestyle are much more emotionally resilient and focused. There also seems to be some evidence that physical exercise helps people with depression and ADHD, which are commonly co-occurring conditions with autism," says Dr. Jean Gehricke, Ph.D., licensed clinical psychologist and associate professor at The Center for Autism and Neurodevelopmental Disorders at University of California, Irvine (UCI). UCI is part of the Autism Speaks Autism Care Network (ACNet), a network of 20 health centers in the U.S. and Canada that is delivering better care to children with autism and their families. To find your local ACNet site, go to **autismcarenetwork.org/locations**.

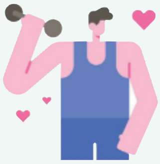
Seth is seeing these benefits firsthand. According to his mom, becoming healthier has helped both his body and mind. Since starting his exercise regiment, Seth has become more focused at school and no longer struggles with behavioral outbursts. "Putting his body to the test and making him do hard work like running, throwing a ball and lifting weights is really helping him stay grounded. I haven't seen any self-injurious behavior in years, any aggression in school – all of that is gone completely," says Muhsinah.

THE SWING OF IT: *(Below left)* Seth in the batter's box; *(Below right)* Playing golf with his dad has become a great new hobby for Seth.

---

[1] www.cdc.gov/physicalactivity/basics/pa-health/index.htm#

TRIPLE PLAY : THESE THREE TIPS CAN PUT YOU AND YOUR CHILD ON THE PATH TO A HEALTHIER FUTURE



TIP #1: TURN EXERCISE INTO A HOBBY

Being active doesn't have to mean hitting the gym three times a week. It's more important to get autistic youth engaged in healthy activities that they are interested in and feel connected to. That looks different for everybody. Making fitness into a hobby helps motivate children and teens to maintain the activity throughout their lives, even though it challenges them physically.

"We want to help kids develop an appreciation and a motivation to be physically active, and it doesn't have to be part of a physical exercise program," explains Dr. Gehricke. "We don't need them to become competitive. That might be way too much. It's more important to go out, take a walk, or run and chase each other, always keeping in mind the playful aspect, whatever the child reacts to positively. That's a very important part of reinforcement."

Dr. Gehricke recommends observing what your child enjoys and what kind of activities they do when they are relaxed in their natural environment. You might see them running around or bouncing up and down. All of that can help inform the activities you involve them in. Team sports can be challenging for some kids on the spectrum, so it's important to choose activities where they feel included.

Giving your child a choice of activity can also be helpful, Muhsinah says. "Instead of telling Seth what activities we think he can do, he gets to choose the activities that he wants to do. For example, instead of telling him that he has to walk on the treadmill, we ask if he wants to walk in the neighborhood or in the park. Maybe he wants to go run bases at the baseball diamond or go to the basketball court. We are giving him a choice to decide what he wants to do, and I think it gives him agency over his own health. Then, we talk to him about what fuels his body to be able to do the things that he enjoys."

TIP #2: INVOLVE THE WHOLE FAMILY

Motivating yourself to be healthy is a challenge for anyone, but family support can help. For Seth, a big motivation to stay healthy is working out with his dad and brothers.

In addition to participating in the Sunshine League baseball team and the Special Olympics of Georgia, Seth walks twice a week and weightlifts with his three older brothers. As he grows, Muhsinah says his regiment adapts to his changing interests. Recently, he has begun hosting and participating in a golf tournament with his dad. "Seth is excited that he's part of the big boys, gets to work out with his brothers and be his dad's golf caddy," says Muhsinah.

Getting family involvement can also be very helpful for maintaining a healthy diet. Muhsinah encourages Seth to eat healthy by limiting the number of unhealthy options available at their home. The whole family is committed to eating clean and healthy food.

"In terms of food choice, I realized that it was me as a parent that needed to set the boundaries," she says. "I always make fruit and vegetables available. He can always get an apple or an orange. I don't keep any sweets in the house, and chips and popcorn stay locked up. As a family, we try to avoid processed foods, as much as possible. The whole family conforms to only having water and Powerade in the house, and not a whole lot of Powerade. When we began this journey, I had to shift in my mind that this is what our groceries look like now. We don't buy the junk that looks so good."

TIP #3: BE PATIENT WITH ANY FOOD AVERSIONS AND SENSORY DIFFERENCES

Physical exercise is only one piece of a healthy lifestyle. Another equally important piece is diet and nutrition. Many people with autism have sensory aversions that make them very selective with their diet, which can make encouraging healthy eating more difficult for parents. To learn more about how sensory differences can cause feeding issues, download our Parent's Guide to Feeding Behavior in Children with Autism.[2]

"A lot of autistic kids are very picky eaters. Expanding their palette and bringing in heterogeneous foods that are healthier, is a challenge for any parent," says Dr. Gehricke. "It's hard to explain nutrition to a younger child, so behavioral strategies that reinforce trying different foods are the go-to techniques with younger kids. It requires persistence. Let the child have their favorite meal, but encourage them to have a spoon of peas or one piece of broccoli, before they eat. It takes an observing and persisting parent to gently push and remind them how important it is to eat other things."

Muhsinah had to get creative in order to encourage Seth to eat a healthy diet. Because he has an aversion to soft textures, he is only willing to eat foods that are crispy or crunchy. So, his diet primarily consists of salads, lots of fruit, meats, and crunchy raw vegetables, like carrots and celery.

Explaining the importance of healthy eating is critical, particularly for adolescents and teens. "As they grow older, oftentimes their tastebuds change, so naturally they become more willing to try different things," explains Dr. Gehricke. "For older kids, explaining the value of healthy foods is important. You can talk about the nutrients and vitamins a person needs, and make an activity where you identify which foods have those ingredients."

---

[2] www.autismspeaks.org/tool-kit/atnair-p-guide-exploring-feeding-behavior-autism

MEASURING SUCCESS: *(Above left)* Seth with his mom Muhsinah and little brother; *(Above right)* Seth's goal is to become a baker one day.

TIPS FOR A HEALTHIER LIFE

Learning to enjoy exercise and prioritize physical fitness doesn't happen overnight – developing healthy habits takes time and dedication. Instilling the importance of health and nutrition in children is another matter altogether, particularly when your child is autistic.

The symptoms of autism can make it more difficult for autistic children and teens to get involved with physical activities or eat healthy foods. For example, communication challenges and issues with motor control and balance might make joining a game of ball at recess very stressful. Sensitivities to certain food textures or flavors might limit a child's diet, making healthy eating more difficult.

Because of these challenges, research shows that young people with autism are at higher risk of being overweight or obese,[3] which can result in a host of health issues later in life. This risk is especially high because some medications commonly prescribed to autistic people have a side effect of weight gain. To avoid these risks, it is important for parents to start teaching their children healthy habits as early as possible, and in a way that includes their needs, interests and preferences.

> "PUTTING HIS BODY TO THE TEST AND MAKING HIM DO HARD WORK LIKE RUNNING, THROWING A BALL AND LIFTING WEIGHTS IS REALLY HELPING HIM STAY GROUNDED."

Depending on your child's level of communication, explaining facts about diet and nutrition may be difficult. What has worked for Muhsinah and Seth is watching videos together of kids his age working out and taking care of their bodies. Seth wants to be a baker, so he and his mom also spend time talking about portion sizes and appropriate quantities of certain unhealthy foods. Though he does not always express his understanding in the moment, Muhsinah says that these videos and the guidance she gives him every day have made a big difference in his eating habits.

"I am teaching him healthy habits through our daily interactions," she says. "I also try to remember that he's a teenager, and boys eat everything. He is growing, so everything in moderation. I don't police his food, but I do set limits and allow him to choose."•

For more physical fitness resources, head over to https://www.autismspeaks.org/physical-fitness

ABOUT THE AUTHOR:

Marta Chmielowicz is the Content Manager of Mission Delivery at Autism Speaks, where she leads science communications to advance the mission of Autism Speaks to create an inclusive world for all individuals with autism throughout their lifespan.

---

[3] https://journals.sagepub.com/doi/abs/10.1177/1362361318791817

BanTec
SANITIZING
EXPOSURE RESPONSE

BANTEC SANITIZING IS YOUR ALLY IN THE FIGHT AGAINST COVID-19

With efficient and affordable solutions for cleaning and safely sanitizing residential, school and business settings, Bantec Sanitizing can help you prepare for living, learning and working in a safe and healthy environment.

COMMERCIAL AND RESIDENTIAL CLEANING PRODUCTS & SERVICES

HOME

SCHOOL

OFFICE

EXCLUSIVE OFFER

BANTEC DISINFECTING KIT

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

CleanSmart

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

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

INDUSTRY INNOVATOR

BANTEC AUTONOMOUS SOLUTIONS

Bantec Sanitizing has expanded its variety of products and services to help facility managers, safety professionals, and maintenance personnel to include autonomous health monitoring, sanitizing and teaching self-driving humanoid robots. Systems such as the Cruzr Health Monitor, below, can improve workplace safety and present helpful information.

Autonomous Mobile Solution

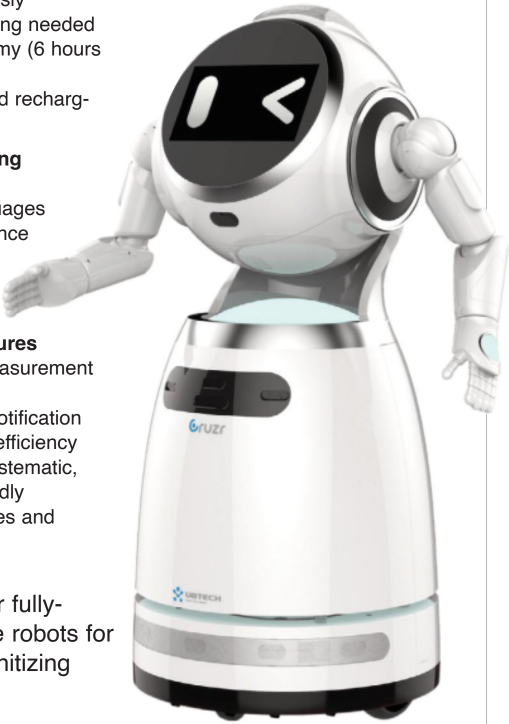
- Navigates autonomously
- No manual repositioning needed
- Up to 8 hours autonomy (6 hours to recharge)
- Automatic docking and recharging

Interactive and Engaging Humanoid Robot

- Speaks multiple languages
- Detects human presence
- Deploys information (text, pictures, videos and more)

Heath Monitoring Features

- Body temperature measurement and notification
- Mask detection and notification
- Increases workplace efficiency
- Engaging, reliable, systematic, tireless and user-friendly
- Reduces infection rates and associated costs



Learn more about our fully-programmable mobile robots for health monitoring, sanitizing and education:

https://bantec.store/products/cruzr-health-monitor

BanTec SANITIZING EXPOSURE RESPONSE

A DIVISION OF BANTEC

www.bantec.store

Children and Youth with Special Health Care Needs (CYSHCN) are children and youth who have or are at increased risk for chronic, physical, developmental, behavioral, or emotional conditions and who also require health and related services beyond that required by children generally.

HOW PEOPLE WITH DISABILITIES AND THEIR FAMILIES CAN BE INVOLVED IN, LEAD, AND CHANGE SYSTEMS OF CARE

BY LAUREN AGORATUS, M.A.

WHY ENGAGE SELF-ADVOCATES AND FAMILIES?

Approximately 25% of households in the US have children and youth with special health care needs, who have (or are at risk for) chronic physical, developmental, behavioral, or emotional conditions. (https://mchb.hrsa.gov/programs-impact/focus-areas/children-youth-special-health-care-needs-cyshcn) The esearch is clear that engaging families of children with special healthcare needs in improving systems of care, leads to better outcomes for their children. That's why the US Department of Health and Human Services HRSA Maternal and Child Health Bureau funds a network of 59 Family to Family Health Information Centers (F2Fs) around the country to help individual families navigate systems of care, and a national technical assistance center, Family Engagement and Leadership in Systems of Care (FELSC). There is a Family to Family Health Information Center in every state, plus in three Tribal Nations and five US territories.

Family Voices National, in collaboration with the SPAN Parent Advocacy Network, leads this important initiative intended to support F2Fs, state Title V Maternal and Child Health Programs, and others to be more effective in reaching and engaging diverse families of children with special health care needs at all levels. The technical assistance center elevates the experience and expertise of diverse parents and others with lived experience, to ensure that

FALLING SHORT: 14 million children in the US are children and youth with special health care needs, making up 19.5% of children under 18. Less than 1 in 7 CYSHCN receive healthcare in a well-functioning system.

project activities create better outcomes for children with special health care needs. Families and self-advocates with disabilities are involved across all activities, and share their experiences to help create systemic change nationally.

HOW WILL THIS HELP FAMILIES AND PEOPLE WITH DISABILITIES?

People with disabilities, including youth and their families, partner with family-serving organizations including the F2Fs, other family organizations, and state and local MCH agencies (see Resources). As F2Fs, Title V programs, and others improve at reaching and engaging diverse parents and youth/young adults, these voices will help point out the strengths and challenges of existing systems, policies, and procedures, and plan for systemic improvements.

WHAT ARE FAMILY-TO-FAMILY HEALTH INFORMATION CENTERS (F2FS)?

F2Fs are led by families and help support other parents of children and youth with special health care needs. In each state and territory, the center is staffed by knowledgeable families who have lived experience of the challenges faced by children with special health care needs and their families. F2Fs are uniquely qualified to support other families caring for children with special health care needs, because their staff can offer peer-to-peer support. This is especially true for families with children who have medical complexity or are from underserved communities. This project will involve diverse families and youth “in direct patient care, organizational design, and governance.”

WHAT IS THE BLUEPRINT FOR CHANGE?

FELSC, the technical assistance center for the F2Fs, is guided by the Maternal/Child Health Bureau Blueprint for Change: Guiding Principles for a System of Services for CYSHCN. The Blueprint focuses on key areas affecting children and youth with special health care needs and their families. These include:

- **Health equity:** Ensuring everyone gets equitable care that meets their needs.
- **Quality of life and well-being:** Wellness and quality of life aren’t often thought of in relation to disabilities.
- **Access to services:** All families can access the health care and other related supports that they need.
- **Financing of services:** Children with special healthcare needs can access healthcare that is affordable.

By involving families of children with special health care needs and their families, meaningful improvement can be made in the areas of health care equity, wellness, access, and affordability. •

SELF-ADVOCACY RESOURCES

FAMILY ENGAGEMENT AND LEADERSHIP IN SYSTEMS OF CARE (FELSC)
https://familyvoices.org/felsc

FAMILY-TO-FAMILY HEALTH INFORMATION CENTERS (F2FS)
https://familyvoices.org/felsc/whataref2fs

MATERNAL/CHILD HEALTH BUREAU (MCHB) BLUEPRINT
https://mchb.hrsa.gov/programs-impact/focus-areas/children-youth-special-health-care-needs-cyshcn/blueprint-change

SPAN PARENT ADVOCACY NETWORK
https://spanadvocacy.org

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 two academic journals (**https://pubmed.ncbi.nlm.nih.gov/?term=agoratus+l**). Lauren was named a Hero Advocate by Exceptional Parent Magazine (**www.epmagazine.com**) Archives June 2022.

ENGAGED & EMPOWERED

SUPPORTING PEOPLE TO TAKE CHARGE OF THEIR HEALTH

TRAILBLAZER: Callyn Groff and The Arc of Lexington staffer Pete Giblin began taking short walks on a local bike path. Callyn came to enjoy hiking and walking so much that he started Club 72 to encourage people to hike the 72 local trails in the The Arc Lexington area.

The Engaged and Empowered Program is a wellness-based initiative for people with intellectual and developmental disabilities (I/DD) that both engages and empowers people with I/DD to take charge of their health. The program was created by The Arc Lexington.

SUBMITTED BY THE ARC LEXINGTON

PHOTOS PROVIDED BY THE ARC LEXINGTON

The Arc Lexington is an innovative organization that constantly monitors the services it provides to find possible gaps in programming, or areas in need of improvement.

Gina Warsaw, Senior Director and one of The Arc Lexington staff members integral to the creation of the program said, "We developed the Engaged and Empowered program in 2013 because we saw a need for better health outcomes for the people we support, while also looking to transform our day habilitation model into something that was more meaningful for people. In doing so, a wellness program made perfect sense and once we decided on that direction, we felt that it was important to build a program that was dynamic and evidence-based."

People participating in the Engaged and Empowered program, about 650 people per week, are offered wellness activities on a daily basis, that encompass seven different dimensions of wellness: Physical, Social, Spiritual, Intellectual, Occupational, Emotional and Environmental. All activities can be modified for people with the sensory needs of autism, as well as for people with physical challenges. Activity examples include book club, music appreciation, poetry readings, and spirituality. An adaptive sports club, L3 (Living Life Without Limits), is part of The Arc Lexington's Engaged and Empowered program that offers participation in adaptive activities such as: water skiing, sailing, downhill skiing, ice skating, zip lining, fishing, archery, roller skating and many other exciting and challenging sports activities.

NEWFOUND STRENGTH: Since participating in program classes, activities and more, Allison Patnode has found great success in her relationships, career and overall happiness.

Anchoring the Engaged and Empowered program was multiple-level wellness training of The Arc Lexington staff members, by Mayo Clinic. Mayo Clinic worked with these staff members to teach motivational techniques that helps them have the greatest impact on the wellness goals of the people they support. Three staff members were certified as Wellness Coaches by Mayo Clinic and they continue to lead the Engaged and Empowered Program.

When looking for evidence- and research-based health, and wellness programs for people with I/DD, The Arc Lexington found the University of Illinois' HealthMatters™ and HealthMessages™ curricula. The authors of this program from the University of Illinois' Department of Disability and Human Development provided staff members at The Arc Lexington hands-on training, in its techniques and curriculum to engage participants in actively learning about their health. This program was specifically written to be used with individuals with developmental disabilities and covers a large spectrum of wellness-based topics. HealthMessages™ is a program in which people with I/DD become peer coaches and lead groups. Both HealthMatters™ and HealthMessages™ are offered to everyone supported at The Arc Lexington. Participants with the most challenging health risks such as diabetes, obesity and heart conditions, are offered this program in a support-group format called Wellness Confidential, with skilled clinicians who are wellness coaches. Wellness Confidential is based on the principles of positive psychology that focus on positive experiences rather than on dysfunction, helping people become happier and achieve their full potential.

People who participate in the Engaged and Empowered program at The Arc Lexington complete a personalized health assessment and interest survey and develop an individualized wellness plan with the members of their team. The Arc Lexington collects data on wellness goals and looks at this data and people's wellness plans every six months, to assess any possible needs for adjustments, as well as to celebrate wellness successes, large and small. In addition, every six months it collects biometric data on program participants to help steer the program.

Now in its tenth year, Engaged and Empowered has helped many people at The Arc Lexington, achieve their personal wellness goals and become healthier, which leads to not only physical and mental wellness, but also success in other areas of their lives. A selection of examples of how Engaged and Empowered has affected the lives of participants includes the following success stories.

Allison Patnode joined the Engaged and Empowered Program at its inception in 2013. When she started the program, she was exhibiting severe diabetic symptoms, with multiple trips to emergency rooms, with high blood glucose numbers. These frequent ER visits and her ill health caused her to be depressed and experience social isolation. Since participating in program classes, activities and more, Allison has found great success, not only with her health and wellness goals, but also in her relationships, career and overall happiness. With the full support of her team at The Arc Lexington, she has been working on exercise goals, choosing healthy foods, and balancing her interests with her goals. She has taken control of her diabetes, and has experienced weight loss, and a reduction of ER visits related to her health complications. She sets her own goals and takes responsibility for achieving them, but also welcomes the supports she receives from many people at many levels at The Arc Lexington.

Allison has also made strides in her career by taking a job as a custodian. Her supervisors have been impressed with her work ethic, social skills on the job, and dedication to being on time, working productively and performing her assignments well. She is rightfully proud of her job success and loves the reward of getting a paycheck in exchange for a job well done.

Anyone who meets Allison at work, in her program, in her home, or when she is out getting some exercise, can see how well she is doing and how happy she has become through meeting the goals she has set for herself.

"Without The Arc Lexington and its wellness program, I would not be where I am today," said Allison. "I cannot wait to see what this journey is going to become in the future. I know anything is possible if you keep looking up. I am so happy to have a job, friends, and my own apartment. I am now looking forward to an even better me!" said Allison.

David Barton is one of the leaders of Living Life without Limits Club (L3), the adaptive sports club at The Arc Lexington. David has cerebral palsy and participates in a great number of adaptive sports activities through the club, including downhill skiing, using a Trek wheelchair to hike, zip lining, sailing, water skiing, and fishing for salmon on New York's Pulaski River, to name a few. David has given presentations about L3 to a number of groups, both within The Arc Lexington and to its communities. He is up for any challenge, and advocates for his group and its members to access new sports opportunities, in New York State and beyond. When asked about participating in these sports activities, David gets emotional, "I feel awesome," he said. "I feel like a bird, flying free. It makes me so happy and also helps me look forward to the future." His favorite sports involve skiing – whether its downhill in the snow, or water skiing in the summer months.

"David is amazing," said Bonnie Reuss, L3 Club Advisor and Physical Therapy Assistant at The Arc Lexington. "He always is willing to try new adventures and encourages the other members of the Club to do the same." She continued, "When we go to the Adaptive Sports Center at Windham Mountain (Windham, NY), the volunteers know David by name, and know him as a skiing enthusiast, not as someone with a disability. He is a great champion and ambassador for our L3 Club with other self-advocates and to the community at large."

Mark Riley, who has autism, joined The Arc Lexington near the end of 2018. He came to the organization from a nursing home, and at the time was battling some serious health issues. Because he was at an unhealthy weight, Mark had difficulty walking, needed a special bed to sleep in, and his general activity and mobility overall were limited.

As Mark started to settle in to his new home, he began his journey towards better health, with support from his team at The Arc Lexington. Mark worked with an agency dietician to have a healthy diet, and learned ways to make good food choices to help him feel better and to lose weight. Mark started attending the HealthMessages™ classes through the Engaged and Empowered

ROLE MODEL: "David is amazing," said Bonnie Reuss *(left)*, L3 Club Advisor and Physical Therapy Assistant at The Arc Lexington. "He always is willing to try new adventures and encourages the other members of the Club to do the same."

Wellness Program and learned about nutrition and healthier eating habits. At the same time, he chose to become much more physically active through walking clubs, volunteer work, and community activities. He also took part in cooking classes to learn how to make healthier meals at home.

Mark has been able to meet his personal wellness goals to be more active and to eat better and has lost over 250 pounds! His remarkable work in making healthier choices has affected his entire life in many positive ways. Mark is observed to present himself with far greater self-confidence in social situations. His ability to be more mobile and feel better about himself has truly changed him. He continues to stay active and engage in a healthier lifestyle through a combination of all of these supports provided by his entire team at The Arc Lexington. Mark's wellness story also inspired and led one of his support staff members to lose 50 pounds.

ADDITION BY SUBTRACTION: Mark Riley's ability to be more mobile and feel better about himself has truly changed him.

Callyn Groff is a young man who participates in day habilitation programming at The Arc Lexington. The COVID-19 pandemic was hard on everyone, but Callyn found it especially challenging when his day program at The Arc Lexington was shut down for everyone's safety. When restrictions lifted and Callyn returned to his program, he was determined to work on his new wellness goal, which was to stay physically active throughout his day, as well as to be more active in the planning of what he did throughout the day. Prior to the pandemic, Callyn's physical activity consisted of some basketball drills and playing baseball, but only a couple of times per week. At that time, he spent a lot of quiet time indoors on his iPad, and preferred wearing headphones while doing so. When he was able to return to his program, he found he had a new staff member, Pete Giblin. Pete, who is trained in the Engaged and Empowered techniques, started encouraging Callyn to go for short walks on a local bike path. Their walks became longer, and they soon started discovering many of the other recreational trails and paths in the community, and then in the Adirondacks close to where The Arc Lexington is located. These walks and hikes improved Callyn's health, while also developing in him a love of the outdoors. His team observed that these walks and hikes helped Callyn to feel better about himself and to be less stressed. In fact, Callyn came to enjoy hiking and walking so much that he started Club 72 to encourage people to hike the 72 local trails. He is the President of this new Club that has 15 members, so far. The Club presents awards as members complete hikes on specific numbers of trails, and encourages club members to take photos to document and share with other walkers and hikers. Winter has slowed down the club a bit, but Callyn and his group are really looking forward to spring when they can add even more trails to their travels.

Callyn's life has changed in such a positive way, and it shows. In fact, the positives that he has found on his wellness journey can be summed up in a letter The Arc Lexington received from his mother. "There aren't enough Thank Yous on the planet….I can't say enough about Pete and how he treats my boy. He is patient and flexible and respectful beyond words. This new life for Callyn is a game changer and I am so excited for his future!"

These are just a select few of the dozens of health and wellness success stories that people with developmental disabilities have found through the Engaged and Empowered health and wellness program at The Arc Lexington. The organization has learned through this program that for people with I/DD, participation in simple health and wellness changes can have a dramatic impact on many other areas of a person's life. •

ABOUT THE ARC LEXINGTON

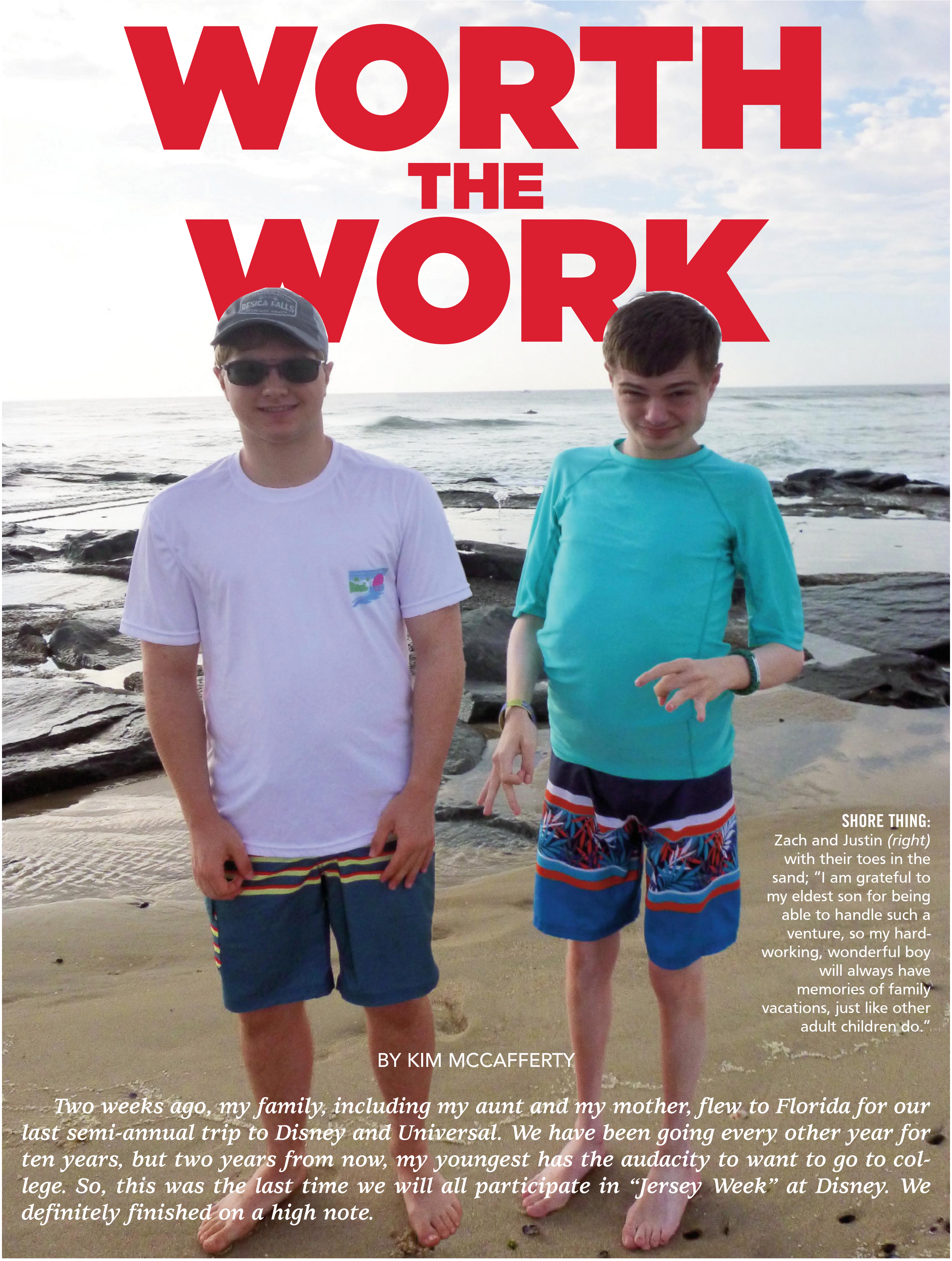
The Arc
Lexington
New York

The Arc Lexington, a not-for-profit, award-winning provider of supports to people with I/DD in Fulton, Schoharie and Albany Counties of New York State. A chapter of The Arc New York, The Arc Lexington employs 1,600 people who support 1,300 children and adults who have disabilities including autism, mental illness, cerebral palsy, physical disabilities, epilepsy and traumatic brain injury. Visit **www.thearclexington.org**

Footnote: The University of Illinois HealthMatters™ Program curriculum is available in two books that can be purchased on Amazon for people who may want to reference and use this research-based, field-tested program. The books are entitled Health Matters for People with Developmental Disabilities: Creating a Sustainable Health Promotion Program by Beth Marks, RN, Ph.D., Jasmina Sisirak, M.P.H., Tamar Heller, Ph.D. and Beverly McElmurry and Health Matters: The Exercise and Nutrition Health Education Curriculum for People with Developmental Disabilities, written by Beth Marks, RN, Ph.D., Jasmina Sisiraak, M.P.H. and Tamar Heller, Ph.D.

– Note: This article was republished from EP Magazine, February 2023

WORTH THE WORK



SHORE THING: Zach and Justin *(right)* with their toes in the sand; "I am grateful to my eldest son for being able to handle such a venture, so my hard-working, wonderful boy will always have memories of family vacations, just like other adult children do."

BY KIM MCCAFFERTY

Two weeks ago, my family, including my aunt and my mother, flew to Florida for our last semi-annual trip to Disney and Universal. We have been going every other year for ten years, but two years from now, my youngest has the audacity to want to go to college. So, this was the last time we will all participate in "Jersey Week" at Disney. We definitely finished on a high note.

There were some years with some definite low notes. On our first trip, Justin, our now twenty-year-old profoundly autistic son, wasn't feeling well, and his behavior was challenging. I will never forget how we pulled in to my mom's after our return flight, and Justin emitted his loud, hi-pitched "eee" sound with a smile, ecstatic to be home, and my six-year-old burst into tears, because we were home. Yin and yang, yin and yang.

There was the year, five adults managed to be so distracted, that the two boys wandered off, with my sister-in-law discovering them minutes later staring at the water gushing down from Splash Mountain, and my youngest telling me afterwards that he saw Justin head off and "just took his hand to stay with him so he wouldn't get lost." Good times.

In the good old days, I watched my husband run to the future disability ride to book a time, then hustle back to meet us at our fast pass ride. He would do this all day long. At least he got his steps in. In the old days at Disney, once you finished one ride on your disability pass, you could run ahead and book the next one, and you had to physically do this at all the rides. In between, you could use the three "fast passes" that Disney gave you free with each ticket. You either had a bracelet or a card that was scanned at each ride for both.

Now those free fast passes are gone. You have to purchase passes if you want to skip the lines on a few rides, and you have to book your disability rides on your phone. You no longer do it physically at each attraction.

I've always said Disney is a working vacation, and it is. I will never get back the hours I've spent trying to acquire the disability pass and requisite passes to daily rides (a system which seemed to change with every trip, as grateful as I am that the system exists); or figuring out why the only time Justin tried to flee anywhere was to FutureLand for a pretzel, while making sure we didn't lose any of my family members while in hot pursuit; or figuring out the particulars of the DAS on our phones; or making sure we didn't lose any of our cards in the old days, so Justin wouldn't have a meltdown if we didn't get on a ride.

Was every second of aggravation worth it to create indelible memories with my family on the only vacation my eldest would ever tolerate, and actually enjoy? Absolutely. Every fall that we were scheduled to go. Justin picks out the scrapbooks with the Disney trips in them, and starts playing his Disney DVDs, as soon as school started up again. Without us even saying anything, he just knew.

We will figure out a way to get him there in the future, which will be challenging, since when he (hopefully) enters a day program after graduation in June he can only miss a certain amount of days, but we will work it out.

The truth is a tremendous amount of work went into creating an


FULL EXPOSURE: Justin with his Dad Jeff at Great Adventure; "No matter how difficult it is, get your kids out in the world – have them wait on lines, expose them to times when a ride is broken or the weather turns bad, or something happens and you simply have to leave a venue early."

environment and a set of circumstances that enabled our son to be able to go on this vacation, and I'm glad we accomplished that when I was much younger.

We took Justin to the boardwalk and other venues to teach him how to wait on line, because no matter what advantages you have, at Disney you will still wait on line.

We participated in a fabulous program with American Airlines, where Justin, my mom, and I went through every aspect of a flight except an actual flight, before Justin's inaugural takeoff to Disney.

The staff at his school worked on a "wait" program with him.

It all paid off eventually, and I have been able to take my son on a two-hour round-trip flight, six times to a crowded destination where he sometimes had to wait an hour for a ride, and despite his penchant for carbs, we never permanently lost him. A win for all.

I am so grateful to my mom for underwriting so much of these trips for us, all these years, and for my aunt for helping us out this year, when I couldn't attend the entire trip.

I am grateful to all the many people who helped teach Justin the skills he needed to enjoy and remain safe and to Disney and Universal for making the parks more accessible to children like my own. I have much gratitude to be privileged enough to take my kids a half dozen times to the "happiest and most expensive place on earth," and have it be a safe and pleasurable trip.

I am grateful to my eldest son for being able to handle such a venture, so my hard-working, wonderful boy will always have memories of family vacations, just like other adult children do.

I have much gratitude to be privileged enough to take my kids a half dozen times to the "happiest and most expensive place on earth," and have it be a safe and pleasurable trip.

I know not all families will be able to go on such a grand venture, even once with their profoundly autistic children. I am well aware of how fortunate we are.

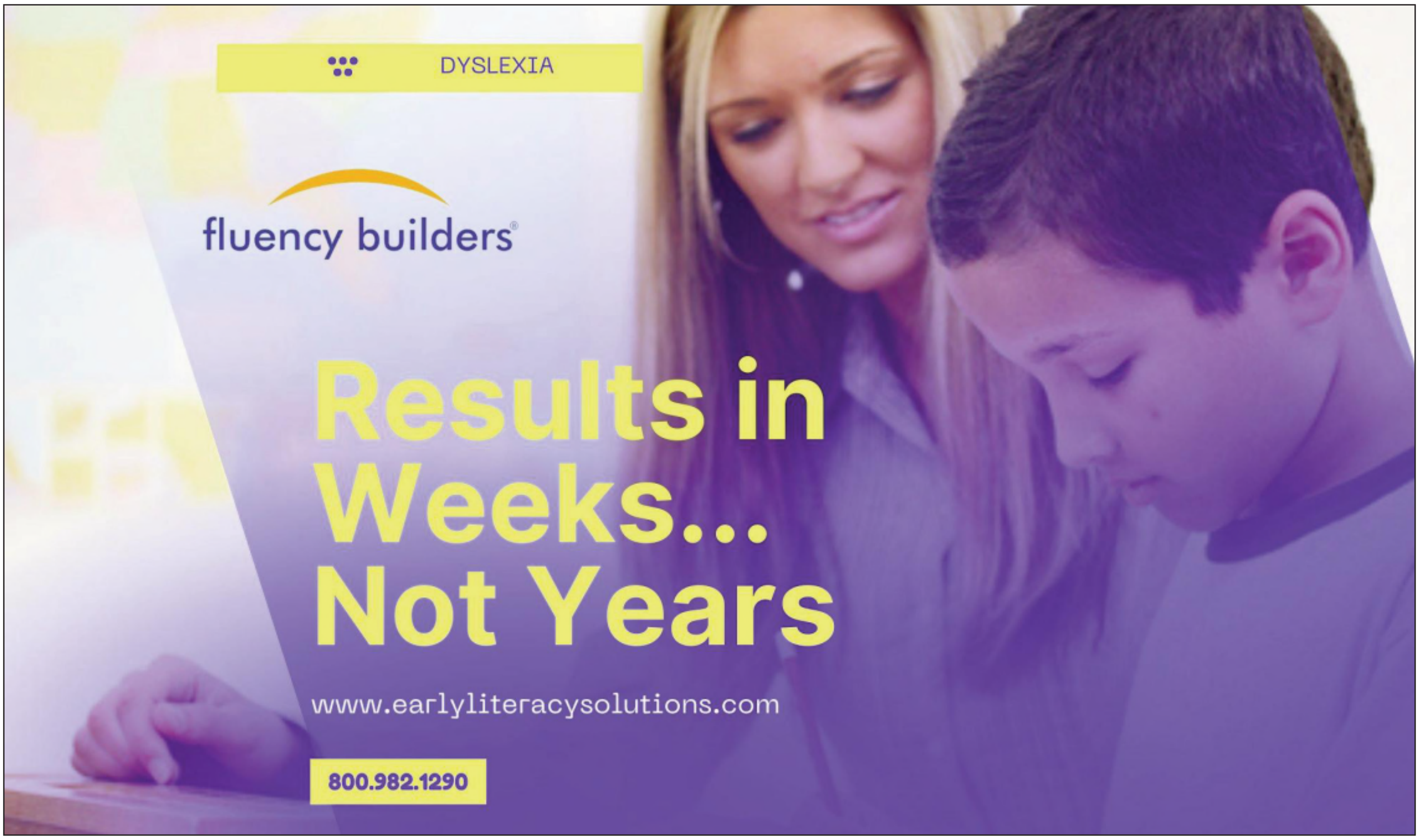
But my point is this. It doesn't have to be Disney. No matter how difficult it is, and it will be difficult sometimes, get your kids out in the world, have them wait on lines, expose them to times when a ride is broken or the weather turns bad, or something happens and you simply have to leave a venue early. Do it while they're young. Get these challenges in their repertoire, get overcoming disappointment in their repertoire, and do it while they're small enough for you and/or another person to physically carry them out if necessary.

If you can, do the work. Ask for help from their school. Ask for help through Performcare, as I have, or engage RBT/BCBA services through your insurance. Just get out.

After I find the time to relegate this excursion to the most current scrapbook, my son will pull it out periodically, and we will sit together and go over our trip. I ask him if he had fun. He will give me the slightest nod, yes. He may gift me with a smile. He is worth the work.

ABOUT THE AUTHOR:

Kimberlee Rutan McCafferty is mother to two sons on the autism spectrum, and an Autism Family Partner at the Children's Hospital of Philadelphia (CHOP). Kim is also the author of *Raising Autism: Surviving the Early Years,* which is on sale at Amazon. **https://autismmommytherapist.wordpress.com/me-and-my-blog**




From Red Hawk to
Digital Marketing Specialist
Aaron Smith
Class of 2022
#1
SOCIAL
MOBILITY
in New Jersey
U.S. News & World Report

YOUR DYSLEXIC CHILD

THE IMPACT OF NUTRITION, EXERCISE, AND OTHER HEALTH MEASURES ON READING SUCCESS

BY GEORGIE NORMAND, M.A.

Since dyslexia is neurobiological in origin and brain differences can be seen on MRIs as early as infancy, many parents wonder if there is any way to improve intervention outcomes through nutrition or other health related measures. In addition to structural brain differences, dyslexia is characterized by reduced plasticity and connectivity in the brain, all of which come together to make learning to read difficult.

These differences are not related to IQ and children with dyslexia may even score in the high IQ range while struggling to become proficient in reading. We know that early screening and evidence-based dyslexia interventions are critical for both preventing and remediating reading failure, but can other measures help to accelerate a child's progress in reading?

NUTRITION AND THE BRAIN

Even though the role of nutrition in dyslexia is an emerging science, from studies that already exist about nutrition and the brain, we can conclude that good nutrition can only help in dyslexia, as it helps with so many other aspects of overall health. The results from studies on nutrition and the aging brain present promising data on the link between nutrition and a wide range of brain functionalities. It is already well established that diet and nutrition play an important role in structural brain plasticity, the development of gray matter volume, and the maintenance of white matter integrity.

Much has been said about omega-3 supplementation for dyslexia. Even though recent evidence suggests there is a connection between defects in highly unsaturated fatty acid metabolism and neurodevelopmental disorders, when supplementation has been studied, evidence supporting it has been limited. More studies are needed before it can be recommended as beneficial for dyslexia.

Dyslexia frequently co-occurs with attention-deficit/hyperactivity disorder (ADHD), and problems with executive function are com-

BRAIN FOOD: Diet and nutrition play an important role in structural brain plasticity, the development of gray matter volume, and the maintenance of white matter integrity.

mon in both dyslexia and ADHD. A deficit in executive function impacts reading acquisition because it is involved in both self-regulation in behavior and in managing complex higher order cognitive processes like learning to read. A major study on nutrients necessary for executive function development and related brain connectivity identified specific nutrients and micronutrients that are associated with executive function development, but stopped short of recommending specific supplementation. In fact, the findings from supplementation studies tend to be very inconsistent and many of these nutrients are already contained in a normal healthy diet.

However, a study of diet in ADHD did find that those eating less fruits and vegetables were likely to have more severe symptoms of inattention. Learning to read requires focus. If your child has both ADHD and dyslexia, adding more fruits and vegetables to the diet may enhance the progress made during intervention.

> "If your child has both ADHD and dyslexia, adding more fruits and vegetables to the diet may enhance the progress made during intervention."

Anecdotally, and not surprisingly, students who are tutored after school (when they are generally tired and hungry) perform much better when they eat a non-sugary healthy snack right before the tutoring session. This may also help them to better retain what they learn in each session, an important consideration, since learning retention related to reading instruction is an ongoing challenge in dyslexia. So, even in the short term, good nutrition contributes to learning. This is a small step every parent can take to ensure that their child gets the most out of each tutoring session. This is supported by many studies on the relationship between nutrition and learning.

EXERCISE CAN MAKE A DIFFERENCE

Physical exercise increases brain function throughout life, and there are strong correlations between physical activity and academic achievement in school age children. This is especially true of aerobic exercise which positively impacts attention, processing speed, as well as executive and memory function – some of the most important baseline components for fluent reading.

Exercise also specifically targets one of the greatest barriers to retaining what has been learned during reading instruction – reduced neuroplasticity. Because of this feature of dyslexia, most dyslexic students require a repeated cycle of learning and relearning the same reading instruction content before it can be retained. For the best cognitive improvement, regular moderate-intensity exercise, rather than high or low-intensity exercise is recommended.

DYSLEXIA-RELATED ANXIETY AND DEPRESSION… IT'S REAL

Many dyslexic students struggle with anxiety and depression as they fall behind their peers in reading. They may lose ground in other academic areas as well, because reading is the basis for achievement in all academic subjects. Just learning the truth that their struggle is not related to intelligence, but represents a difference in the way they learn, helps many dyslexic children to overcome their low self-esteem. Their dyslexia may be accompanied by dysgraphia (difficulty with handwriting and writing skills) and dyscalculia (difficulty in grasping math concepts). Until their reading improves, they will especially struggle with word problems in math. These multiple challenges can create an avalanche of anxiety for the child, that leaves them in an overwhelmed state at the start of every new school day, and as they approach every new homework assignment.

Dyslexia-related depression and anxiety can be prevented with early screening and early evidence-based reading intervention. Many states are mandating early dyslexia screening in kindergarten, but parents should vigilantly watch their child's response to early reading instruction even in PreK. Dyslexia shows up very early in classroom instruction. Are they having trouble learning their letter names and sounds? Do they find it hard to blend several sounds together to make a word? Do they have an awkward pencil grip? Is there a family history of reading problems? Did the child experience early language delay? These are some of the early risk factors and signs that should trigger an immediate response from both the parent and the teacher.

Parents need to aggressively advocate for their child at school, at the very first sign of reading difficulty, and insist that there be no delay in testing and putting an IEP in place. They should not be persuaded to "wait and see" because this morphs into "wait to fail." The wait to fail approach is behind most of the depression and anxiety seen in dyslexic students. For parents with older struggling readers, it's never too late to advocate for your child.

It's also important to help dyslexic children and teens identify, focus on, and develop their strengths and talents – especially while they are working on their reading proficiency. They need encouragement to pursue activities that will bring them the recognition and sense of achievement that every child needs. There are also many digital learning tools available that can be harnessed to keep learning stress-free.

> **"Students who are tutored after school (when they are generally tired and hungry) perform much better with a non-sugary healthy snack right before the tutoring session"**

WHAT ABOUT VISION THERAPY?

One of the more controversial topics in dyslexia treatment is the use of vision therapy (VT). VT has been the subject of many studies to evaluate its impact on dyslexia. While it's important to rule out vision problems early in a child's life, VT for dyslexia has not been supported by the research.

Interestingly, a study that appeared in a 2018 issue of JAMA Ophthalmology found that visual deficits like ocular motor tracking and vergence impairment are far more prevalent in school-age dyslexic children compared to children without dyslexia. But at this time, there are no studies that have found that using VT to address these deficits can remediate dyslexia. In fact, several randomized, controlled double-blind studies did not show that treatment consisting of repetitive ocular motor tasks do anything to improve learning disabilities, reading, dyslexia or ADHD.

By contrast, evidence-based reading intervention by itself has produced a long history of success for dyslexic students. Could it be that the intensity and visual focus required in dyslexia-related reading interventions indirectly address visual deficits, as well as, the phonological and fluency deficits in dyslexia? Certainly, more research is needed to answer this and other questions about visual deficits in dyslexia.

The American Academy of Pediatrics and the American Academy of Ophthalmology, along with several other related medical associations, issued a joint statement on vision therapy and dyslexia. According to their statement, scientific evidence does not support vision therapy as a treatment for dyslexia.

Multiple appropriately controlled studies have found that although convergence training reduces problems with binocular vision and fusion, these improvements do not lead to improved reading skills. The same is true for the use of colored lens or overlays, changes in font, and "brain training." According to the results and implications of one major study released in 2022, "there is little evidence that interventions that do not involve actual instruction in reading generalize to improve reading skills."

DYSLEXIA RESEARCH CONTINUES...

Although we've learned so much about dyslexia, there is still work to be done. Dyslexia is finally getting the attention it deserves in terms of research funding, legislation, and teacher training. In addition to evidence-based reading interventions, new research will continue to shed light on how health and nutrition can contribute to the formula for success. •

References

Al Dahhan, N.Z., Halverson, K., Peek, C.P., Wilmot, D., D'Mello, A., Romeo, R.R., Meegoda, O., Imhof, A., Wade, K., Sridhar, A., Falke, E., Centanni, T.M., Gabrieli, J.D.E., & Christodoulou, J.A. (2022). Dissociating executive function and ADHD influences on reading ability in children with dyslexia. Cortex, 153, 126-142.

Chaire, A., Becke, A., & Düzel, E. (2020). Effects of physical exercise on working memory and attention-related neural oscillations. Frontiers in Neuroscience, 14, Article 239.

Costello, S.E., Geiser, E., & Schneider, N. (2021). Nutrients for executive function development and related brain connectivity in school-aged children. Nutrition Reviews, 79(12), 1293-1306.

Fletcher, J.M., Lyon, G.R., Fuchs, L.S., & Barnes, M.A. (2019). Learning disabilities: From identification to intervention. NY: Guildford Publications.

Joint Statement: Learning disabilities, dyslexia, and vision. Reaffirmed 2014. https://www.aao.org/clinical-statement/joint-statement-learning-disabilities-dyslexia-vis

June 2022: Results and implications of the convergence insufficiency treatment trial – Attention and reading trial. Summary by Jack M. Fletcher, Ph.D. Texas Center for Learning Disabilities. https://texas-ldcenter.org/education-research-matters/item/june-2022

Lin, T. W., Tsai, S. F., & Kuo, Y. M. (2018). Physical Exercise Enhances Neuroplasticity and Delays Alzheimer's Disease. Brain plasticity (Amsterdam, Netherlands), 4(1), 95–110. https://doi.org/10.3233/BPL-180073.

Livingston, E.M., Siegel, L.S., & Ribary, U. (2018). Developmental dyslexia: Emotional impact and consequences. Australian Journal of Learning Disabilities, 23(2). 107-135.

Moreau, D. (2022, April). How malleable are cognitive abilities? A critical perspective on popular brief interventions. American Psychologist, 77(3), 409-423.

NIH-Funded study finds dyslexia not tied to IQ. (2011). https://www.nih.gov/news-events/news-releases/nih-funded-study-finds-dyslexia-not-tied-iq

Raghuram, A., Gowrisankaran, S., Swanson, E., Zurakowski, D., Hunter, D.G., & Waber, D.P. (2018). Frequency of visual deficits in children with developmental dyslexia. JAMA Ophthalmology. 136(10), 1089-1095.

Robinette, L.M., Hatsu, I.E., Johnstone, J.M., Tost, G., Bruton, A.M., Leung, B.M.Y., Odei, J.B., Orchard, T., Gracious, B.L., & Arnold, L.E. (2022). Fruit and vegetable intake is inversely associated with severity of inattention in a pediatric population with ADHD symptoms: the MADDY Study. Nutritional Neuroscience. https://doi.org/10.1080/1028415X.2022.2071805

Rucker, J.C., & Phillips, P.H. (2018). Efferent vision therapy. Journal of Neuro-Ophthalmology, 38(2), 230-236.

Talukdar, T., Zamroziewicz, M.K., & Zwilling, C.E. (2019). Nutrient biomarkers shape individual differences in functional brain connectivity: Evidence from omega-3 PUFAs. Human Brain Mapping, 40, 1887-1897.

Zelcer, M., & Goldman, R.D. (2015). Omega-3 and dyslexia: Uncertain connection. Child Health Update. Canadian Family Physician, 61.

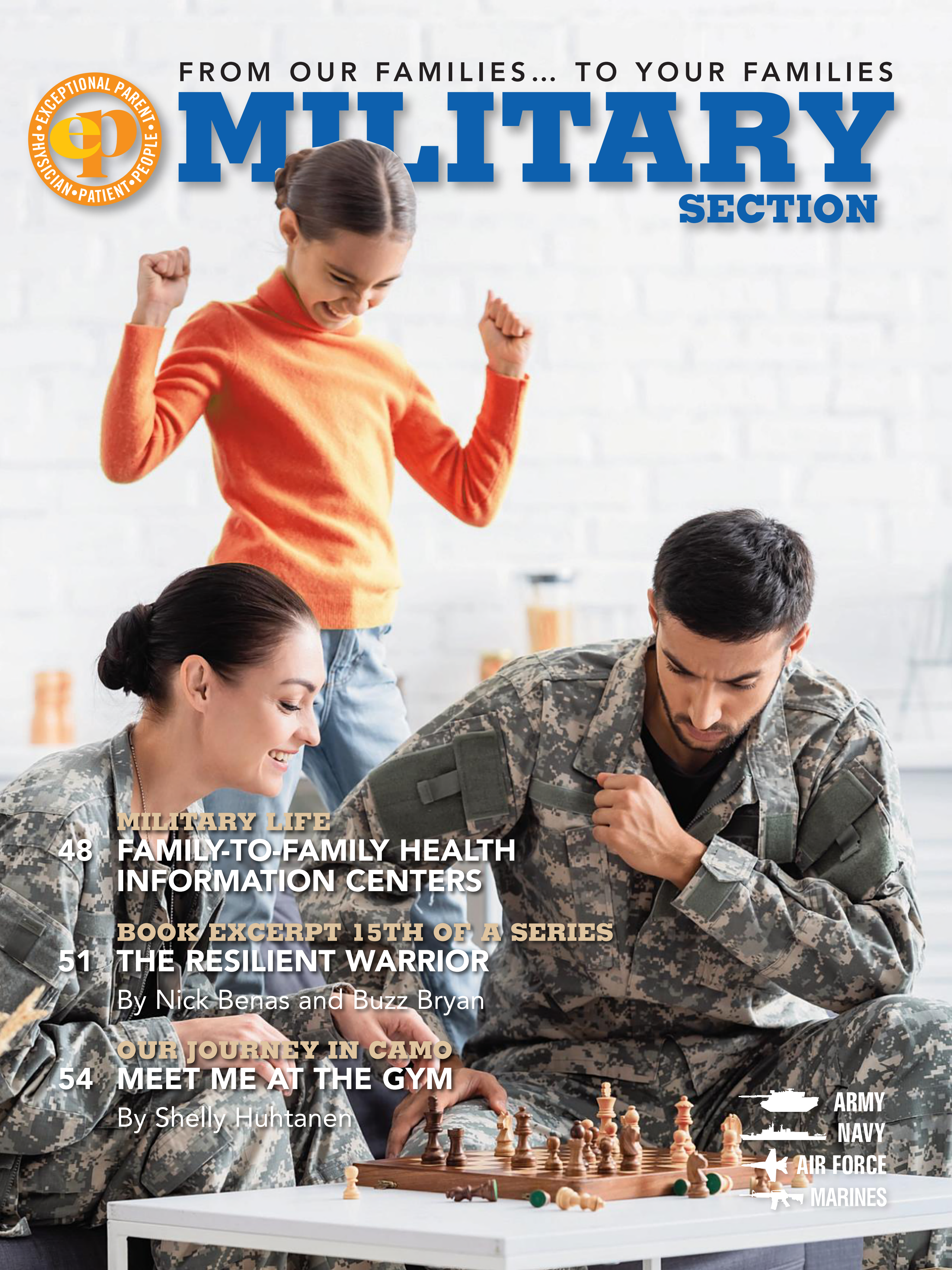
ABOUT THE AUTHOR:

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

– Note: This article was republished from EP Magazine, February 2023

FROM OUR FAMILIES... TO YOUR FAMILIES

MILITARY SECTION



ARMY
NAVY
AIR FORCE
MARINES

FAMILY-TO-FAMILY HEALTH INFORMATION CENTERS

Family-to-Family Health Information Centers are nonprofit organizations familiar with the issues facing families with special needs

In addition to the services for military families that are available at Military OneSource or at your local family support center, Family-to-Family Health Information Centers can connect you to resources that can provide and finance health care for your children, help locate assistance, and explain legislation. Each center has staff – many are parents of children with special needs – who understand available services and programs.

FIND ANSWERS THROUGH FAMILY-TO-FAMILY HEALTH INFORMATION CENTERS

Your local Family-to-Family center can help you find answers to a variety of health care issues. Along with other services, center staff can help you:

- *Learn eligibility requirements for Medicaid*
- *Find answers to questions about Social Security and Supplemental Security Income*
- *Write a health care plan for teachers and therapists*
- *Locate resources to pay for medications*
- *Find support groups*
- *Understand Title V and other programs that can help your family member*
- *Transition between insurance plans*

TAP INTO USEFUL RESOURCES

Get the help you need from your Family-to-Family center through:

- *Support and referrals by telephone, email or in-person contact*
- *Training workshops*
- *Helpful websites*
- *Newsletters and other publications*
- *Guidance on health programs and policy*
- *Evaluation and outcome assessments*

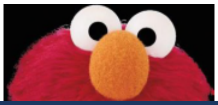
Family-to-Family Health Information Centers can help you navigate the waters of health care and find the personalized tools you need for your family. Learn more about Family-to-Family Information Centers and find a link (https://familyvoices.org/lfpp/f2fs/) to locate the one in your state. For more information on resources for finding access to medical services for families with special needs, read the Exceptional Family Member Program fact sheet on Medicaid and Medicare. •

– Military OneSource

FINDING THE WAY: Family-to-Family Health Information Centers can connect you to resources that can provide and finance health care for your children, help locate assistance, and explain legislation.

MILITARY ONESOURCE

is available to help with your concerns regarding military life.



WE OFFER

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

Sesame Workshop
http://www.sesameworkshop.org

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

WE'RE HERE FOR YOU

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

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

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

WE SERVE

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

---

Connect with Military OneSource

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

U.S. MILITARY ★ BOOK EXCERPT 15TH OF A SERIES

THE RESILIENT WARRIOR

CONSISTENCY THROUGH YOGA

BY HEATHER CLARK

Book Editor's Note: Featuring self-help, mental health, and mind and body tactics from a variety of sources – veterans, former and active U.S. Marines, Navy, Army Rangers, Green Berets, family members and caretakers – ***The Resilient Warrior*** *is collaborative collection providing needed wisdom for complete well-being for all of us. The first step to thriving is surviving, and the first step to surviving is knowing how to get what you need, when you need it. The following excerpt of this essential self-help guide to living a healthy, resilient, fulfilled and better life is the fifteenth in a series that EP Magazine has featured over the last several months.*

Incorporate yoga into your lifestyle for sound mind and body. Consistency in practice of anything is the key element to it becoming habitual. (Keep in mind this applies to negative habits as well.) Being cognizant of this fact is crucial to being able to control your mindset.

Routine is not only a familiar behavior embedded within veterans, but it is an effective method for keeping you on track and accountable. Sticking to what you are already familiar with will make it significantly easier to achieve success. That success is subjective and relative to each individual. You do not need to be a rock star right away. Leveling up doesn't mean having to reach the top immediately, if you are continuing to put into practice regimens that will get you to the next level until you reach the larger goal.

There are multiple elements that contribute to the overall health of a veteran. While I have found yoga to be an effective treatment supplement to physical and mental disabilities, I also realize that there are other areas that need attention. Transitioning successfully into civilian life, requires more than just getting a job. The best life hack as a veteran comes from the knowledge that you need to fulfill multiple needs to transition into civilian life and thrive.

There are eight elements that veterans need to either have in place before they get out or find, if they have already left service. These eight elements are like the eightfold path in yoga, which serve as a set of guidelines for living your best life. I use this holistic veteran path in my own life to ensure that I stay healthy, motivated, and moving forward. Acknowledgement and incorporation of these in veteran lives can serve as a guide in their own goals of recovery and success. For this discussion, we will focus on mindfulness, specifically using the tools of yoga, meditation, and mindset.

THOUGHT FILTER: Throw away the notion that you must clear your mind during meditation and instead let your mind go.

Course of action. Set up your routine, one which is specifically tailored to you. While there are many guidelines to how you should be doing something, each person is different in their schedules, motivations, and capabilities. For example, using the SMART metric, you can set up realistic goals that will keep you focused and accountable. SMART goal setting means setting goals that are Specific, Measurable, Accountable, Realistic, and Timely.

Magic hour. The ancient practice of Ayurveda was created close to the time that yoga came into practice. Its focus was mainly on diet, but also included insightful information about different body types, their sleep cycles and the best hours of the day to create. An example of this is my own body type or constitution of Kappa, which requires 6 to 8 hours of sleep. My magic hour for waking up is 5:00 am. If I wake up at 4:45 am, I feel groggy all day. If I sleep until 6:00 am, then I feel rushed all day. Hitting the magic hour is the first thing that can make or break your day.

MEDITATION AND MINDSET:

Meditation and mindset work hand in hand. Throw away the notion that you must clear your mind during meditation and instead let your mind go where it needs to go. With your eyes open the optic nerve only allows for one thing to be processed at time, closing your eyes during meditation allows you to have access to more thoughts. By not forcing the "clear your head concept" you can filter through and have access to more information that may be beneficial to you. At some point you do need to take the wheel when negative thoughts come. Using methods in cognitive behavior therapy you can change those negatives to positives; Trauma may rewire your brain, but you can rewire it back (Galotti, 2014). Just like you can create new neural circuits to play an instrument you can create new circuits of positive thought. The zero-level theorem describes how thoughts have mass, which means that gravity can act upon them. That means they can be controlled (Ralph Lewis, 2021). It only takes 17 seconds for a new thought to attach itself and 68 seconds to create an entire new circuit. Meditation and positive mindset allow for two things to happen, access to more thoughts and the ability to hold onto a positive thought long enough so it can create an entire new neural circuit (Fannin, 2020),

YOGA AND PRANYAMA:

Yoga is a moving meditation. Combined with pranayama/breathing certain yoga poses can access parts of your nervous system that get damaged in combat. These poses focus on your hip area, where tension and emotion build up, much like they do in your shoulder areas. Breathing with the poses triggers the vagus nerve that increases neurotransmitter activity, which tells your brain to calm down. Trauma also can alter your memory processing and cause more emotion to be attached to memories, often why memories of combat can be overwhelming. Using correct breathing techniques, you change your memory back to its correct operating system. Adding one last ingredient of sound can speed the process of healing. The sound of Om resonates at the same frequency as nature and the mudra or hand gesture used in meditation the thumb to the index finger sends a signal to your brain to relax (Saunders). Often why you will see actors drawing or knitting in between sets. Focus on the fundamentals of both and you will in time make the brain body connection. Both will come naturally to you and you will start to feel the benefits (Yogafit, 2020).

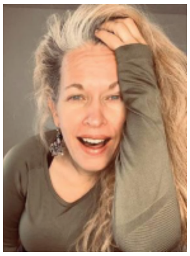
Holistic practices like yoga and meditation are things you as veterans have already been doing since bootcamp. Approximately 80 % of the dynamic and static exercises in military physical training are yoga poses, and techniques like box breathing and mindset are taught in most branches (US Navy, 2020). Throw away your westernized perception of yoga and look at it for what it really is, another tool that will increase your mental edge, help with injuries acquired during service and make you into an elite warrior.

Using the technique of Vetspeak I have tailor made military wellness program created using military culture, yoga and cutting-edge science (Garcia, 2019). These programs use fitness knowledge that veterans already are familiar with that are choregraphed in a way that they will be doing trauma yoga without realizing it. •

References

Fannin, J. (2020). Dr. Jeffrey Fannin. (H. C. Clark, Interviewer)
Galotti, K. M. (2014). Cognitive Psychology. Thousand Oaks: Sage.
Garcia, J. (2019). Former Secretary of the VA. (H. C. Clark, Interviewer)
Ralph Lewis, M. (021). What exactly is a thought and infomration physical? Retrieved from Psychology Today: https://www.psychologytoday.com/us/blog/finding-purpose/201902/what-actually-is-thought-and-how-is-information-physical
Tiwari, M. (1995). A Life of Balance, The Complete Guide to Ayurvedic Nutrition & Body Types. Rocherster: Healing Arts Press.
US Navy. (2020). US Navy Regulations. Retrieved from US Navy PRT Regulations: www.mynavyhr.navy.mil
Yogafit. (2020). Yoga for Veterans with PTSD. Yogafit.

ABOUT THE AUTHORS:



Heather Clark is a US Navy Veteran, served as Intelligence analyst for navy intelligence and special operations. She was also a military spouse and ombudsman. Heather holds a B.S. in Psychology, minor Evolutionary Anthropology and is a graduate student in Public Health at Purdue University. When her military community was taken away, she was devasted. Her sense of purpose was gone, and she found herself without a community to belong to and was left with mental and physical disabilities from her service. A decade later she re-discovered the healing properties of yoga and became a yoga teacher with a mission of sharing this healing skillset with fellow veterans. She has created a unique military style yoga program combined with cutting edge neuroscience research from the leading universities in the country to help fellow veterans with their own health challenges.

Nick Benas grew up in Guilford, Connecticut. The author of *Mental Health Emergencies, Warrior Wisdom, Tactical Mobility,* and co-author of *The Warrior's Book of Virtues,* Benas is a former United States Marine Sergeant and Iraqi Combat Veteran with a background in Martial Arts (2nd Dan Black Belt in Tae Kwon-Do and Green Belt Instructor in Marine Corps Martial Arts Program). Nick attended Southern Connecticut State University for his undergraduate degree in Sociology and his M.S. in Public Policy. He has been featured for his business success and entrepreneurship by more than 50 major media outlets, including *Entrepreneur Magazine, Men's Health,* ABC, FOX, ESPN, and CNBC.

Richard "Buzz" Bryan is currently the Outreach Coordinator for the West Palm Beach VA medical center. The co-author of *The Warrior's Book of Virtues,* Buzz previously served as the OEF/OIF Transition Patient Advocate (TPA) for the Veterans Integrated Service Network (VISN4) based in Pittsburgh, PA for ten years, working specifically with Iraq and Afghanistan veterans. Buzz was a member of the Navy/Marine Corps team and retired from the United States Navy in July 2011 after 22 years of honorable service as a Fleet Marine Force Senior Chief Hospital Corpsman.

Meet Me at the Gym

Abu said, "I'll be right back."As I sat there motionless, I heard this stern voice from the office door, "Shelly, stand up." I looked over and Abu was standing there with boxing gloves.

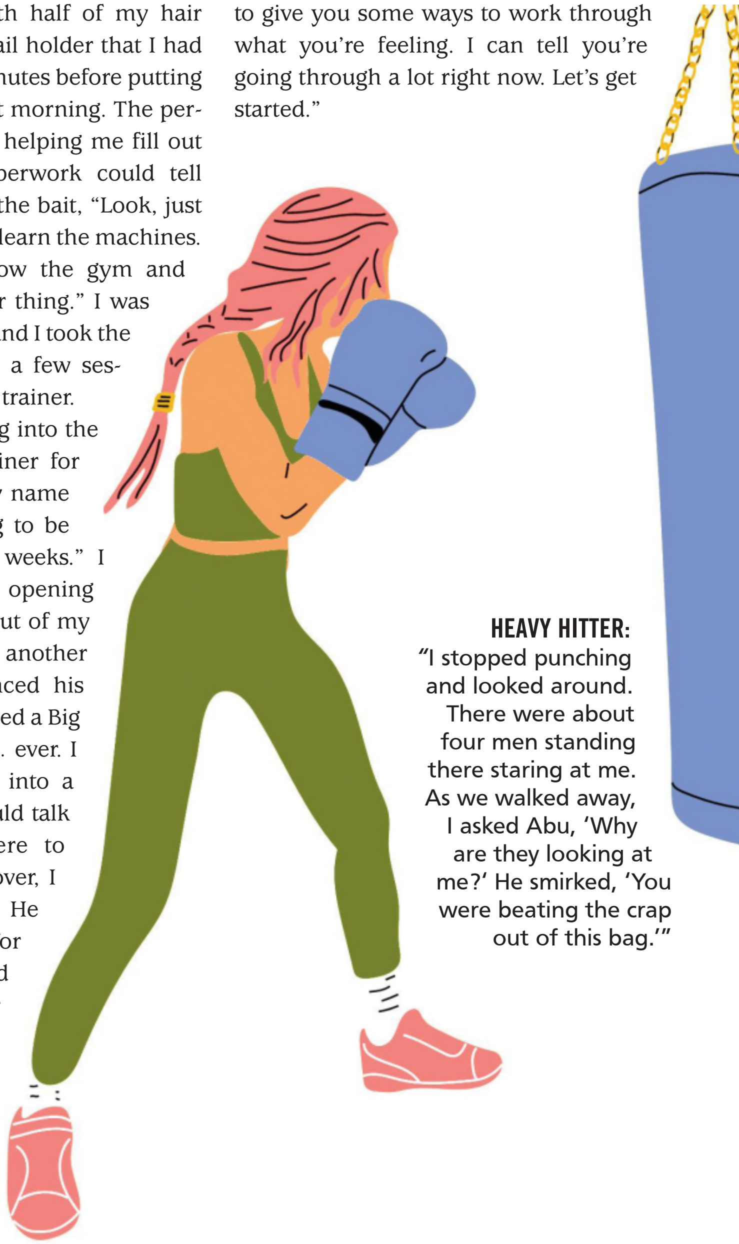
A few weeks ago, I had triggered a memory that I had filed away for many years. I was zoning out on the couch while watching movie credits scroll across the screen. I saw the name "Abu" and thought to myself, I knew someone named Abu, years ago. I hadn't thought about him in years. In a way, I had purposefully filed many of those moments away because it had reminded me of a time when I was in fight or flight mode, while living in Kansas. Autism was new to our family. Broden was only two years old.

A friend of mine was taking Hayden to preschool for me, so I could drive Broden an hour away to receive services, because that was the closest clinic available. That time in my life was chaotic and I felt like I had been thrusted into a culture that was foreign to me and frankly, a culture I wanted no part of. In a way, I was a bundle of nerves and emotion on the inside, and I worked very hard to operate almost "robotic-like" on the outside to stay focused. I didn't have time to process my feelings of hopelessness, panic, and fear. I worked hard to try and be present for Hayden in the evenings, after I got home from being in town with Broden. As I look back, I failed miserably My focus seemed to be wrapping my mind around this bazaar diagnosis of autism that had been dropped on us like an atomic bomb.

A few weeks into my routine of shlepping Broden downtown and sending Hayden off with Mark to our friend's house in the morning, I decided to join a gym in the local area. During the day, I was mostly journaling at a local coffee shop, researching autism, or sleeping in the back of my car while Broden was receiving therapy. I would nap in my car because I wasn't sleeping very well at night. I usually woke up in the morning to a book about autism on the floor that had slipped off my bed, from me eventually passing out from exhaustion. One day, I remember looking in my review mirror and noticing my alarm clock and blanket in the back, "Surely, there's a more productive way I could spend my day."

I walked into the gym closest to Broden's ABA clinic and signed up for a membership. They asked me if I wanted to see a personal trainer to help me get started. I chuckled inside as I stood there in a frumpy sweatsuit with half of my hair falling out of a ponytail holder that I had thrown in my hair minutes before putting my son in the car that morning. The person at the front desk helping me fill out the membership paperwork could tell that I was not taking the bait, "Look, just take a few sessions to learn the machines. After that, you'll know the gym and then you can do your thing." I was in a vulnerable state, and I took the bait. I agreed to take a few sessions with a personal trainer.

I remember walking into the gym to meet my trainer for the first time, "Hi! My name is Abu and I'm going to be with you for a few weeks." I remember my mouth opening and my gum falling out of my mouth. He was from another planet. I was convinced his body had never ingested a Big Mac or a Dr. Pepper… ever. I slowly followed him into a sitting area so we could talk and figure out where to start. As we walked over, I looked in the mirror. He had his work cut out for him. Once I turned away from the mirror and looked at him, he asked, "Shelly, why are you here?" I don't know if it was the question he asked or how he asked it, but I started to cry. I began by telling him what my family had experienced for the last three months involving Broden's diagnosis, and having to leave Hayden with friends so I could drive an hour away for Broden's therapy. Abu didn't flinch. He just listened and calmly said, "I see. I'm glad you're here and I'm going to give you some ways to work through what you're feeling. I can tell you're going through a lot right now. Let's get started."



HEAVY HITTER:
"I stopped punching and looked around. There were about four men standing there staring at me. As we walked away, I asked Abu, 'Why are they looking at me?' He smirked, 'You were beating the crap out of this bag.'"

Each week, Abu would ask me how I was doing and would show me something new in the gym. I started taking notes and I could tell I was getting stronger. Instead of sitting in my car in the parking lot all day at my son's clinic, I was dropping Broden off and then running to the gym to see what I could accomplish there.

After a few weeks, my personal training sessions with Abu ended. He had taught me quite a bit, and I felt he had slowly become my friend. Abu would still say hello to me and check in to make sure I was keeping up with what he had taught me. One morning, I was having a terrible day. Juggling everything in my life was becoming very difficult, and that morning I felt my plate was too heavy to carry. I walked into Abu's office, but he was not there, so I sat in a chair and cried. About 15 minutes later, Abu walked in and sat down in front of me, "What's wrong?" I told him that my life was too hard. After laying my head on his desk with snot dripping from my nose, Abu said, "I'll be right back."

> "Abu taught me how to find ways to work through my frustration. I still like to journal, but throwing on a pair of tennis shoes to work out is in my tool kit, as well."

As I laid there motionless, leaning on his desk, I heard this stern voice from the office door, "Shelly, stand up." I looked over and Abu was standing there with boxing gloves. I wiped off my face and said, "Abu, I don't do that stuff. I don't know how to box." He said again sternly, "Stand up." I slowly stood up and let him put the gloves on me. I begrudgingly followed him out into the gym area where I was surrounded by men lifting heavy weights, "Ok Shelly, I'm going to hold this punching bag. I want you to beat the crap out of it." I started to go through the motions of punching the bag. In the beginning, I don't think I was punching the bag, I was mostly nudging the bag to the point where it wasn't even moving. Abu yelled, "C'mon! That's all you got? Aren't you pissed? Your life is not what you wanted! Don't you feel robbed? Aren't you pissed at autism?" I started to hit the bag harder and harder and harder. Abu, held the bag as tight as he could, "That's it. Beat this bag! Beat the crap out of it!' I started to cry and I was soon yelling at the bag, "I hate you!" After a while, I didn't notice anyone around me. I only focused on the bag in front of me and Abu's angry face yelling at me. And just like that, Abu said, "Ok. That's enough. Take a deep breath." I stopped and looked around. There were about four men standing there staring at me. As we walked away, I asked Abu, "Why are they looking at me?" He smirked, "You were beating the crap out of this bag."

In military fashion, I moved about six months later, but in Kansas I made a choice. Instead of hanging out in a coffee shop every day and sleeping in my car, I met Abu. He taught me how to find ways to work through my frustration. I still like to journal, but throwing on a pair of tennis shoes to work out is in my tool kit, as well. I have Abu to thank for that. He was there at a time when I needed someone to empower me. He triggered something in me that over the years has been valuable. When I'm down, I very rarely stay down for too long. I eventually get up and mentally put on those boxing gloves. •

OUR JOURNEY IN 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.

CLEANING/SANITIZING SOLUTIONS

BANTEC SANITIZING

www.bantec.store

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

FINANCIAL PLANNING/ ESTATE PLANNING/ INSURANCE

MASS MUTUAL SPECIALCARE

www.massmutual.com/specialcare

Financial planning products and services by a company that cares.

THE AMERICAN COLLEGE OF FINANCIAL SERVICES

www.theamericancollege.edu

A private college focused on professional training for financial practitioners

NON-PROFIT

IRENE AND ERIC SIMON BRAIN RESEARCH FOUNDATION

www.iesbrainresearch.org

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

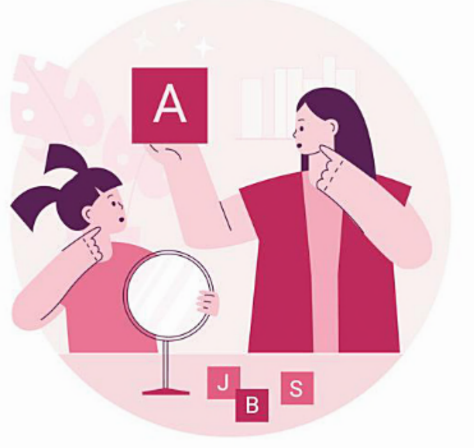
SCHOOLS AND CAMPS

PERKINS SCHOOL FOR THE BLIND TRANSITION CENTER

Perkins.org/TransitionSupport

Explore our tailored programs, discover expert resources and services for families, and join our upcoming caregiver community.

COMING NEXT MONTH IN EP:

VISION
HEARING
SPEECH

THE ANNUAL ISSUE

TO LEARN MORE ABOUT ADVERTISING OPPORTUNITIES

CALL 973-726-6218
OR EMAIL EPMAGAZINEVP@GMAIL.COM

ADVERTISE IN EP MAGAZINE

Exceptional Parent Magazine, a print and digital publication for over 50 years, provides information on disabilities and special health care needs and is available for free (EP for Free) at **www.epmagazine.com**

EP provides informative articles, resources and inspirational stories for children and adults with disabilities and special healthcare needs. The information covers all ages from infancy to elderly. *EP Magazine* also includes a military section dedicated to the unique challenges of military families caring for loved ones with disabilities, including returning veterans.

EP Magazine has a varied and constantly growing readership of individuals, families, caregivers, education and medical professionals. Our partnership with various organizations and universities greatly increases our exposure nationwide.

We offer digital and print advertising opportunities for companies whose PR plan includes corporate warmth and/or companies with products & services they would like to advertise to our readers. Custom advertising packages can be created to meet your needs. Contact Faye at epmagazinevp@gmail.com

IT CAN BE HARD TO GET HIS ATTENTION.

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

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

www.underagedrinking.samhsa.gov

SAMHSA
Substance Abuse and Mental Health Services Administration

SMA-18-5086FLY