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MAGAZINE

FEBRUARY 2023
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IN THIS ISSUE:

**THE IMPACT of
ADOPTION ON
EDUCATION**

ALSO INSIDE:

**DENTISTRY and
THE ELDERLY**

EP's ANNUAL HEALTHCARE ISSUE:

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for ALL
AGES

SPECIAL OLYMPICS:

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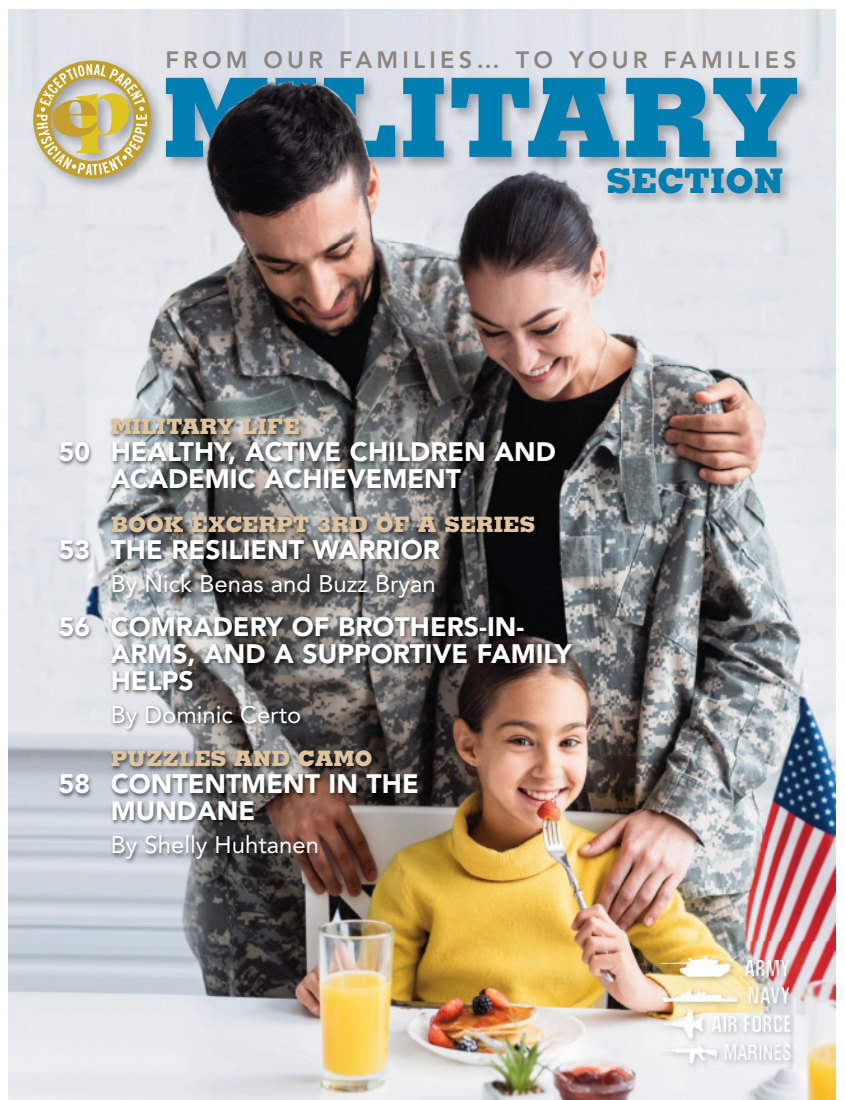
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EP FOR FREE!

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Never Assume

Never assume that a person is incapable of doing something because they have a disability.

As Editor in Chief of *EP Magazine*, I receive a lot of feedback. The vast majority of the comments have been extremely positive, appreciative and supportive of the magazine, like the following remark “your website and magazine are truly phenomenal and I believe you are making such a difference in the special needs



community.” There was one comment not in that vein, that inspired me to share something that I have learned from the many people I have met and talked to who have a disability or special healthcare need.

Never assume someone is incapable of doing something because they have a disability. How they

“Despite the challenges that people who live with a disability face, do not underestimate them.”

do it may be different or take more time because for them it may be more difficult, but they may very well be able to accomplish the task. As Gianna, the “One Handed Lady Golfer” featured in our June 2022 issue said, “Disabled is the right word when it’s used in the right context. I love differently-abled, because it is just different – I’m going to do it differently” In my opinion, someone who is able to find a way to accomplish something, despite a challenge, is to be respected and admired. That person, in my opinion, is an inspiration.

Many people create activities to make it more of a challenge, for example: tying one hand behind their back, wearing blindfolds, running hills instead of flat, creating an obstacle course. People applaud those who perform despite the challenges. So how could anyone do anything, but applaud, respect and be inspired by those who attempt, achieve and succeed, despite the challenges that life has naturally given them? We are proud to provide stories about many of these remark-

able people. I have learned that despite challenges some people may face, one should never underestimate them. “Wheelz,” who has spina bifida, is a wheelchair motocross athlete. When he was interviewed for our May 2022 issue, he said “There are obviously things a disability stops you from

being able to do, like I can’t walk, but life did give me a different set of wheels.” Wheelz came in second on *America’s Got Talent Extreme*.

During my time at the magazine and teaching, I have met and gotten to know many wonderful, inspiring, uplifting people, who live with

a disability or face special healthcare challenges. I have learned that despite the challenges, they can accomplish amazing things in their lives. I constantly learn from, have much respect for, and never underestimate them.

Faye Simon



Editor In Chief

THE EDITOR IN CHIEF'S DESK

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



Information and Support for the Special Needs Community

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WHAT'S HAPPENING

CAN LIMITING SCREEN TIME AND FOCUSING ON SOCIAL ENGAGEMENT IMPROVE AUTISM SYMPTOMS?

Excessive early-life screen media exposure has been associated with developmental delay and autism symptoms. Improvements in developmental trajectory in young children with ASD and high digital screen exposure have been reported when screen time is replaced with socially oriented activities.

Now, a pilot study from researchers at Drexel College of Medicine suggests that cutting back on screen time and increasing focus on social engagement may decrease symptoms among kids with autism. The parents of nine children (18 to 40 months) with autism received a training on screen time and child development and were asked to reduce screen viewing by their children to no more than 1 hour per week. The screen time of the children was reduced from an average of 5.6 hours of media on screens each day to about five minutes per day.

Up until recent studies, there has been little research examining whether interventions can decrease screen media exposure and ASD behaviors among children with ASD. The research team also incorporated weekly one-hour in-home support visits to replace screen time with engagement with an adult over the six-month study. After six-months of less television time and more social time incorporating strategies to gain eye contact and attention of the children, authors saw significant reductions in children's autism symptoms and parent stress.

The participants in the pilot study were nine children, 18 to 40 months old, with an ASD diagnosis who watched screens at least two hours per day. Screen viewing history and weekly screen viewing and social interaction were assessed. The intervention involved a parent education program fol-



OFF SCREEN: "There is consistent evidence that prolonged viewing of screens in the youngest children is associated with negative developmental outcomes."

lowed by weekly one hour in-home support visits aimed at replacing screen time with social engagement time over a 6 month period. Child autism symptoms, functional behavior, and development were assessed before and after intervention. The children's parents completed questionnaires on parental stress and their perceptions of the intervention.

"After six-months of less television time and more social time incorporating strategies to gain eye contact and attention of the children, authors saw significant reductions in children's autism symptoms and parent stress."

"The literature is rich with studies showing the benefits of parent-infant interaction on later child development, as well as the association of greater screen viewing with developmental delays," says lead author Karen F. Heffler, a researcher in the College

of Medicine. "Our study expands on this previous research by associating early social and screen media experiences with later ASD-like symptoms."

The results of the pilots study were promising; significant improvements were observed in core autism symptoms and parental stress from pre- to post-intervention as children's screen viewing decreased during the study.

Parent education and training/support to minimize screen time and increase social interaction for young children with ASD was tolerated well by parents and children. These promising preliminary results suggest that further research on early screen media viewing, ASD, and screen reduction intervention is warranted.

"There is consistent evidence that prolonged viewing of screens in the youngest children is associated with negative developmental outcomes," Heffler says. "There is no evidence that prolonged viewing of screens in the early years has a positive impact on development."



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The study is available to read online at <https://onlinelibrary.wiley.com/doi/10.1111/ped.15343>

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WHAT'S HAPPENING

NIH-SUPPORTED DASH AND TLC DIETS EARN TOP SPOTS IN "BEST DIETS" REPORT

Two National Institute of Health-supported diets, Dietary Approaches to Stop Hypertension (DASH) and Therapeutic Lifestyle Changes (TLC), together earned five No. 1 spots in U.S. News & World Report's 2023 "Best Diets" rankings.

The National Heart, Lung, and Blood Institute (NHLBI), part of NIH, researched, developed and tested both diets. Of 24 diets evaluated, DASH, which supports overall heart health and helps lower blood pressure and cholesterol, ranked first in the "Best Heart-Healthy Diets," "Best Diets for Diabetes," and "Best Diets for Bone & Joint Health" categories. TLC, which focuses on lowering cholesterol, ranked first in the "Easiest Diets to Follow" and "Best Family-Friendly Diets" categories. To receive top rankings, a diet must be nutritious, safe, easy to follow, effective for weight loss, and protective against diabetes and heart disease.

HOW THEY WORK

DASH, a long-term healthy eating plan, emphasizes vegetables, fruits, and whole grains, and includes fat-free or low-fat dairy products, fish, lean meats and poultry, beans, nuts, and vegetable oils. It limits foods high in saturated fat, tropical oils, sodium, and those with added sugar. Studies show that by increasing fiber, protein, and minerals, such as potassium, calcium, and magnesium, people following DASH can naturally lower their blood pressure by 3-20 points (link is external) within weeks or months – the greatest benefit

coming when they also limit salt intake to about 1,150 mg each day.

"This style of eating isn't telling you that you have to eliminate food groups, but instead gives you guidelines on how many servings per week you should ideally consume," explains Lindsey Pine, a culinary dietitian in Los Angeles and author of the *Mediterranean Diet Meal Prep Cookbook* and *Quick & Easy Mediterranean Diet for Beginners*.

bles, and fruits; limit saturated fats, trans fats, and dietary cholesterol; reach and maintain a healthy weight; and get regular exercise, such as 30 minutes most days. Studies show TLC could lower low-density lipoprotein (LDL) levels by 20-30% among people with borderline high or high LDL levels.

"TLC is a non-pharmacologic strategy for reducing the risk of cardiovascular disease and therefore does not require

dependence on prescription medications for most people, nor does it require making separate meals for you and the rest of your family," says Luis Rustveld, a registered dietitian and assistant professor in the department of family and community medicine at Baylor College of Medicine in Houston. "Adherence to the TLC diet also does not require buying special foods or eliminating the foods you like. The emphasis is on making product comparisons by reading food labels and choosing healthier versions of the foods you like."

The TLC diet's eating pattern is safe for people of all ages. Since there is a growing number of children with obesity who are grappling with some very adult health problems – such as Type 2 diabetes and high cholesterol – doctors sometimes prescribe the TLC diet to combat or prevent those ills.

LEARN MORE

Nutrition researchers (www.nhlbi.nih.gov/grants-and-training/funding-opportunities/clinical-applications-prevention) from NHLBI are available to discuss DASH, TLC, and other ways to support heart-healthy living. Get more information about each diet and access free recipes and meal plans: <https://www.nhlbi.nih.gov/education/dash-eating-plan> and <https://www.nhlbi.nih.gov/resources/your-guide-lowering-cholesterol-therapeutic-lifestyle>.



DASH AND DINE: The DASH diet can help lower high blood pressure, cholesterol and other fats in your blood. It can help lower your risk for heart attack and stroke and help you lose weight. This diet is low in sodium and rich in nutrients.

"DASH isn't a weight loss diet per se, but you certainly can lose weight if you create a calorie deficit," says Rosanne Rust, a registered dietitian and co-author of several books in the For Dummies health series, including the *DASH Diet For Dummies*. "Often when people transition from their normal food choices to a DASH eating style, they may automatically reduce calories since they're adding more vegetables and balanced meals to their diet."

TLC expands on DASH by helping people eat more plant sterols and fiber, such as whole grains, vegeta-



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WHAT'S HAPPENING

DEPARTMENT OF EDUCATION CALLS ON SCHOOLS TO LIMIT SUSPENSIONS OF STUDENTS WITH DISABILITIES



BY VALERIE C. WILLIAMS

Over seven million children with disabilities and their families rely on the effective, high-quality implementation of the Individuals with Disabilities Education Act (IDEA) to support a lifetime of success.

Make no mistake about it, IDEA — and the rights and protections it affords — impacts a child's future, how they view themselves as learners today and leaders tomorrow. In fact, the National Center for Educational Outcomes (<https://nceo.info/Resources/publications/OnlinePubs/report413/default.html>) estimates that 85–90% of children with disabilities can be expected to achieve at grade-level when they are provided with the best instruction, supports, and accommodations. Indeed, the promise of IDEA rests with the full implementation of the law.

High-quality implementation of IDEA starts with a clear understanding of the law's requirements, and that is why OSEP recently released the most comprehensive guidance package (<https://sites.ed.gov/idea/new-guidance-helps-schools-support-students-with-disabilities-and-avoid-discriminatory-use-of-discipline>) on IDEA's discipline and behavior requirements since the law was reauthorized in 2004.

As our country's first African American OSEP Director, and as the parent of a child with a disability, this guidance holds special meaning to me. It gives hope to parents, strategies to educators, and direction to state and local leadership.

Perhaps, most importantly, it motivates us at the federal, state, district, school, and program levels to have conversations about current disciplinary practices, their immediate and long-term impact on children with disabilities, and how we can change our systems and practices to focus on preventing interfering behaviors rather than relying on punitive, exclusionary approaches. Bottom line: this guidance package compels us to take a smarter approach to addressing discipline in our schools.

The data trends are longstanding and clear: children with disabilities, particularly children of color with disabilities, are disciplined at far greater rates than their peers without disabilities and these trends start as early as preschool and extend throughout high school. For example:

- *Preschool students served under IDEA accounted for 22.7 percent of total preschool enrollment but 56.9 percent of preschool students who were expelled.*
- *School-age students with disabilities served under IDEA represented 13.2 percent of total student enrollment but received 20.5 percent of one or more in-school suspensions and 24.5 percent of one or more out-of-school suspensions.*
- *During the 2019–20 school year, Black children with disabilities made up 17.2 percent of children with disabilities aged 3–21 served under IDEA yet 43.5 percent of all children with disabili-*

2017-18 OVERVIEW OF STUDENT DISCIPLINE K-GRADE 12

Students with disabilities include students served under the Individuals with Disabilities Education Act (IDEA) and students served only under Section 504 of the Rehabilitation Act of 1973 (Section 504).

50,922,024

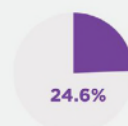
OVERALL STUDENT ENROLLMENT



Enrollment of Students with Disabilities
N=8,108,190

8,108,190

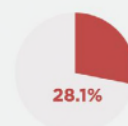
STUDENTS WITH DISABILITIES, 6,728,046 SERVED UNDER IDEA AND 1,380,144 SERVED UNDER SECTION 504



In-School Suspensions of Students with Disabilities
N=645,987

3,145,559

MISSED DAYS OF SCHOOL BY STUDENTS WITH DISABILITIES DUE TO OUT-OF-SCHOOL SUSPENSIONS



Out-of-School Suspensions of Students with Disabilities
N=704,523



Expulsions of Students with Disabilities
N=25,414

ities aged 3–21 served under IDEA who were suspended out of school or expelled for more than 10 school days.

The impact is alarming:

- Over 3 million missed days from school due to out-of-school suspension
- Out-of-school suspensions do not serve as a deterrent for future problem behavior and can lead to school dropout

We cannot suspend our way to better behavior, but we can invest in what works.

I am proud that OSEP has invested millions of dollars over decades to deeply consider how to best address the behavioral needs of children with disabilities. These investments have yielded powerful, evidence-based strategies and approaches that can be used by schools and early childhood programs to mitigate or even prevent interfering behavior before it occurs. In fact, according to the Center on Positive Behavioral Interventions and Supports (www.pbis.org) and the National Center for Pyramid Model Innovations (<https://challengingbehavior.org>), implementation of positive behavioral interventions and supports (PBIS) results in:

- Improved outcomes, such as increased academic achievement and social and emotional competence for children with disabilities, and reduced bullying behaviors;
- Significant reductions in inappropriate behavior;
- Reduced use of exclusionary discipline, including reduced discipline referrals and suspensions; and
- Reduced use of restraint and seclusion.

When we pair these tools with leadership and motivation to have honest and reflective discipline discussions, the outcomes can be powerful for children with disabilities and their families.

Over the next few months, I will be writing a series of blog posts that highlights challenges and opportunities before us and connects stakeholders with OSEP funded resources. I will address topics such as informal removals, alternatives to exclusionary discipline, and proactive approaches to supporting a child's behavioral needs; and will provide you with resources you can use in your own discipline discussions. •

Additional information about OSEP's *Guidance to Help Schools Support Students with Disabilities and Avoid Disparities In the Use of Discipline*, see *References*.

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 OSEP 2022 Behavior, Discipline Guidance Video (July 2022): <https://vimeo.com/731089146>
 Resource Guides on Positive, Proactive Approaches to Discipline: <https://osepideasthatwork.org/federal-resources-stakeholders/topical-issues/2022-osep-discipline-behavior-guidance>

ABOUT THE AUTHOR:



Valerie C. Williams serves as the director in the Office of Special Education Programs (OSEP) within the Office of Special Education and Rehabilitative Services at the U.S. Department of Education. In this role, she is responsible for overseeing administration of the Individuals with Disabilities Education Act (IDEA), which authorizes formula grants to states under IDEA Part B and to lead agencies for the infants and families program under IDEA Part C. IDEA also authorizes discretionary grants under IDEA Part D to institutions of higher education and other non-profit organizations to support grants for state personnel development, technical assistance and dissemination, technology, and parent training and information centers. Williams most recently served for six years as senior director of Government Relations and External Affairs at the National Association of State Directors of Special Education. She has decades of experience, which include supporting state-level special education leaders by overseeing federal government public policy activities, federal regulatory affairs, public relations, and key initiatives to promote equity and guide positive systemic change, thereby improving outcomes for students with disabilities.

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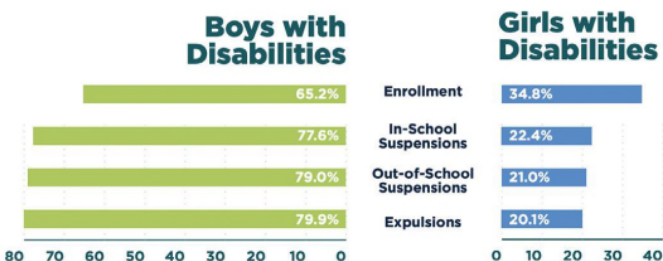
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STUDENT DISCIPLINE BY DISABILITY AND SEX

Boys with disabilities served under IDEA and Section 504 were disproportionately represented in student discipline, receiving suspensions and expulsions that were **greater than their share of total enrollment** for students with disabilities.



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CHILDREN'S MENTAL HEALTH: A NATIONAL FAMILY GUIDE

SUBMITTED BY SPAN ADVOCACY NETWORK

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

SCHOOLS AND MENTAL HEALTH

Collaboration and education on mental health in the school setting is critical. Schools have a responsibility to identify children who may have emotional, behavioral, and/or mental health challenges. When there are concerns, the child may go through the Intervention and Referral Services (I&RS) Team. The team may decide that the child just needs extra supports in school and then look at Response to Intervention (RTI), which requires the school to provide "evidence-based" interventions and then determine whether those interventions had the desired effect. In most cases, this should be done before a child is evaluated for eligibility for special education. (However, if a child already has a diagnosed mental health condition, or if the parent or school staff suspect that the child has an emotional or other disability, the child should be referred to the special education team for a meeting with the parent to decide whether or not a special education or Section 504 evaluation will be conducted). Some children with mental health issues have IEPs (Individualized Education Program) while others may just need accommodations under a 504 plan. For more information on this process, see <https://spanadvocacy.org/wp-content/uploads/2022/06/Guide-to-IDEA-NJ-Special-Ed-Code-Section-504-Overview.pdf>.

An important piece for success at school is the use of Positive Behavioral Interventions and Supports. Behavior is the result of

the child trying to communicate the best he/she can. Family information on positive supports is found at www.pbis.org/family.

Sometimes children need to have a Functional Behavioral Assessment done at school to decide why the child is acting in a certain way and what supports can be put in place. Also, schools can't change the child's placement without holding a meeting, unless it's an emergency situation. In addition, if the child does something or even breaks the conduct code and the school wants to remove the child, they must do a Manifestation Determination to decide if the behavior was caused by the disability.

Authors Ross Greene, PhD and J Stuart Ablon, PhD strongly believe that "children will do well if they can." This philosophy takes a non-blameful approach based on decades of research which indicates that many challenging behaviors are actually the result of skill deficits, not on manipulation or a lack of motivation, as many adults believe. This explains why traditional forms of intervention, such as rewards and punishments, often do not work for the most challenging children.

The Collaborative Problem Solving model (or Collaborative Proactive Solutions as the model is also referred to), articulated in their books:

1. Allows adults to pursue expectations
2. Reduces challenging behaviors
3. Teaches lagging skills
4. Improves the relationship between the child and adult
5. Solves problems




The model includes a step-by-step approach on how to help children and adults work together toward realistic and mutually satisfactory solutions underlying difficult behavior. The model can be used with children of all ages and works in home or school settings. For information, visit www.livesinthebalance.org or www.thinkkids.org


NAMI's Provider Education as well as Parents & Teachers as Allies (PT&A) programs are designed to help school staff understand mental health challenges in children. Two other programs are designed for student audiences: NAMI NJ's Every Mind Matters (EMM) for middle or high school students and NAMI national's Ending the Silence (ETS) high school students. Provider Education may be able to offer professional development credits and EMM is aligned with the NJ Core Curriculum Content Standards. For more information on NAMI school programs: www.nami.org/Support-Education/Mental-Health-Education/NAMI-Provider. For general information on mental health and schools visit www.nami.org/Support-Education

The Parent Center Hub has information on mental health and schools at www.parentcenterhub.org/?s=mental+health. In each state there is a Parent Training and Information


SATISFACTORY SOLUTIONS : MENTAL HEALTH IN THE SCHOOL SETTING



SPAN ADVOCACY NETWORK
Guide to IDEA - NJ Special Ed
Code-Section 504 Overview
<https://spanadvocacy.org/wp-content/uploads/2022/06/Guide-to-IDEA-NJ-Special-Ed-Code-Section-504-Overview.pdf>





POSITIVE BEHAVIORAL INTERVENTIONS AND SUPPORTS
Family Information on Positive Supports
www.pbis.org/family



LIVES IN THE BALANCE
Collaborative Proactive Solutions
www.livesinthebalance.org

Think:Kids
RETHINKING CHALLENGING KIDS
THINKKIDS
Collaborative Proactive Solutions
www.thinkkids.org


NATIONAL ALLIANCE ON MENTAL ILLNESS
Provider Education
www.nami.org/Support-Education/Mental-Health-Education/NAMI-Provider
Mental Health and Schools
www.nami.org/Support-Education

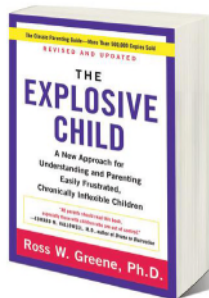

PARENT CENTER HUB
Mental Health and Schools
www.parentcenterhub.org/?s=mental+health
Find Your Parent Center
www.parentcenterhub.org

Center (PTI). PTIs help families with early intervention and school issues at no cost. For NJ, the Statewide Parent Advocacy Network is the PTI. SPAN is also a chapter

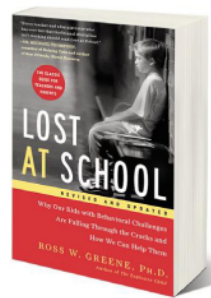
of the National Federation of Families for Children's Mental Health. Our warmline is (800)654-SPAN. Find the parent center in your state at www.parentcenterhub.org •

FURTHER READING : COLLABORATIVE PROBLEM SOLVING

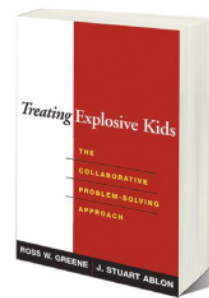
Ross Greene, PhD and J Stuart Ablon, PhD strongly believe that many challenging behaviors are actually the result of skill deficits, not on manipulation or a lack of motivation, as many adults believe.



Title: **The Explosive Child**
Author: **Ross W. Greene**
Publisher: **Harper Paperbacks**
Publication Date: **July 2021**
Paperback: **272 pages**
ISBN-13: **978-0063092464**
Available at: amazon.com and www.barnesandnoble.com



Title: **Lost at School: Why Our Kids with Behavioral Challenges are Falling Through the Cracks and How We Can Help Them**
Author: **Ross W. Greene**
Publisher: **Scribner**
Publication Date: **September 2014**
Paperback: **320 pages**
ISBN-13: **978-1501101496**
Available at: amazon.com and www.barnesandnoble.com



Title: **Treating Explosive Kids: The Collaborative Problem-Solving Approach**
Author: **Ross W. Greene and J. Stuart Ablon**
Publisher: **The Guilford Press**
Publication Date: **October 2005**
Paperback: **25y pages**
ISBN-13: **978-1593852030**
Available at: amazon.com and www.barnesandnoble.com

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

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.

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.



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

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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.

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!"



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

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



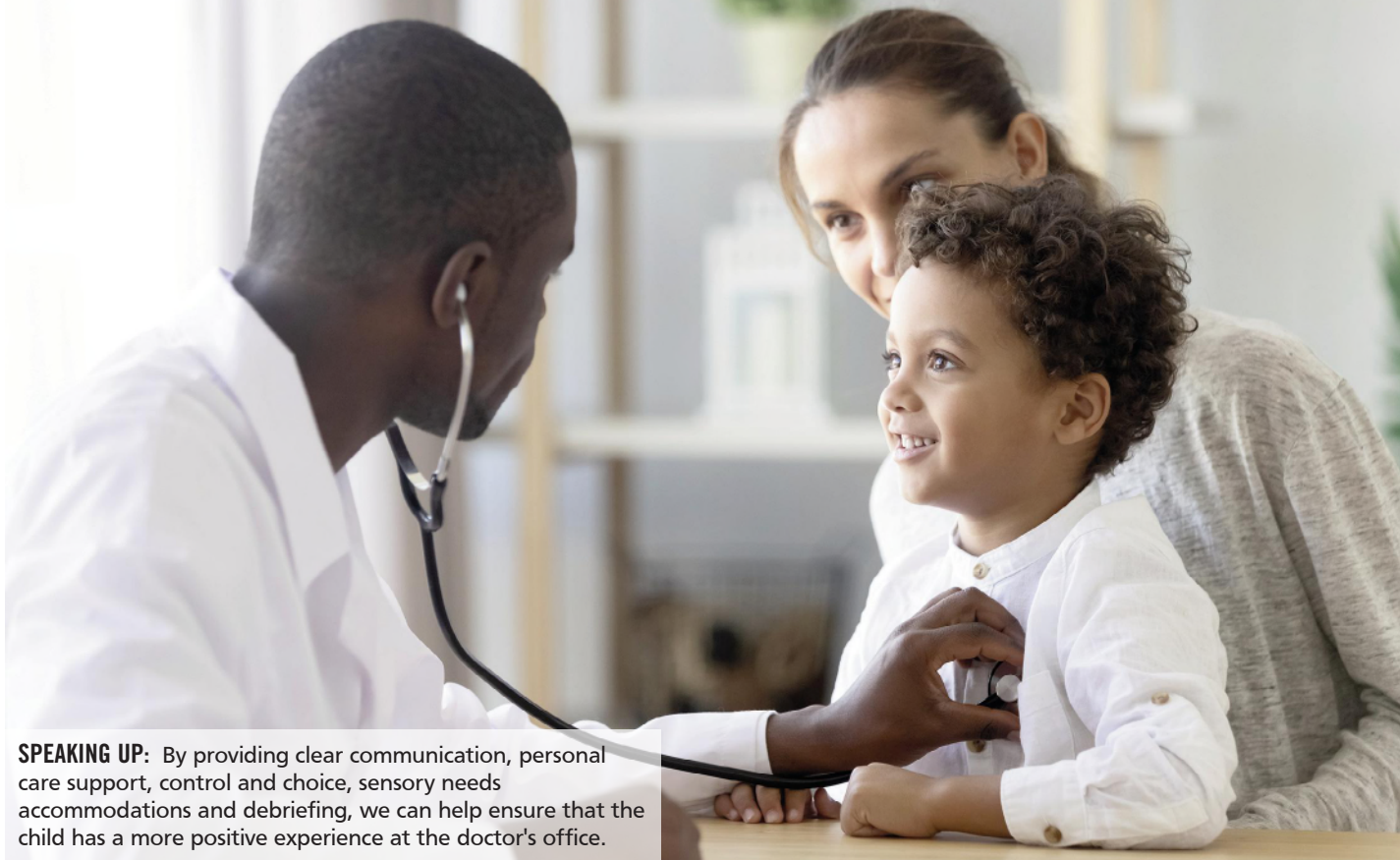
The Arc Lexington, a not-for-profit, award-winning provider of supports to people with I/DD in Fulton, Schoharie and Albany Counties of New York State. A chapter of The Arc New York, The Arc Lexington employs 1,600 people who support 1,300 children and adults who have disabilities including autism, mental 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.

WAYS TO REDUCE ANXIETY ABOUT GOING TO THE DOCTOR

BY JENN ADAMS

Going to the doctor can be a challenging experience for anyone, especially for children of any age with disabilities. It is important for educators and parents to work together to prepare a child with a disability for a visit to the doctor.



SPEAKING UP: By providing clear communication, personal care support, control and choice, sensory needs accommodations and debriefing, we can help ensure that the child has a more positive experience at the doctor's office.

By providing the child with the right tools and support, we can help make the experience less stressful and more successful. One of the first things to consider is how to best communicate with the child. Many children with disabilities may have difficulty understanding or expressing themselves, so it is important to use clear, simple language, and to provide visual aids if necessary. For example, you can use picture cards, social stories or videos to help explain the process of going to the doctor. It would be great to talk about what kinds of scenarios may arise at the doctor, and what types of tools and vocabulary are associated with a visit.

Another important aspect to consider is the child's personal care needs. Many children with disabilities may need assistance with dressing, grooming, or other personal care tasks. It is important to work with the child and their family, to ensure that they have the necessary supplies and equipment for the appointment. For example, if the child uses a wheelchair, it is important to make sure that the doctor's office is wheelchair accessible.

Additionally, it is important to provide the child with some sense of control and choice in the process. For example, you can offer choices on what to wear to the appointment, or let the child pick a toy or book to bring along. You may even want to create a visual schedule for the child about the steps of the trip there, things they can do once in the waiting room, and what they will do after. If something the child enjoys can be placed at the end of the visit, this might also help the children be motivated to follow directions during the time of the visit.

It is also important to prepare the child for what they might expect during the appointment. For example, the child might be asked to undress, have their blood pressure taken, temperature taken, or get a shot. Explaining what will happen in a simple, clear way can help reduce the child's anxiety. Using social stories or even mini-schedules can be a great resource.

Using a first aid kit or a pretend doctor's kit can help to simulate the experience for a child with a disability, that may have a fear of going to the doctor, by allowing them to learn about and become familiar with medical tools and procedures in a safe and controlled environment. By allowing the child to play with and manipulate the tools and items in the kit, they can become more comfortable with them and have a better understanding of what to expect when they visit a real doctor.

Additionally, using a first aid kit or a pretend doctor's kit can also help to teach a child with a disability about the importance of self-care and basic first aid. By learning how to properly clean a wound, bandage an injury, or take care of minor illnesses, a child can gain a sense of empowerment and independence, which can help to reduce their fear of going to the doctor, and may also make them less reliant on others for care. This can greatly improve their quality of life and sense of self-worth, in addition to promoting better health outcomes.

It is also important to consider the child's sensory needs. Many children with disabilities may have sensory sensitivities, such as being sensitive to loud noises or bright lights. If this is the case, it is important to let the doctor's office know, and to make sure that the child's needs are met during the appointment.

Finally, it is important to debrief with the child after the appointment. This can help the child process the experience and understand what happened during the appointment. It's also a good opportunity for the child to express any concerns or ask questions.

In conclusion, preparing a child with a disability for going to the doctor requires a team approach. By working together, educators, parents, and healthcare providers can help make the experience less stressful and more successful for the child. By providing clear communication, personal care support, control and choice, sensory needs accommodations and debriefing, we can help ensure that the child has a more positive experience at the doctor's office. •

ABOUT THE AUTHOR:



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

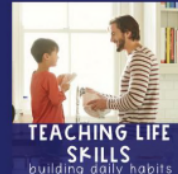
TEACH LOVE AUTISM

Providing information, services, and resources to parents, providers, and teachers working with individuals with disabilities.

(570) 485-3085 jenn@teachloveautism.com

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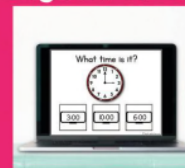
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EP MAGAZINE: THE JOURNAL FOR SPECIAL NEEDS FAMILIES AND PROFESSIONALS

FEELING ALONE WITH YOUR UNDIAGNOSED SYMPTOMS?

BY ELLEN LENOX SMITH

Too many of us have had times living life knowing that something is just not normal with our bodies. To make this even worse, many of us get lost and ignored when the medical world doesn't help us solve the issue. Does that sound like something you have had to face, too? You have a choice to let them win or to pick up the pieces of your mystery condition and try to find an answer, which was what I had to do.

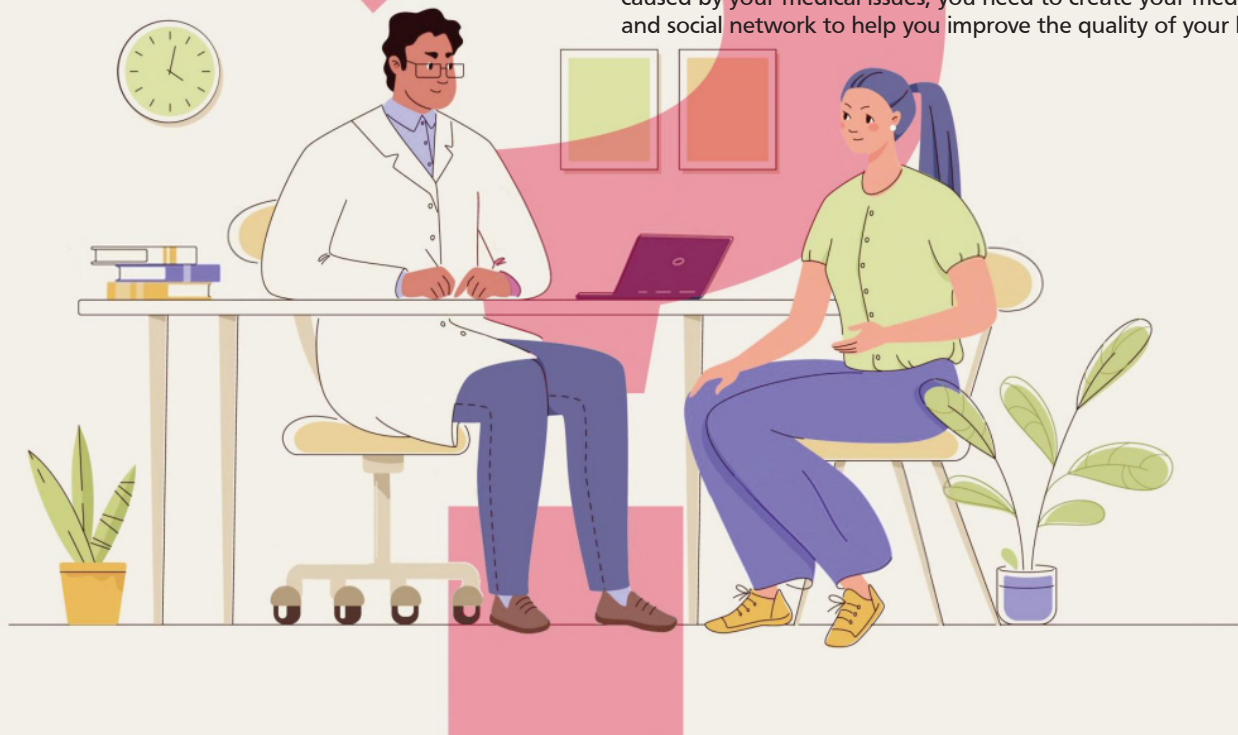
I was born with a condition called Ehlers-Danlos Syndrome and all I ever knew was my normal of living in this body. But as time progressed and strange things kept happening, despite trying to live a healthy happy life, I was turned away over and over, and told I “looked fine and all was normal” and given no explanation.

Was it normal to be on the parallel bars in high school and ask which way should I put my elbows, due to them rotating almost 360 degrees? Was it normal to find myself reacting to one healthy food after another with stomach aches, exhaustion, headaches and irritated bowels? Was it normal as life progressed to get thinner and thinner despite trying to eat healthy, and then have my bowels totally shut down caused by a motility issue? And what about becoming a master swimmer and developing excruciating pain in the shoulders and neck, to eventually hav-

ing to have both shoulders repaired along with two neck fusions? How many experience bones subluxation and dislocating from receiving a loving, simple hug? After a bladder prolapse repair, was it normal that it prolapse again one year later? Clearly something had to be wrong and this second prolapse became my final straw, realizing this was not a normal body I was expected to live in. I needed help and began an endless search to create the team to help me find answers.

It was thanks to needing a second bladder repair that I met a smart caring doctor who sat me down, asked question after question and said to me: “I think you have EDS and want you to go to a geneticist before I will do the repair.” After being turned away from finding the answer for fifty-four years, I thought this was a magical day, hearing this doctor's words to me. But upon going home and looking up this condition and thinking I was

FACING FACTS: After you allow yourself time to mourn your losses caused by your medical issues, you need to create your medical and social network to help you improve the quality of your life.



IMPROVING QUALITY OF LIFE : FINDING HELP TO ADDRESS YOUR CONDITION

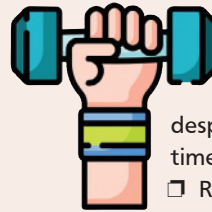
Here are my suggestions to consider doing, to help find answers to move forward with whatever you are expected to cope with. I hope sharing some of my tactics might be helpful to find your answers:

- Listen to yourself and trust your gut and ignore the doubters and try to find your answer.
- Begin to keep a medical notebook of test results, appointments, strange symptoms and anything else related, that might help to put these pieces together for an answer.
- Don't be afraid to move on to new doctors if you are not comfortable with the ones you have encountered. Each one has their own personality and techniques, so look to build a medical team you feel comfortable with and that shares mutual respect.
- I know you want answers, but you are in the driver's seat. Don't be afraid to say no if something seems too radical that they want you to try.
- If a description you hear from someone else sounds familiar to your life, be sure to search reputable sources for accurate information to learn more.
- Reach out to others and see if you hear of another experiencing something similar. You just never know what you might learn that they did, that helped to find the correct reason for their medical issues, that might be helpful to you.
- Be willing to try things that can't hurt you, but might help you. I have tried for instance, prolotherapy that wasn't always successful, yet has helped strengthen certain body parts from no longer dislocating. Being drug resistant to all opiates and even aspirin and Tylenol, a doctor suggested trying cannabis. I thought he was delusional,



yet listened to his suggestion and today, sleep well with a simple night oil from our home-grown plants. After twenty-seven corrective surgeries, I only take the night oil and no day medications, since for me, the cannabis oil has allowed continued calm to my body into the next day.

- I have allowed myself to be a guinea pig for EDS here in RI and for NIH research. I won't get cured, but having a goal of wanting to not have another person wait so long for a proper diagnosis, helps me feel purpose and meaning again.
- Find an outlet to cope with the frustration and feeling of loss in life. I started writing poetry at one point to release my emotions. This was strange for me to turn to, as I don't tend to pay attention to poetry. Yet I ended up writing over a hundred poems. I found writing helped me learn to cope with the new life I was expected to take on. Releasing my emotions in words helped me learn to accept and move forward.
- Continue to eat well, exercise, and try to live as active a life as you can, despite the limitations you are given at times.
- Reach out to friends or family that are compassionate and supportive, and that are comfortable allowing you to vent
- I have found it helpful to speak out and share what I have learned, in hopes that just one person's life will improve and not have the endless unknown journey I had to experience. I have educated the hospital ER staff and even new first year medical students at Brown University, to make them aware of this condition that so often is passed over as fibromyalgia.



going to now work towards my cure, I confronted the word: Incurable. Yet, now I knew this was real, I wasn't making these symptoms up and there was a need for a new battle to figure out how to improve the quality of my life.

It is rough enough to not feel yourself, but to also not be able to get help and guidance on how to address the condition and strive towards an improved quality of life is devastating. Many of us, in time, know in our hearts that things are off, but then get judged and dismissed to go home and are expected to ignore it.

Remember, this is the one life you get to live. After you allow yourself time to mourn your losses caused by your medical issues, you then need to get up, get to work and create your medical and social network to help you improve the quality of your life. You will find if you take some control in this process, it will help you learn to accept the changes to your life, and empower you to work towards ways to improve your life.

May life be kind to you •

ABOUT THE AUTHOR:



Ellen Lenox Smith has emerged as a leading voice for patients living with pain in Rhode Island and the country. She suffers from two rare conditions, Ehlers-Danlos Syndrome and sarcoidosis. She enjoyed a career, predominantly in the field of education, before having to resign due to health. She devotes much of her time to advocacy. Presently, she is a co-director for Cannabis Advocacy for the US Pain Foundation, along with being on their board, runs Rhode Island Patient Advocacy Coalition, and was appointed by the governor to both the Adaptive Telephone Equipment Loan Program and the RI Medical Cannabis Oversight Committee representing patients, and helps run the RI EDS Support group. A proud mother of four sons and five grandchildren, Ellen is also an organic gardener, and prior to her disability, was a master swimmer and high school swim coach. She was a staff writer for National Pain Report and *1000 WATTS Magazine* before they shut down, was a former staff writer for Pain News Network, and with her husband speaks out to educate others about her condition and pain management. She has spoken to: the FDA, Brown Medical students, Blue Cross nurses, and physical therapy students in RI and CT, along with speaking at the EDS national conferences. She is also the author of two books: *It Hurts Like Hell!: I Live With Pain – And Have A Good Life Anyway* and *My Life as a Service Dog!*




**“Working
lets me...**

**keep
contributing.”**



**earn
a living.”**



**be there for
the team.”**

**provide
for my family.”**

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THE POWER OF FRIENDSHIP

POWER PLAYER: Montclair State University alumnus Steve Way appears as a guest speaker at a 2022 on-campus event sponsored by the Disability Caucus, as part of the ReelAbilities NJ Film Festival.

BY LAURA GRIFFIN

When Steve Way, now an actor and advocate, befriended the Muslim kid in fifth grade who was being bullied in the wake of the 9/11 terrorist attacks, it was the start of a lifelong friendship that would later lead to Way's television acting career and sow the seeds of his passion for social justice.

The moment he and Ramy Youssef became friends, would also one day become a scene in the Hulu hit show *Ramy*, about a Muslim American 20-something living in New Jersey, and dealing with conflicts between his faith and American culture. In the show, Way plays the title character's best friend – a role he also plays in real life.

"We really bonded over shared feelings of pain of being an outcast, but we didn't really realize that until we were filming that scene," Way says. "Ramy has always been my biggest supporter and helped me out every step of the way."

Way, who graduated from Montclair State in 2013, is no stranger to being in the public eye. Growing up with muscular dystrophy, he spoke at fundraisers beginning at age 9, and spoke at the College of Humanities and Social Sciences convocation the year he graduated – about resilience and rising to life's challenges.

In recent years, he has also become an advocate for people with disabilities, using his platform to call for change. He currently leads the Rutherford Civil Rights Commission and is working to change laws that discriminate against marginalized groups, including those with disabilities.

"I have this growing platform, and I feel I would be remiss if I didn't use it to raise awareness of everything that we go through," he says.

Prior to the pandemic, when he was not on set or advocating, Way worked as a substitute history teacher by day and as a stand-up comedian at night. Now that he's fully vaccinated and the world is opening up a bit, he's starting to get some gigs again, and *Ramy* has been renewed for another season. It was also Ramy Youssef who helped launch Way's comedy career in 2010, when his improv group did a show to raise money for muscular dystrophy.

"Ramy's always seen that talent in me and wanted to bring out the best of me," Way says.

Working on the set of *Ramy*, Way says, has been one of the best experiences of his life. "It's a family. We're all really rooting for each other. It's a great environment."

"I HAVE THIS GROWING PLATFORM AND I FEEL I WOULD BE REMISS IF I DIDN'T USE IT TO RAISE AWARENESS OF EVERYTHING THAT WE GO THROUGH."

Way has added his colleagues to the list of those who help get him through each day, saying his "incredible support system" includes his parents, teachers, friends, doctors, girlfriend and, of course, Ramy. "I wouldn't be here without them."

"I take it one day at a time, understanding that tomorrow won't be like today," he says. "It could be better, it could be worse. There's no need to worry about what hasn't happened when I have the power to figure out what I can do right now." •

ABOUT THE AUTHOR:

Laura Griffin is the Editorial Director at Montclair State University.



RIISING TO THE CHALLENGE: Steve works on an advocacy project at home; "I take it one day at a time, understanding that tomorrow won't be like today,"



DENTISTRY AND THE ELDERLY

BY SCOTT RUVO, DDS

The Baby Boomers, post-World War II Americans born between 1945 and 1964, are one of the nation's largest generations. During their lifetimes, they have benefited from vast improvements in medicine, dentistry, and public health education, and are our longest-living generation.

When the Baby Boomers were born, Americans could expect to live about 63 years. These days US life expectancy is about 79 years, allowing Baby Boomers well over a decade more time to enjoy family, friends, retirement and hobbies.

As people age, though, they can face more health challenges. For example, bone density and immune systems naturally weaken, which effects oral health by increasing the risk of gum disease and tooth loss. Patients can also face physical and mental disabilities due to accidents, strokes, Alzheimer's and other dementia-related diseases. Other forms of disabilities stem from neuropathy or loss of mobility due to chemotherapy and other medical treatments or severe arthritis. Whatever the root cause, patients can be left unable to properly brush their teeth for two minutes a day, twice a day, or floss. Lack of proper hygiene can lead to poor oral health, which many recent studies have linked to developing other chronic medical conditions, including diabetes and heart disease. However,

while disabilities may present challenges to maintaining one's oral and overall health, there may be simple solutions to overcome these obstacles.

One of the most common problems dentists see with elderly patients is xerostomia – or what's commonly known as dry mouth. This condition is often a side effect of medications used to treat other diseases. Patients with dry mouth don't produce enough saliva to keep their mouths wet, which can cause several problems. A moist mouth helps prevent the growth of bacteria, which can cause Halitosis or bad-smelling breath. Saliva is also essential for helping you swallow food better. Saliva has enzymes that help break down sugars and fats that help you process these foods. Lastly, saliva helps wash the teeth after eating. (Think of it like a car in a car wash.)

So, not producing enough saliva can result in plaque on the teeth after patients eat, leading to rapid, rampant tooth decay, and an increased risk of developing cavities.

The first defense against dry mouth is to drink plenty of water during and after eating. "Swish and swallow" water after eating to help get the food off your teeth and into the stomach. You don't want the plaque (food and bacteria) to sit on the teeth for too long and cause decay. When not eating, you can use sugar-free lozenges and gum to help stimulate saliva flow, helping keep the mouth moist. Artificial saliva products such as "Biotene," "Xerostom" and others can also help. Patients might also consider speaking to their physicians about changing to a different medication that doesn't cause dry mouth, or decreasing the dosage of the one they're on, to decrease the side effect of dry mouth. Oral rinses with extra fluoride also help prevent decay.



TEETH WISDOM: Bone density and immune systems naturally weaken as people age, which effects oral health by increasing the risk of gum disease and tooth loss. However, patients can retain their teeth for a lifetime with proper care and maintenance.

Another issue many older patients with physical and mental disabilities have, is routine oral hygiene, such as brushing and flossing. Sometimes this is due to problems with dexterity, like not being able to firmly grasp a toothbrush or complete the motions needed to clean their teeth properly. This can be overcome by utilizing an electric toothbrush (there are many brands on the market), a water-pik (Waterpik), or an Air Flosser (made by Phillips Sonicare). Handles of these devices can also be modified with straps to help hold them.

Many older, disabled patients have caregivers, or they live in retirement homes with assisted living care. Caregivers must understand the importance of maintaining a loved one or patient's oral health.

Another issue is lost dentures. You have no idea how many dentures I've had to remake because a caregiver has lost or accidentally thrown out a patient's denture. Dentures can be made with the patient's name on them, which helps caregivers make sure the right patient has the right denture. It is also essential to place dentures in a regular spot where the denture can soak overnight, and the patient and caregiver will always know where it is.

Often, the food served in nursing homes and other senior living facilities is cooked softer to make it easier for patients to chew and

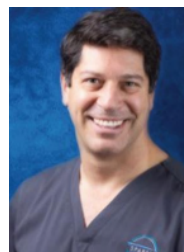
prevent choking. The downside is that soft foods can get stuck between a patient's teeth and be more difficult to remove. This can cause decay in between and circumferentially around the teeth. Thus, it's important to ensure caregivers understand and properly maintain their patient's oral hygiene.

Regular dental checkups are also a must. It is far better to catch a cavity early, than wait until it is a bigger, more severe problem. Older patients with higher levels of decay may consider seeing their dentist as frequently as every 2-4 months to keep things manageable, even if just to get an exam. It is far less expensive to do small fillings than to have to do major dental work.

“REGULAR DENTAL CHECK-UPS ARE ALSO A MUST. IT IS FAR LESS EXPENSIVE TO DO SMALL FILLINGS THAN TO HAVE TO DO MAJOR DENTAL WORK.”

Aging is a natural process and doesn't have to result in patients suffering painful dental problems, losing their teeth, or being unable to chew properly and enjoy their food. Patients can retain their teeth for a lifetime with proper care and maintenance. Maintaining good oral health also significantly contributes to more personal confidence and a better quality of life. •

ABOUT THE AUTHOR:



Scott Ruvo, DDS graduated from University of Illinois Chicago Dental School and has been in private practice in Sparta NJ for over 25 years. Dr. Ruvo is an attending at the Morristown Hospital Dental clinic where he enjoys teaching residents. He is an active member of the American Dental Association and is a Trustee in the New Jersey Dental Association. Dr. Ruvo grew up and lives in Sussex County, where he enjoys fishing, hiking, biking and Photography, with his wife and two children.

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NEW REPORTS TO HELP YOU ADVOCATE FOR HEALTH EQUITY FOR PEOPLE WITH DISABILITIES

BY CRAIG ESCUDE, MD, FAAFP, FAADM

In the last year, we have seen three significant announcements relating to improving healthcare for people with disabilities, including those with intellectual and developmental disabilities (IDD).

In this article, I'll summarize all three. That's my part. Your part as advocates for people with IDD is to use this information to inform legislators, physician groups, hospitals, insurance plans, managed care organizations, medical schools, nursing schools, dental schools, medical licensure boards,

and other healthcare entities to TAKE ACTION to incorporate training and education for students, optimize physical environments to make them more accessible, and to build a healthcare system where people with IDD can receive equitable healthcare.

SOURCE 1 : THE NATIONAL COUNCIL ON DISABILITY



The Release of the National Council on Disability's Framework for Health Equity for People with Disabilities February 2022

and thirty-eight other recommended changes to foster health equity for all. The five core components include:

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

The additional thirty-eight items cover a wide range of recommendations, including making medical offices “sensory-friendly,” creating an “essential disability benefits” list of home and community-based services, mandating Medicare coverage for many services specifically beneficial to people with disabilities, including dental coverage, and mandating that health plans include a person with a disability in the peer review process for claims, among others.

https://ncd.gov/sites/default/files/NCD_Health_Equity_Framework.pdf

The NCD's framework “provides a roadmap for fixing systemic barriers within our healthcare system and references many examples of the well-documented health disparities and inequities that demand action for over 61 million people with disabilities.” The framework calls for five significant changes

RECOMMENDATIONS FROM THE CENTER ON DIGNITY IN HEALTHCARE FOR PEOPLE WITH DISABILITIES

BY LAUREN AGORATUS, M.A.

Inaccessible doctor's offices? Non-adaptive medical equipment and testing? Provider bias in medical decisions?

GAPS IN HEALTHCARE

The Center for Dignity in Healthcare for People with Disabilities examined key areas in healthcare and identified the following areas of concern:

- Mental health
- End-of-life care
- Organ Transplantation
- Prenatal diagnosis

The Center conducted a literature review and gap analysis in each of these areas and issued a set of recommendations for healthcare providers, families and patients, and systems. There is also an easy read version of each set of recommendations for people with intellectual/developmental disabilities.

There are also additional recommendations specifically for disability organizations, policymakers, healthcare educators, and testing labs.

Care denials, bias, rationing, ableism regarding disability in healthcare must be addressed in order for medical care to be equitable. •

ABOUT THE AUTHOR:

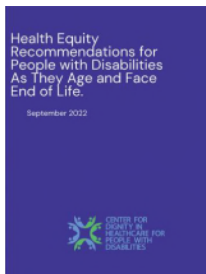
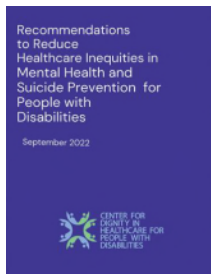


Lauren Agoratus, M.A. is the NJ Coordinator for Family Voices, NJ Regional Coordinator for the Family-to-Family Health Information Center, and Product Development Coordinator for RAISE (Resources for Advocacy, Independence, Self-Determination, and Employment). She also serves as NJ representative for the Caregiver Community Action Network as a volunteer. Nationally, Lauren has served on the Center for Dignity in Healthcare for People with Disabilities transplant committee (antidiscrimination), Center for Health Care Strategies Medicaid Workgroup on Family Engagement, Family Advisor for Children & Youth with Special Health Care Needs National Research Network, National Quality Forum-Pediatric Measures Steering Committee, and Population Health for Children with Medical Complexity Project-UCLA. She has written blogs and articles nationally, including publications in 2 academic journals (<https://pubmed.ncbi.nlm.nih.gov/?term=agoratus+>). Lauren was named a Hero Advocate by Exceptional Parent Magazine (www.epmagazine.com Archives June 2022).

MIND THE GAPS : ADDRESSING SYSTEMIC INEQUITIES IN HEALTHCARE

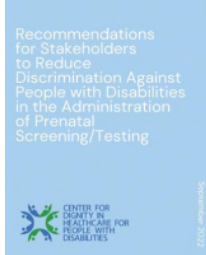
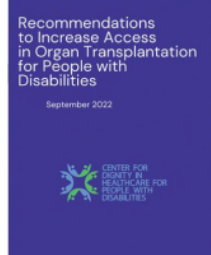
This work was conducted as part of the Center for Dignity in Healthcare for People with Disabilities. While the grant funding that effort ended, the work continues as part of the new National Center for Disability, Equity, and Intersectionality.

Recommendations to Reduce Healthcare Inequities in Mental Health & Suicide Prevention for People with Disabilities
www.centerfordignity.com/mental-health-and-suicide-prevention



Health Equity Recommendations for People with Disabilities as They Age and Face End of Life
www.centerfordignity.com/subcommittee-on-aging-end-of-life

Recommendations to Increase Access in Organ Transplantation for People with Disabilities
www.centerfordignity.com/organ-transplantation



Recommendations for Stakeholders to Reduce Discrimination Against People with Disabilities in the Administration of Prenatal Screening/Testing
www.centerfordignity.com/prenatal-diagnosis-subcommittee



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.

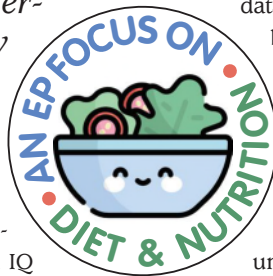
We know that early screening and evidence-based dyslexia interventions are critical for both preventing and remediating reading failure, but can other measures help to accelerate a child's progress in reading?

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 kinder-

garten, 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."

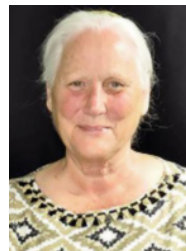
DYSLEXIA RESEARCH CONTINUES...

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. •

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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

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KAYLA CORNELL HAS A MESSAGE FOR FELLOW SPECIAL OLYMPICS ATHLETES: LET'S GET HEALTHY TOGETHER

BY RJ NEALON

Kayla Cornell is the head chef in her cooking class for individuals with intellectual disabilities. Dressed in a blue Special Olympics shirt and surrounded by Special Olympics athletes, she gives instructions and demonstrates knife skills in the kitchen at the Mary Free Bed YMCA in Grand Rapids. Cornell's goal is simple: teach her students how to be healthier. The class is aptly named Let's Get Healthy Together.

The 33-year-old focuses on cooking healthy recipes and teaching specific skills during the seven-week program. Sharing her passion for eating well is important to Cornell because she once struggled with making healthy choices. This inspired her to endeavor to become a dietitian. Her hope is to work specifically with people with intellectual disabilities. Her message to others? That it is okay to struggle, but having a great support system in place makes all the difference.

Cornell was introduced to Special Olympics in the seventh grade when a teacher suggested she try downhill skiing. Uneasy at first with large competitions and sharing a room with a teammate while traveling, she tried to have an open mind. "My mom convinced me in high school that I needed to try it out again, so I drove an hour to ski practice and ended up loving down-

hill skiing," Cornell says. "It wasn't until 2014 that I broke out of my shell and played more sports and got more involved in Special Olympics."

Soon Cornell added gymnastics, softball and other disciplines to her list of sports, and started to ingrain herself in the Special Olympics community. This helped her warm up to uncomfortable situations, and with the support of her coaches, family and therapist, she says she now gladly shares a room. "Special Olympics has forever changed my life," she says. "It's helped me grow into areas that I didn't know I could grow into."



CUTTING EDGE: Kayla Cornell uses her talent in the kitchen and passion for healthy eating to encourage her fellow athletes to make healthy choices.



PEAK PERFORMANCE: Cornell got her start in Special Olympics on the ski slopes. “My mom convinced me in high school that I needed to try it out again, and I ended up loving downhill skiing.”

One of those areas is her work with Special Olympics Michigan. Cornell is Michigan’s first official Health Messenger, and her cooking class is just one aspect of that position. Cornell is trained to be a health and wellness leader, and she also focuses on being an advocate and role model for the community. During trips to Washington, D.C., she and her colleagues meet with lawmakers and leaders in health care to improve access for people with intellectual disabilities. They are pushing to add more public health programs, improve health systems and engage community support.

Heather Burke, Director of Sports and Training for Special

Olympics Michigan, says Cornell’s efforts have opened the eyes of many athletes. In fact, some want to follow in her Let’s Get Healthy Together footsteps. “We’ve got a couple of athletes who are now going to be learning the cooking class themselves, and offering it so that we can expand our reach outside of the southwest region here,” Burke says.

Cornell recognizes and appreciates the opportunity she has to influence others in a positive way and to bring about change. “Being a Health Messenger has been super important to me because I’m able to help other athletes,” Cornell says. “I see the changes and the differences that are made in the athlete’s life. I sit on Zoom calls and listen to athletes say, “Hey, I learned that in Kayla’s cooking class. I learned to drink more water and eat healthier.”

As a result, she started a college program this year to focus on becoming a dietitian. Cornell is taking online nutrition classes through the Community College of Denver, and her first class is human nutrition. With no graduation date set and taking one course at a time to start, she says, “I’ll figure out how long it’s going to actually take, but I will get there, it doesn’t matter how long it takes.”

Once a certified dietitian, Cornell plans to continue her work with people with intellectual disabilities and eventually help people who are hard of hearing as well. “I think that a big reason why I want to work with them is because I understand and can relate to what they’re going through,” Cornell says. “I can relate to understanding mindful eating. You know, a lot of the eating stuff is they’re bored. They’re stressed, they get anxiety—and I get that.”

Soon, Cornell will have a degree to back up the natural leader and encourager in her, and she will no doubt continue to inspire others along the way.

ABOUT THE AUTHOR:

RJ Nealon is a Special Olympics athlete, reporter, communications fellow, alumnus of the University of Alabama and former ESPN intern.



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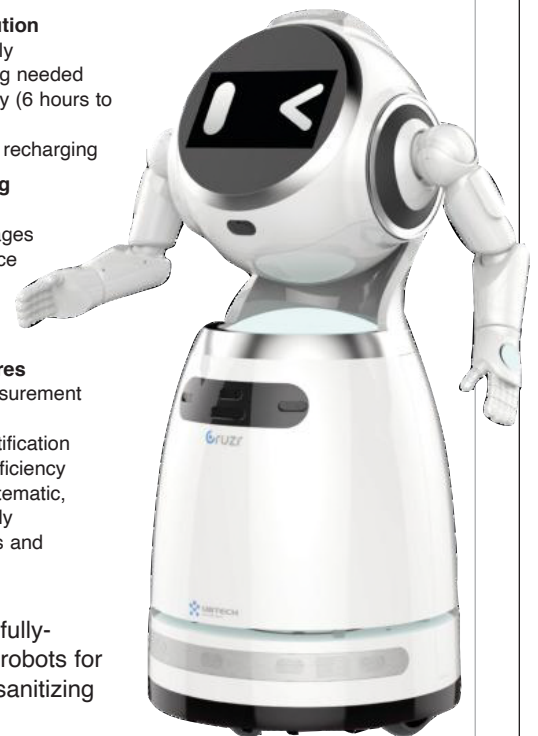
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Diet and nutrition are a vital part of every person's daily life, neurodivergent or neurotypical. We all have to make sure that we are eating enough sustaining nutrients to stay healthy.

And for individuals with disabilities, we often need to teach them how and why to make healthy food choices.

8 COOKING SKILLS AND ACTIVITIES FOR ANY AGE

BY STEPHANIE DELUSSEY

Cooking is an important life skill. Life skills are essential for students as they transition from childhood to adulthood. Cooking is great for helping students develop a good work ethic, time management skills, math, and literacy, e.g. reading recipes.

Here are eight cooking skills and activities that can help individuals learn how to make healthier food choices and cook.



1. READING A RECIPE

One of the most important skills in cooking is knowing how to read a recipe. A recipe is just a set of instructions that an individual follows to prepare a specific meal. And there are four parts to a recipe that need to be understood and followed: the ingredients list, the recipe instructions, how many people the recipe will feed, and how long it will take to prepare the meal.



2. FOLLOWING A RECIPE

Just like reading a recipe, following a recipe is an important part of cooking. For some recipes, you need to follow the steps in succession or the recipe will taste different or not come out right (like making a cake). For other recipes, you can mix up a few steps and the recipe will be okay (like making a sandwich). The good news is, that reading a recipe and following a recipe can be taught in school or through home instruction, and simple visual recipes are a huge help. Visual recipes give students the picture steps, as well as the written directions so that they can be accessed by all students.



3. KITCHEN SAFETY

The kitchen can be a dangerous place if you've never cooked before. There are big appliances, hot stoves, sharp objects... and

this is one place you don't want to learn safety skills through trial and error. This is why teaching individuals safety skills in the kitchen, is important. Here are some safety skills to consider teaching: (1) washing your hands before cooking, (2) not letting certain foods touch, due to cross contamination, (3) cooking foods to the proper temperature, (4) using pot holders and mitts to touch hot items, (5) cleaning up after cooking, and sanitizing, (6) using kitchen appliances and utensils, including knives, and (7) what foods can and cannot go in the fridge. This is not an extensive list, but a great starting place.



4. SETTING THE TABLE

Whether you sit together at the dinner table each night together as a family or not, knowing how to set the table is an important skill to have. What needs to be on the table and what doesn't? What serving utensils are needed for the meal? You also need to make sure you have enough place settings for everyone who will be eating, and enough spots and chairs at the table.



5. HEALTHY FOOD VS. JUNK FOOD

This one may seem like a no brainer, but sometimes you really are craving a donut... and that's okay! Junk food is okay in moderation, and this is a skill that we can teach. Using the Kid's Healthy Eating Plate chart and the Healthy Eating Pyramid is a great place to start. Your child's teacher is also a great asset in this learning.



6. CONNECT FOOD TO ANOTHER LESSON OR ACTIVITY

I love to connect food to any lesson or activity, because the possibilities are endless! Maybe you're reading a story and the main character is making chicken noodle soup. You could take this opportunity to talk about how to make the soup and what ingredients are needed, and maybe even go a step further and make it together or have your child help you order a bowl of chicken noodle soup from a local diner for dinner. Maybe you're at the zoo and the zookeepers are feeding the giraffes. You could take the opportunity to talk about what the giraffe is eating, if it is a healthy or unhealthy food, if a human could eat what giraffes eat... so many possibilities! And all of these conversations lead to a larger understanding of food and nutrition in our world.



7. TRIP TO THE GROCERY STORE

Allowing your child to go to the grocery store with you is a great way to introduce him or her to different foods and experiences. Here are some skills you can practice at the grocery store: (1) writing up a grocery list to purchase items, (2) locating items in the grocery store, (3) using a shopping cart, (4) making sure you have enough money to purchase the items in your cart, and (5) paying for your groceries (6) Counting the change.



8. ORDERING FOOD AT A RESTAURANT

This is a great skill for any individual, and with the power of technology this can be done in a physical restaurant, through drive through, over the phone, or through an app. This skill is very closely tied to communication, and is a great skill to practice!

There are so many ways to teach a child about proper nutrition and healthy foods, and it is my hope that this list is a helpful starting place for you and your child. •

ABOUT THE AUTHOR:



Stephanie is a dual-certified special education teacher, Master IEP Coach®, children's book author, and teacher mentor. She has a passion for creating engaging, adapted resources for teachers and students with disabilities, and is self-proclaimed #datanerd. She understands that not everyone will love IEPs as much as she does, but it is her hope that with the appropriate training and resources, teachers will not only advocate harder for student services and supports, but also bridge the gap between teachers and families to foster a true IEP Team.

She also provides professional development for teachers. You can connect with her at www.mrdsdcorner.com and www.theintentionaliep.com. Stephanie is also a huge mental health advocate, sharing her experiences and struggles to let others know that you can survive the dark seasons and thrive in life and teaching with a mental illness.

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10 TIPS FOR POLICE, PARAMEDICS AND EMTS WHO RESPOND TO INDIVIDUALS WITH SPECIAL NEEDS

BY NANCY MUSARRA PH.D.



Police officers, paramedics and emergency medical technicians (EMTs) are often the first to respond to an emergency situation. Emergencies often involve children and adults who have chronic health challenges.

Conditions such as seizure disorders, physical disabilities or developmental challenges are complex. The symptoms that often accompany these challenges can be exasperated during an emergency, making the situation even more difficult for the individual. The unpredictability of a crisis can magnify the person's anxiety,

sensory responses and inability to communicate their needs. As a result, first responders, who try to assess, treat or transport an individual to a hospital may find this task challenging.

By being prepared, first responders can help these individuals manage the overwhelming stress of an emergency.

EMERGENCIES AND INDIVIDUALS WITH SPECIAL NEEDS : TEN TIPS FOR FIRST RESPONDERS

Here are 10 tips police officers, paramedics and EMTs need to know to achieve the best outcome in an emergency situation.



1. SPEECH QUALITY DOES NOT DETERMINE INTELLECT

Many chronic health challenges affect one's muscle tone and quality of speech. Difficulties, such as slow, stuttered, odd or flat speech can affect how one talks and responds to questions or commands. Many times, others assume that if an individual has poor speech, they also have low intelligence.

This assumption is not correct. In fact, many individuals with speech, physical or sensory challenges have average to above-average intelligence. However, when experiencing a crisis situation, their speech challenges may be exacerbated due to anxiety.

FIRST RESPONDER TIP

Work to calm the individual and decrease anxiety. Modify the pace of your questions. Paramedics or EMTs who ask individuals about symptoms should ask one question at a time. Listen and give the person time to answer. Wait for a response to your first question before you ask the next.



2. SOME INDIVIDUALS ARE 'NON-VERBAL'

Some individuals cannot utter a word, while others may be able to say their name and address, but beyond that, they too are non-verbal. They cannot answer questions verbally, because they are unable, not unwilling. They may react with frustration

by running away or with aggression. When this occurs, the situation often deteriorates.

Non-verbal individuals are taught to communicate through I-Pads, phones or other technological devices and are often eager to talk to you. You may not succeed with the first method you try and that's ok. Don't second guess yourself, try again.

FIRST RESPONDER TIP

Make available non-verbal alternative ways to communicate, such as through typing, writing, signing, drawing, picture cards or other forms of technology. If the individual has a phone, they may be able to text you or use other resources available in their phone to communicate. It is a good idea for paramedics and EMTs to learn a few basic signs such as pain, hurt, eat, ambulance, drink, etc. If possible, include picture cards in the ambulance so that EMT's and paramedics can communicate with non-verbal individuals.



3. TOUCH, SOUND, LIGHT OR SUDDEN MOVEMENTS CAN TRIGGER A PANIC

Some individuals are sensitive to lights, sounds, smells and movement of the environment and respond with panic. Even when EMTs and paramedics are called to a home where the individual is familiar and comfortable, the individual may panic. To decrease a possible panic response, move slowly and observe. Some individuals will react with a fight, flight or freeze response when overwhelming stimulation feels painful.

FIRST RESPONDER TIP

Approaching the individual suddenly, touching them without warning or approaching them with loud verbal commands may destabilize or jar them. This may cause them to flee or become aggressive. Once the scene is secured, approach the individual calmly and if possible, keep a distance. Try to eliminate sounds and lights, such as radio chatter and lights from your vehicle. If you need to touch the individual, explain what you will do first, so they understand and can anticipate your next move.



4. UNAWARE OF THE DANGER, THEY MAY RUN BACK INTO A BURNING HOME

There is a lot of activity during a house fire. In addition to smoke and fire, the sounds of fire truck engines, gushing water and people crying can be confusing. Bright flashing lights can be upsetting.

Individuals with sensory conditions may hide under a bed or in a closet, making it difficult for firefighters to find and save them. Once rescued from the home, they may find the chaos of the fire scene unbearable. As a result, paramedics and EMT's must be aware that even if the individual is hurt, they may still run back into their burning home because it is comfortable and familiar to them. In a panic, they seek to avoid stimulation and get back to their comfort zone. Other reasons they may run back

in their home (even if it is burning) is to resume an activity they were doing, to save a pet or to help firefighters.

Teaching fire safety and becoming familiar with the sounds of the alarms and sirens will help prepare the individual for a fire emergency. Family practice drills will help everyone in the home be prepared about what to do in a fire.

FIRST RESPONDER TIP

Secure the child or adult once they are removed from the burning building. Try to place them in a calm, non-stimulating place away from the sights and sounds of fire rescue. Provide headphones and/or sunglasses to decrease stimulation. If possible, pair them with a responsible and trusting adult who understands their needs and can calm them and help them understand the situation.



5. INDIVIDUALS WHO ARE HYPER-SENSITIVE MAY RUN

First responders encounter many individuals who have a sensory challenge that makes it very difficult for them to regulate their sensory systems. They are hypersensitive and easily overwhelmed. These individuals are often comfortable and better able to focus while wearing headphones and sunglasses to decrease light and noise.

Hypersensitive individuals are triggered by too much information coming at them at once, causing them to overreact. For them, sounds are louder, lights are brighter and touch is more intense, and sometimes painful. Hypersensitive responses can be misinterpreted as a mental health crisis when it's not. Instead, this over-reaction indicates the need for less stimulation so that they can function.

FIRST RESPONDER TIP

Decrease stimulation by moving them away from onlookers, barking dogs, sirens, flashing lights, and radio chatter. Their lack of eye-contact, use of headphones or sunglasses is not a sign of disrespect. Allow them to wear these items during your encounter to decrease environmental stimulation and help them focus on your com-

mands and questions. EMTs and paramedics treating an individual after an accident or illness can ask the individual (or parents) about what interests them. If the situation allows, try to get to know the person. Talk with them about their interests (a movie, athlete, space, cars, video game), so they begin to feel connected, calm and engaged with the professionals trying to help them. By focusing on their topics of interest, they may be distracted from overwhelming stimulation and gain a sense of control.



6. INDIVIDUALS WHO ARE HYPO-SENSITIVE CAN SAY THEY ARE 'FINE', WHEN THEY ARE SEVERELY HURT

Some individuals with a sensory challenge can be hyposensitive. As a result, they under-react as their sensory system shuts down due to too much information coming at them all at once. Their reaction is often misunderstood as indifference, avoidance, or uncaring.

First responders should be mindful that during a crisis, fire, or accident, a hyposensitive individual may not tell you they are sick, hurt, burned, cut or in pain. They are vulnerable because they are unable to respond to fear, pain or danger. They may not moan, cry or appear in pain, even though they are bleeding or have an obvious burn or broken limb.

FIRST RESPONDER TIP

When called to a home or site of an accident, EMTs and paramedics should investigate beyond what the individual tells them. They may be bleeding, sick, hurt, or significantly burned, but when asked, say they feel "fine". Observe carefully. Look at their stomach, back, feet and head area, even if they are not complaining.



7. STIMMING IS NOT A SIGN OF DISRESPECT OR INTOXICATION

Stimming is a repetitive behavior that individuals engage in to calm themselves. Stimming behaviors can include, but are not

limited to, repetitive flapping of the hands, swinging a piece of string, tapping, rocking, or any other rhythmic movement that the individual finds calming. Individuals who stim often carry a self-soothing device (string, stick, toy car, rubber band) that could be mistaken for a weapon in a tense situation.

Sometimes stimming is interpreted as an effort to distract and manipulate the situation. Other times it is misinterpreted as being intoxicated or impaired by a mood-altering substance. Both interpretations are incorrect.

 **FIRST RESPONDER TIP**

Become familiar with “stimming” behaviors and know that stimming usually keeps the person calm while interacting with you. Unless stimming behaviors become aggressive and harmful, stimming should not be stopped.



8. LOOK FOR ‘WANDERERS’ NEAR PLACES WITH RHYTHMIC MOVEMENT OR SOUND (THESE ENVIRONMENTS OFTEN MIMIC STIMMING)

Many frantic 911 calls occur because an individual is wandering or missing. Places that attract individuals on the Autistic Spectrum or with other sensory disorders, provide rhythmic stimulation. The rhythmic sight and sound of pools, streams, lakes, ponds, trains, or traffic are attractive to individuals on the Autistic Spectrum, because it is very similar to the rhythmic movement of ‘stimming’. They do not always recognize the dangers of water, traffic or trains.

Unfortunately, children with Autism are 160 times more likely to die from drowning compared with the general pediatric population. They are often unaware of the danger that exists in these situations. Special needs

therapists work with parents to develop emergency plans in the event a child is missing.

 **FIRST RESPONDER TIP**

When police are called because an individual is wandering or missing. Ask for a copy of the emergency plan (if available). This often includes identifying information.

Look first at nearby bodies of water, traffic, trains or even a swing in a neighbor’s yard. Wanderers often go back to places with rhythmic sights and sounds to feel calm. They may also return to familiar places (a McDonalds or neighbor’s home) or to the last place they visited.



9. NOT KNOWING WHAT TO EXPECT CAN CAUSE A TOTAL LOSS OF CONTROL AND PANIC

Many individuals with chronic conditions have already experienced many hospital stays, blood draws and multiple surgeries. Being poked with a needle or squeezed with a blood pressure cuff is not new. They need a sense of control. Knowing what is going to happen next can help them feel control. Telling them what to expect before it happens can decrease panic and anxiety and prevent them from resisting or trying to run away.

You can eliminate a panic response by remaining calm. Many times, a parent or caregiver can inform you of best ways to calm the individual.

 **FIRST RESPONDER TIP**

When possible, EMTs and paramedics should explain step by step exactly what is going to happen next, before you do it. Explanations such as, “You are going to feel a small poke of this butterfly needle” or “You are going to feel a squeeze on your arm to

check your blood pressure and you will be ok,” can give the person a sense of control. Often, the individual will ask you to put the cuff over their sleeve or take pressure on their lower arm so their skin feels less of a squeeze. Their requests are often based on their sensory triggers and past experiences.



10. PARENTS AND CAREGIVERS KNOW THE INDIVIDUAL BEST

Parents and caregivers are often available and willing to share important information with police, paramedics and EMTs during a crisis or emergency situation. This gets difficult when an adult with special needs, who does not have a legal guardian, refuses treatment. In some cases, the patient’s right to refuse treatment trumps the parent or caregivers’ opinion about treatment needs. In any event, parents and caregivers are an excellent resource for police officers, paramedics and EMTs, because they know what calms and what triggers the individual, especially during an emergency.

 **FIRST RESPONDER TIP**

Ask parents, caregivers and those who know the individual about how best to communicate. EMT’s and paramedics can inquire with parents and caregivers about an updated emergency medical sheet that lists medications, doctors, treatment facilities, triggers, calming techniques and best ways to communicate. In some cases, the fire department has already been alerted. This is because, prior to an emergency, some families alert the fire department about an individual in the household who has a care plan regarding a chronic condition. This helps first responders know what to expect if they should encounter this individual.

ABOUT THE AUTHOR:

Nancy Musarra Ph.D. is a licensed clinical psychologist who provides forensic services regarding psychological and competency evaluations. In her private practice, she consults with parents regarding developmental, neurological and mental health challenges at home, school and in the courts. She authored *The New Normal*; *7 Things to Know as You Care for and Love a Child with Special Needs*. She also facilitates First Responder Training Workshops for law enforcement, fire and EMS: Dealing with Autism and Neuro-Developmental Challenges in Public Safety and How Do Professionals Who Deal with Stress and Trauma Everyday Maintain Resilience? Contact her at nancy@drnancymusarra.com.

Nothing can take the place of a first responder who is knowledgeable about this special population. Police officers, paramedics and EMTs often save the lives of children and adults with chronic health challenges. Understanding the 10 First Responder Tips allows everyone to be prepared and achieve the best outcome during an emergency. •

THE IMPACT OF ADOPTION ON EDUCATION

BY DENISE GACKENHEIMER VERZELLA, ESQ.

Adoption is a common method of creating or expanding a family. There are many types of adoptions: private, through foster care, domestic, international, embryo adoption, etc. Although paths to adoption are varied, common across all of them is the impact the act of adoption has on the child who is adopted.

Research studies dating back to 1991, show that children who are adopted are more likely to require special education and related services than their nonadopted peers.¹ The reason for this difference can be the result of genetics, trauma, lack of nutrition or neglect in early childhood, or the loss of a primary language. Even in adoptions where the child was adopted as a newborn, the impact of the adoption can present later in childhood, and result in emotional challenges that can impact the child's ability to learn.

To help identify learning problems early, if you are able to communicate with the birth family, ask about learning difficulties in the family. Although not all disabilities that impact learning are genetic, many, such as dyslexia and ADHD, do have a significant familial component.² As disabilities that impact learning, such as: ADHD, specific learning disabilities, neurological or genetic mutations, etc., were not as widely diagnosed in previous generations as they are now, there may be a bit of "reading between the lines" that has to happen when having these conversations.

If these conversations are not possible, there are early warning signs for many disabilities that you should be aware of and discuss with your child's pediatrician. These can include: not making eye contact, not babbling or laughing, delayed speech, pronunciation problems, difficulty learning new words, letters or numbers, difficulty following simple directions, poor grasp of a crayon, and poor coordination. If your child is displaying one or more of these early warning signs, you may want to discuss an assessment through early intervention, if your child is under age 3. If your child is age 3 or older, you should discuss these with the school district.

As an adoptive parent myself, with a child who has a learning disability, as well as ADHD, I wish I had been more informed about her family's medical and mental health history. Although she was provided with an Individualized Education Program as early as preschool, perhaps if I had known about early warning signs, or been more aware of the signs to look for, her programming could have been more robust and address disabilities that did not become apparent until later in her schooling.

The earlier a child receives services for his/her disability the better. The National Center for Learning Disabilities notes that through early screening, and timely recognition of learning difficulties, support can be provided when children's brains are the most malleable and the early interventions can have greater impact on young students.³ Diagnosing and appropriately supporting my daughter's educational needs remains a constant journey. Thankfully, there is an abundance of private service providers available, as well as resources through my local school district to support her educational and emotional needs. •



If you have questions about adoption, please contact Manes & Weinberg, LLC, to discuss your family's needs and options. (973) 376-7733 www.manesweinberg.com

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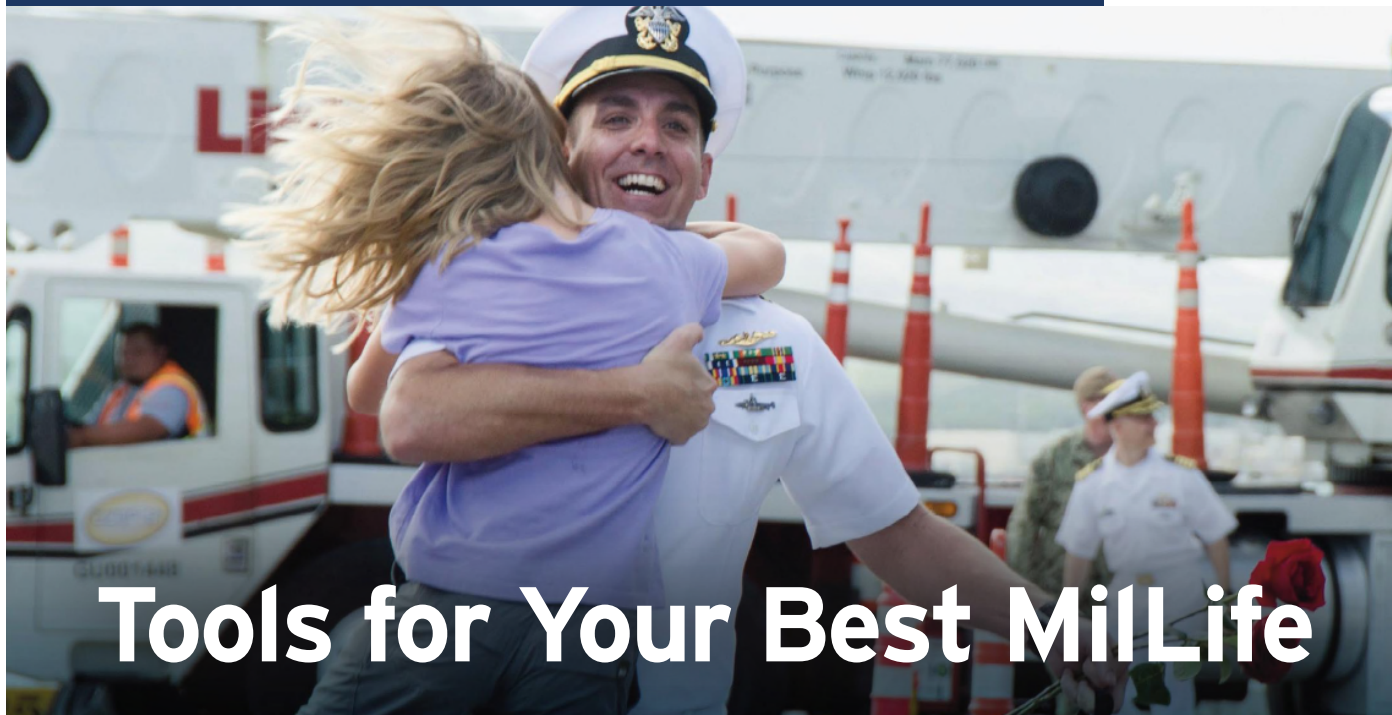
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FROM OUR FAMILIES... TO YOUR FAMILIES

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MILITARY LIFE

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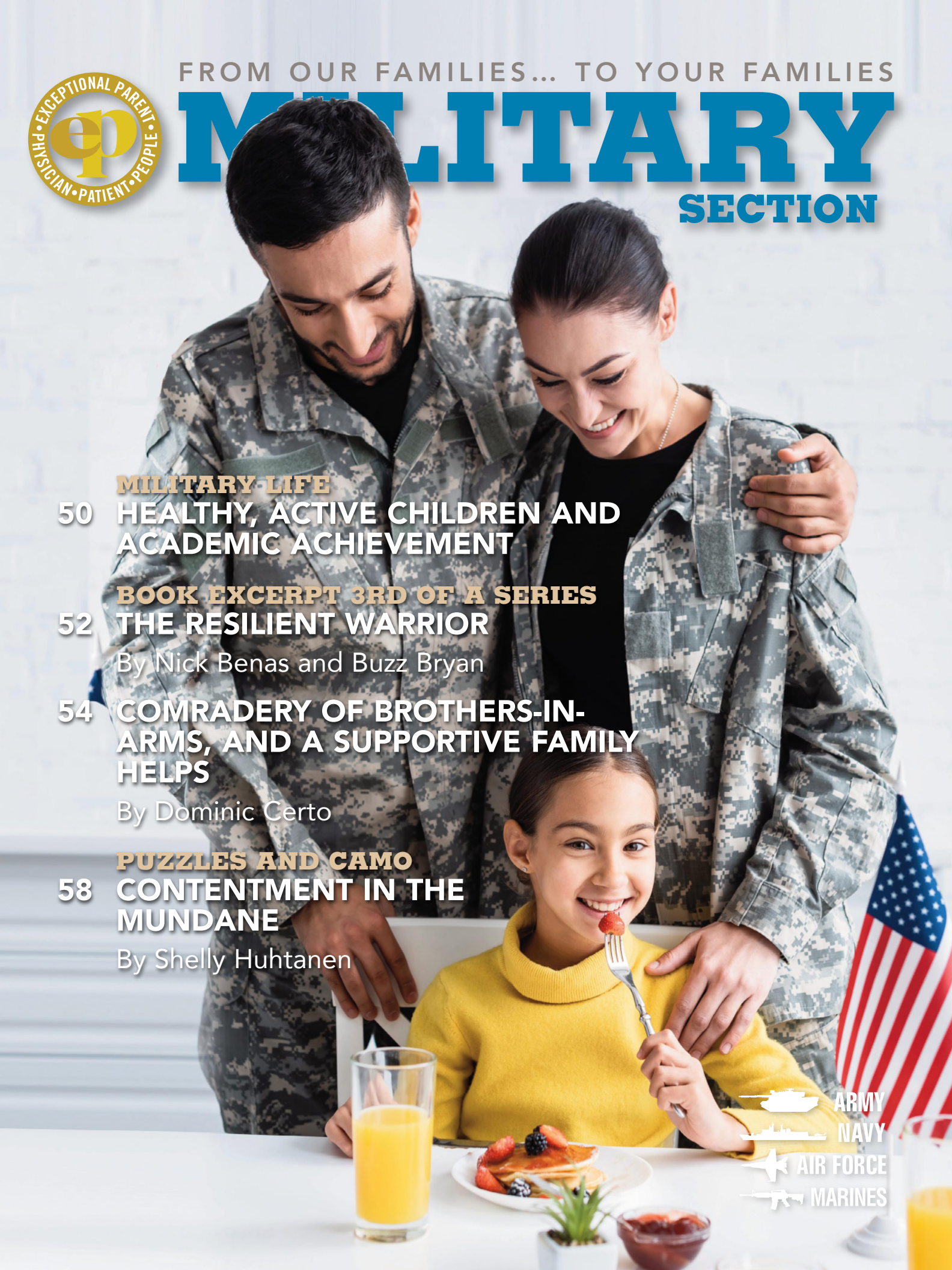
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MILITARY LIFE



FEULING UP: Children need a nutritious breakfast of whole grains, fiber and protein, and snacks throughout the day that are high in protein and low in sugar to boost their ability to listen, process and remember what they are learning. .

HEALTHY, ACTIVE CHILDREN AND ACADEMIC ACHIEVEMENT

We all want our children and teens to enjoy learning, achieve good grades and have academic success.

Nutrition, physical activity and mental well-being are all linked to academic achievement, so making sure your children are healthy and active will fuel them to reach their academic goals. A healthy lifestyle can help improve a child's attention span, thinking ability and memory.

Listed below are some tips for making healthy eating, physical activity and mental well-being part of your child's daily life. For more nutrition, physical activity and mental health help, call 800-342-9647, view international calling options or schedule a live chat with Military OneSource to arrange a specialty consultation for health and wellness coaching.

NUTRITION

According to studies from the Journal of School Health, hungry children tend to have shorter attention spans and have difficulty with problem-solving, math skills and memory recall. Children need a nutritious breakfast of whole grains, fiber and protein. They also need snacks throughout the day that are high in protein and low in sugar to boost their ability to listen, process and remember what they are learning.

PHYSICAL ACTIVITY

According to the Centers for Disease Control and Prevention, children need at least 60 minutes of physical activity every day. Physical activity can include school recess periods, hiking, dancing, playing sports or walking to and from school. Check out the following resources for ideas about how to keep your children physically active:

- Morale, Welfare and Recreation activities are available on your local installation (<https://installations.militaryonesource.mil/?looking-for-a=program/program-service=5/focus=program>)
- Installation youth centers (<https://installations.militaryonesource.mil/?looking-for-a=program/program-service=31/focus=program>) offer a safe environment for youth to explore interests, build skills and experience success. Installation youth centers offer a number of programs for youth and teens ([ww.militaryonesource.mil/family-relationships/family-life/for-military-youth-and-teens/military-youth-and-teen-programs](http://www.militaryonesource.mil/family-relationships/family-life/for-military-youth-and-teens/military-youth-and-teen-programs)), including informal and formal sports and fitness programs, open recreation, youth sponsorship and special-interest instructional classes including dance, martial arts, music and more.
- Boys & Girls Clubs of America's MISSION: Youth Outreach (www.bgca.org/about-us/military) provides a free membership to local Boys & Girls Clubs for military youth ages 6 to 18 who do not live near or have access to a military youth center. Boys & Girls Clubs offers a wide variety of recreational and educational programs.
- 4-H Military Partnership (<https://4-hmilitarypartnerships.org>) provides military youth the opportunity to join 4-H clubs in their communities and participate in summer camps around the country. 4-H offers a wealth of resources in STEM subjects, healthy living, citizenship, public speaking and other military core program areas providing valuable life skills, curriculum and resources for military youth and teens across the country and around the world. Add to your child's summer lineup by exploring the 4-H Military Teen Adventure Camps (<https://extension.purdue.edu/4-H/get-involved/military-teen-adventure-camps/index.html>), offered coast to coast for teens age 13-18. Visit the 4-H Military Partnership website to learn more.

- Explore healthy living articles available through Military OneSource, including Fun and Fitness — The Essentials, Make Active Living a Priority To Improve Family Fitness and About Morale, Welfare and Recreation: Supporting the Military Community: www.militaryonesource.mil/recreation-travel-shopping/recreation/fun-and-fitness/fun-and-fitness-the-essentials

Boost your child's social and academic success by making healthy eating and physical activity part of your family's daily life.

MENTAL HEALTH

Your youth's mental health is also essential to maintaining energy and engagement in their physical and academic activities. Help your child remain rested and mentally healthy by keeping an eye on these factors:

- Establishing and maintaining routines can help set up your child for success. Keep regular meal and homework times, and be sure to set aside time for physical activity each day. (www.militaryonesource.mil/family-relationships/parenting-and-children/parenting-youth-and-teens/how-to-create-and-maintain-routines).
- Look for signs of mental health challenges or issues that might be troubling your child (www.militaryonesource.mil/health-wellness/mental-health/mental-health-support/mental-health-matters-in-the-military). Child and youth behavioral counselors are available at many child development centers, youth centers and even some schools. Call Military OneSource at 800-342-9647 to ask about the Military and Family Life Counseling Program (www.militaryonesource.mil/confidential-help/non-medical-counseling/military-and-family-life-counseling/the-military-and-family-life-counseling-program).
- MilKids Connect (<https://militarykidsconnect.health.mil/Health-and-Wellness>) offers a health and wellness section for youth to take control of their own wellness goals. And your child has the added benefit of being able to connect with other military children facing the same challenges.
- Health and wellness coaching is also available for teens (www.militaryonesource.mil/health-wellness/healthy-living/fitness-nutrition-active-living/health-and-wellness-coaching-for-teens). This free service is available to teens age 13 and up by phone and video. Consultants offer guidance and resources to assist with weight management, fitness, nutrition, stress management and more. Sign your teenager up for health and wellness coaching sessions today.

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Connecting to comprehensive information on nutrition, physical activity and mental health will help enable you and your family to be mission ready. Military OneSource is your 24/7 connection to information, parenting tips and support — your one source for your best MilLife. If you have additional questions about health and well-being for your family, call Military OneSource at 800-342-9647, view international calling options (www.militaryonesource.mil/international-calling-options) or schedule a live chat (<https://livechat.militaryonesourceconnect.org/chat>).

– Military OneSource

THE RESILIENT WARRIOR

ANGER MANAGEMENT

BY REV. BERNICE “DOC BUNNY” SYKES, PH.D.

*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 third in a series of five that EP Magazine will feature over the coming months.*

Identify, recognize, and manage anger and certain behaviors.

I am a veteran who lives with Post Traumatic Stress Disorder (PTSD). There were times when PTSD managed me instead of the other way around; times when I did not have information about how to effectively deal with life and with the symptoms I was experiencing daily. At that time, I felt lost and without hope. One day, I decided the time of me being helpless was over, and I needed to find a battle plan for accomplishing this task. If there was one thing that helped me understand PTSD, it would be understanding my anger. When people refer to anger, they treat it like the enemy. Yet the approach that helped me most was making my anger my best friend, by embracing it. In understanding your anger like it is your best friend, it ceases to be scary. Since anger is almost always a component in any issue related to mental health, we are taught to repress and/or suppress those feelings when something is bothering us. In the Army, for example, when you are ordered to do something questionable, you learn to “suck it up”. Anger also rears its ugly head when you are going through the transition of leaving service, whether at the end of your contract or during retirement. Anger always seems to be present when receiving a

medical diagnosis or personal news that requires you to make sudden changes to your lifestyle, forcing you to make adjustments you normally would not have. As a veteran or a retiree, our skills for coping with anger are something that we need to work on and develop, to live our best lives after serving our country. Coming to terms with my anger meant taking my symptoms seriously and being committed to making necessary changes in my perspective, when it comes to controlling anger. It meant no more saying that everything is fine when it is not. It meant my guiding purpose in finding happiness in life was planning ways to greatly reduce the role anger played and executing that plan. To make a plan, first you need information. What I am about to discuss is accomplished best when working with a mental health professional. With a few exceptions, most veterans can receive that help at Veteran Administration Centers (VA Centers). But before you take that to mean your counselor is going to do all your work for you, think again. We must participate in our own recovery, which means doing the work. However, if you want to work an issue out on your own and get some assistance when you think you need it, that is fine. Just remember to delegate if it gets to be too much. What helped me most were the following three tools I used when taking my anger management classes:

Identify your triggers. Anger is fear. Probably one of the most important skills that is important in reducing anger is learning to identify situations that bring fear and understanding how you are reacting to what is taking place. The issue is not always what someone else did, it also comes with the emotions of how someone made you feel. If you are continuously being disrespected at work, you may take serious offense to a simple misunderstanding by someone who has nothing to do with the hostile environment and damage an otherwise good relationship, because you are afraid to confront the larger issue of workplace bullying. I had to learn to use a number scale to track my anger. I know it takes a while for me to get to a 6 on my trigger meter, but I also know that once I am a 6, it does not take much more to get me to 10. I am going to use any skill that positively helps to communicate what I am feeling when I get to about a 4, to solve any potential issues before they become a problem. That is why you must know what your triggers are so they can be avoided as much as possible. (I had to take anger management twice to figure that out.)

Nonviolent communication. Nonviolent communication is a practice developed by Marshall Rosenberg, PhD and breaks down your feelings in needs being met or not. When needs are not being met, the fear you have causes angry feelings to continue until they explode. It basically comes down to how you feel and how to express that feeling in a way that brings solutions to everyone involved, so that they feel heard. Check out *Nonviolent Communication* by Marshall Rosenberg; that book is a life saver.

Breathing and meditation. There is a spiritual aspect to anger management that often goes overlooked. You have to go deeper inside to figure out why you are angry. The answers to your anger are within you, and only you have the keys to unlock that answer. If you are living with the wounds of abandonment, you might be anxious if someone stands you up and become angry. You may be upset because they did not value your time, but in truth, issues with abandonment are being trig-



MEANINGFUL MOMENTS: Many people worry that you must spend hours on end in the lotus position, but five to ten minutes twice a day is ideal in a daily practice and will do wonders for your well-being.

gered. It is up to you to breathe through that moment, to understand that difference. Whether you were betrayed by someone close to you or a stranger rear-ended your brand-new vehicle, making the time to meditate and breathe can give you time to react and find a suitable solution for everyone involved. Many people worry that you must spend hours on end in the lotus position, but studies have shown five to ten minutes to quiet your mind, twice a day is ideal in a daily practice and will do wonders for your well-being. Do not worry if it takes a while to do this and your mind still wanders. If you build it, it will come. •

The next excerpt in this series will appear in the March 2023 issue of EP Magazine.

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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

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COMRADERY OF BROTHERS-IN-ARMS, AND A SUPPORTIVE FAMILY HELPS

BY DOMINIC CERTO

In Vietnam, I was a combat corpsman assigned to the battlefield with the 7th Marines. I recall leaping out of a helicopter to rejoin my platoon and feeling the ground rise to meet me like a brick wall, gravity pulling me down into brutal bloody fighting.

At 18, I experienced fear as unbridled anxiety, confusion, and inner conflict, repeatedly having to make the same choice – “fight or flight.” I was motivated reflexively to fight and aid, almost like a body on automatic pilot, due to my training. But the enemy was hidden by the jungle and attacking with frenzy from every direction. In the blinding swirling chaos, I could clearly hear the screams of warriors engaging each other and deadly weaponry.

In that moment of raw truth, I was suddenly aware that all the glamour, of pretended valor from celluloid heroes like John Wayne – was the farthest thing from reality. What kind of shattered glory remained to the Marine right in front of me, riddled with bullets, covered in blood, crying like a child, his eyes focused on my own, his lips begging me not to let him die? It was a cruel revelation for a young idealistic man -- forced to face the real-world seconds before death or life with his limbs blown off.



At the time, coming home from active duty on the battlefield was like readjusting to a culture that bore no resemblance to the one I'd just departed. Scornful, self-righteous, spoiled people, so smug and so certain of their own politically correct vision of the world, began a process of “redefining” who – and what -- I had become. Lucky to be alive, I was a vet home from an unpopular war – an inglorious tainted “anti-hero,” shamed and shunned like I had some form of deadly plague. I found myself fighting a new war on two fronts, inside and outside myself, protecting and defending my own core identity. My strategy was to join a group of positive-thinking vets and to rely upon the resources that surrounded me, even if I was resistant.

In the days during the Vietnam war the VA was of little support. After being discharged from the hospital I had an interview with a psychologist officer assigned to do a discharge review. The meeting was brief, and his closing analysis was a question he presented to me with a little smirk: “...so you're not going to kill or hurt anyone right? And your good to go?” to which I responded sure, I'm fine. But was I really?

In the weeks and months that followed I learned that my greatest support system was my family, especially my kids, my sisters and brothers, my parents, my friends and even my church. They all provided a net to keep me

THE BATTLE BEYOND: “The important thing is not to fight the battle alone, to understand that outside influence and compassion provides a new perspective, and a renewed interest in life and good things that lie ahead.”

U.S. MILITARY ★

focused on better things. For those with limited family and other support resources there is help everywhere from local community support groups and military families who offer assistance, to online social organizations that have experience and empathy for vets with PTSD. And there is the new and improved VA which offers programs for inpatient and outpatient licensed care. There are other licensed and popular programs like “Transformations” which help Veterans and their families and first responders to cope with and alleviate PTSD, anxiety, and other emotional and mental issues. My point is that help is readily available, and we only need to reach for it.

PTSD SUPPORT : HELP IS AVAILABLE

The Veteran’s Administration has expanded their programs for veterans and their families with challenges of PTSD or other related disabilities.



VA.GOV

The VA offers an “About Face Program” with group support as well videos that help show experiences of others who have faced the same problems

www.ptsd.va.gov/apps/AboutFace

For veterans and their families with challenges of PTSD or other related disabilities, the VA’s Program Locator points you to facilities in the area nearest to you for clinical and other care

www.va.gov/directory/guide/PTSD.asp

If you are just looking to get started you can go to any Vet Center and work with them to find the right place to go.

www.va.gov/directory/guide/PTSD.asp

Everyone has a different lifeline and for some it’s professional help for others a compassionate human being. Some of my military friends relied on their spouse. One of my military brothers was injured and paralyzed from his waist down. For the last 50 years his wife took care of him. She was young and beautiful when they were married and in spite of his disability, she stayed with him and more than that labored to give him a life. Let’s call her Carole, Carole would help him with his wheelchair, clothe him, feed him and remain a compassionate ear when his demons crawled out and loving heart for his loneliness. She could have turned her back on him 50 years ago as a beautiful young woman and continued with her life, but her love and devotion were greater than her self-interests. There are people like this, but they are few and far between.

In my case the comradery of brothers in arms, a supportive family and other local organizations made the struggle worthwhile with a positive outcome, which has stayed with me for the rest of my life. The important thing is not to fight the battle alone, to understand that outside influence and compassion provides a new perspective, and a renewed interest in life and good things that lie ahead. Yes, it’s a struggle, but there’s help all around us, and that’s what gives us a positive life to live with purpose and optimism. •

ABOUT THE AUTHOR:



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

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Contentment in the Mundane

In life, a lot of little things that add stress and slowly add weight can become layers like tiramisu. In other words, life can be a “tiramisu of crap.”

The irony of the human condition is that at times, we are so focused on reaching some point on our life’s journey, some form of happiness, or a certain life’s goal, that we lose sight that the journey itself is where it all happens. I read a quote of this nature a few days ago and noticed, unfortunately, the author was unknown. As I say good bye to my oldest son, Hayden, as he heads back to college to start his spring semester, I realize that this is so true. The last fifteen years have encompassed times of joy and relief, only to be overrun with fear, concern, and at times, discontentment. As my oldest son started to drive off down the street to start his seven-hour drive back to college, I started to cry, but then I began to sigh. Maybe I’m a

little bit wiser or maybe I’m starting to realize that what comes with our life’s journey is change, and that can actually be a good thing. When I walked back into the house after Hayden drove off, the house was quiet. Broden was at clinic and all I could hear was the news on the television.

I have spent quite a bit of my time in the last fifteen years looking to my left and right, trying to figure out where we need to be on our journey. I thought about ways to encourage Hayden to connect with Broden, or how can we work on Broden’s life skills and encourage him to be more verbal. I even went through a



stage where I mourned Broden’s birthday, because it was one more year that we had not met a milestone. I’m grateful I was able to begin celebrating Broden for his uniqueness, and spend less time focusing on the milestones he had yet to meet. Last weekend, I was

reminded that when we take time to be grateful for where we are on our journey and appreciate the mundane, stop looking to the left and right as to what others are doing, we can experience a sense of contentment.

The last weekend before Hayden was scheduled to drive back to school, we decided to go for a short hike together.

This is one activity where all of us can be together and electronics are used at a minimum. I can still hear some music playing from Broden's phone, but for the most part, phones are not the focus, and time can be spent taking in what is going on in the moment. I see more interaction between Hayden and Broden on the trail, as Hayden jumps in front to take the lead. On our hikes I always enjoy watching Broden pick up his step to catch up with his big brother.

On our last hike together this month, we chose a trail that we have hiked many times over the last few years. I didn't want to choose a trail that was new to us, because that wasn't the point. I didn't want to try anything new. I just wanted us to be together and take a path that we had already experienced, so we could focus on being together. Broden remembered the route, so after half a mile, he started to gallop alongside Hayden. He had a sense of contentment with the routine, and I knew Broden would enjoy that aspect of the hike.

As the boys moved ahead and weaved around other people on the path, Mark and I looked at each other periodically and smiled. We didn't have to say anything. Smiling at each other translated to many things. We've come a long way, and the hikes that we take with all four of us together are never taken for granted. With Broden in our lives, very few things are taken for granted, as far as being out together as a family.

Towards the end of the trail, there are two ways to get back to our car. Mark and I told Hayden to slow down and let Broden take the lead, "Hayden, let Broden decide what route he wants to take. He knows this trail really well." Broden took a sharp right and headed up the stairs to the parking lot instead of following the trail to a nearby park area. Hayden looked back and smirked at us.

As Hayden matures with new experiences at college, he has realized that Broden is growing too.

As we followed Broden to the car at the end of our hike, I noticed a family of four starting a hike along the trail. There were

two parents a few steps ahead of two teenage boys, "C'mon, this will be fun. We need to do this stuff together more often. Pick your feet up." As I glanced over again, I could see the parents roll their eyes at each

other and the two boys sigh as they started to pick up their pace. Witnessing that interaction made me giggle. I glanced over at Mark, smiling as he glanced back at me with a look of contentment. These

are the times that you don't want to forget. Moments like these are when you remember that it is the journey. It's not the goals you set out to meet, or aimlessly trying to attain a level of "happiness," because you connect "happiness" with winning at life. I've learned to strive for contentment in the mundane, the relaxing stroll down a hiking path that you know, with the ones you love. Life is good when you're experiencing the mundane with the ones you choose to do life with each day. •

"It was time for Broden to have his wisdom teeth extracted. For a child with severe autism, this is not an easy proffice for a consult."

PUZZLES & CAMO

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



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