

PLUS: UNITED STATES NUTRITIONARY SECTION



EXCEPTIONAL PARENT  
MAGAZINE

FEBRUARY 2019  
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IN THIS ISSUE:

PAYING  
ATTENTION  
to NUTRITION

ALSO INSIDE:

ADHD &  
A WHOLE FOOD  
PLANT-BASED DIET

AND: HEALTH AND WELLBEING

THE GUT-BRAIN  
RELATIONSHIP

EP EXPLORES:

THE POSITIVE  
INTENTION of ANXIETY

PLUS:

DEPRESSION  
& ENERGY  
MANAGEMENT

# DIET & NUTRITION

THE ANNUAL ISSUE



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24



## DIET AND NUTRITION

### THE FITNESS PRIORITY

#### 20 PAY ATTENTION TO NUTRITION

By Kristin McNealus, PT, DPT

#### 24 ADHD AND A WHOLE FOOD PLANT-BASED DIET

By Teri Yunus

#### 28 THE GUT-BRAIN RELATIONSHIP AND ROLE IN HEALTH AND WELL-BEING

By Dr. Sten Ekberg



#### 32 THE POSITIVE INTENTION OF ANXIETY

By Jackie Schwabe

#### 36 MINDING YOUTH MENTAL HEALTH

By Janet Haag

#### 40 DEVELOPING APPROPRIATE IEPs FOR STUDENTS WITH ANXIETY OR DEPRESSION

By Lauren Agoratus, M.A.

#### 42 LET'S TALK ABOUT DEPRESSION AND ENERGY MANAGEMENT

By Clarissa G. Hoover, MPH

28



32



## FEATURES

#### 46 AUTISM WITHOUT FEAR IN PRAISE OF AUTISM SURFING ORGANIZATIONS

By Michael John Carley

#### 44 SPRINTING TOWARDS THE FINISH LINE

By Renee Dease and Stephanie Corkett

46



### ON OUR COVER

Children with special healthcare needs face higher risks of being overweight and other dietary challenges. EP's Annual Diet and Nutrition Issue can help parents and caregivers better understand these challenges, while offering advice on increasing physical activity and adopting healthier dietary habits. Coverage begins on page 20.

# CONTENTS

FEBRUARY 2019 VOLUME 49 ISSUE 2

## DEPARTMENTS

### ANCORA IMPARO

- 4 PATENT NUMBER 4,498,586 AND ITS CONTRIBUTION TO CIVILIZATION

By Rick Rader, MD

- 6 WHAT'S HAPPENING

- 9 NEW PRODUCTS

### AMERICAN ACADEMY OF DEVELOPMENTAL MEDICINE AND DENTISTRY

- 12 PARENTS WITH CHILDREN WITH  
DISABILITIES IN A SINGLE-PARENT  
FAMILY

By H. Barry Waldman, DDS, MPH, PHD and  
Steven P. Perlman, DDS, MSCD, DHL (HON)

### ORGANIZATION SPOTLIGHT

- 16 CYSHCNET: CHANGING HOW  
SYSTEMS OF CARE RESPOND TO THE  
NEEDS OF CYSHCN

By Charlene Shelton, RN, MPA, PHD

- 60 PRODUCTS & SERVICES

9



16



## MILITARY SECTION

### MILITARY LIFE

- 54 HOW TO COPE WITH A TRAUMATIC  
EVENT

- 56 HOW TO DEAL WITH COMBAT  
STRESS

- 57 HELPING FAMILY MEMBERS WITH  
SPECIAL NEEDS MEET THEIR  
FITNESS GOALS

### PUZZLES & CAMO

- 58 WORDS OF WISDOM

By Shelly Huhtanen

FROM OUR FAMILIES... TO YOUR FAMILIES



# MILITARY SECTION



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- 54 HOW TO COPE WITH A TRAUMATIC  
EVENT

- 56 HOW TO DEAL WITH COMBAT  
STRESS

- 57 HELPING FAMILY MEMBERS WITH  
SPECIAL NEEDS MEET THEIR  
FITNESS GOALS

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## EP FOR FREE!

THE MISSION OF  
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AND SHARE INFORMATION  
AS TOOLS FOR POSITIVE  
CHANGE FOR THE SPECIAL  
NEEDS COMMUNITY.

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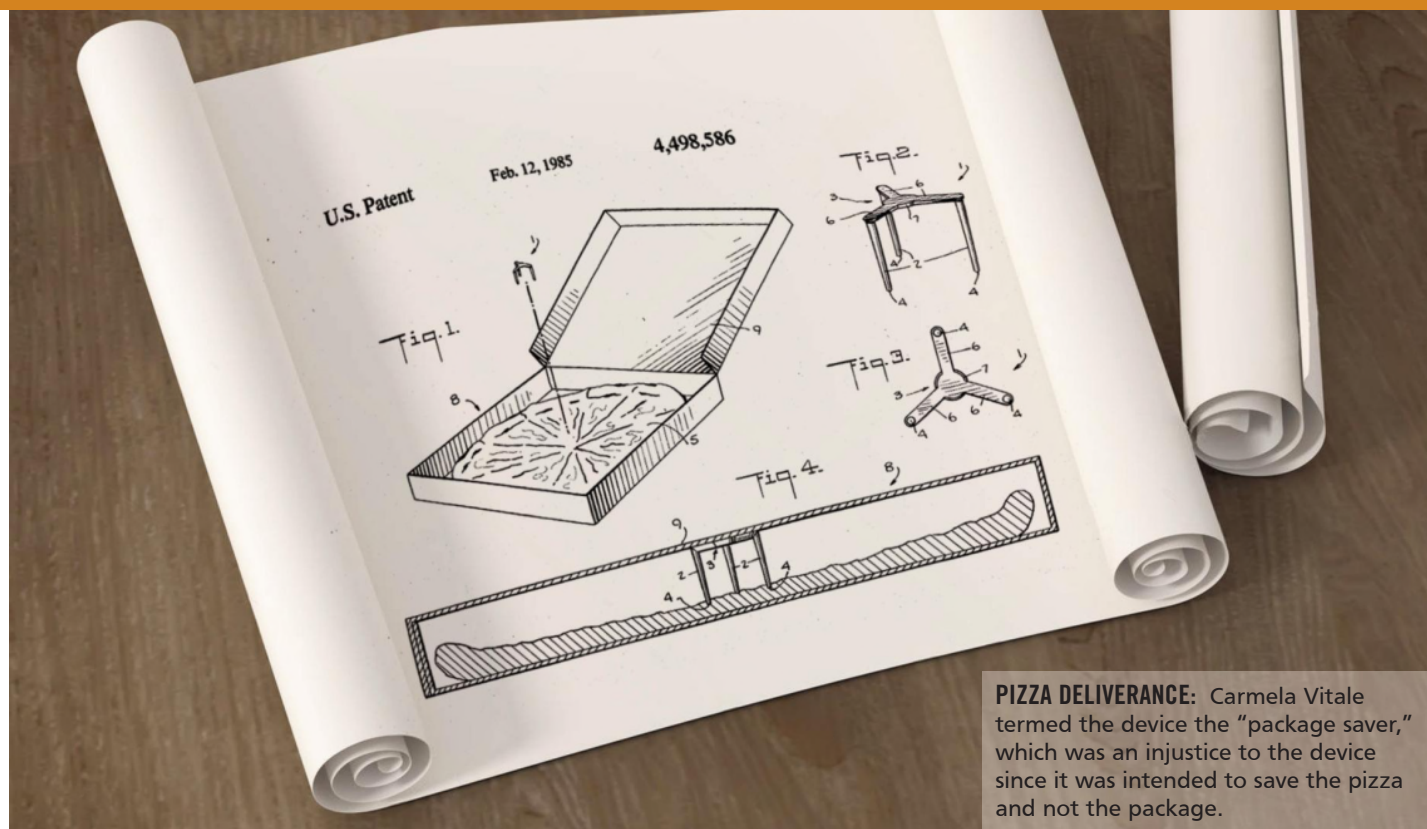
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— Rick Rader, MD

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**PIZZA DELIVERANCE:** Carmela Vitale termed the device the “package saver,” which was an injustice to the device since it was intended to save the pizza and not the package.

# Patent Number 4,498,586 and its Contribution to Civilization

Exceptional Parents don’t expect services to be delivered, they are happy to go out to get them.

It’s Saturday afternoon and, after a hard week of slugging it out in the non-profit world of developmental disabilities, I’m in my sanctuary, the garage.

Surrounded by antique cars, parts, grease, rags, tools, lathes, grinders, dirt, rust and cans of magic elixirs it’s where I try to spend my weekends rejuvenating. Here there are few compromises, power gradients, bureaucracies, deadlines or unfunded mandates. It’s a place where hard work, ingenuity, experience and true collaboration can actually get done. For over 50 years, my brother Phil and I have shared a passion for old cars, the noises they make and the head scratching needed to figure out how to keep them going.

It’s Saturday afternoon and we are struggling, trying to make a car part fit into a place where it was never designed to fit in the first place. It’s frustrating and

agonizing, and it’s lunchtime. We’re covered with grease and can’t justify the time to clean up and go out to get something to eat. We punch some keys on a cell phone and, 15 minutes later, a non-descript car pulls up with a non-descript college kid walking towards us with the familiar flat cardboard box containing a pizza.

Pizza delivery has come to the rescue, and not just for my brother and I on a Saturday afternoon. Today, more than \$10 billion dollars are spent annually on delivering pizzas. Pizza delivery has become a staple of modern culture for seven billion people worldwide.

In 1889, King Umberto I of Italy and Queen Margherita of Savoy were visiting Naples. After eating some specially pre-



pared food for the royal occasion, the Queen became sick and requested to eat some traditional Italian food. They summoned a local chef, Raffaele Esposito, to prepare something that would delight the Queen. To honor the Queen, Esposito made a pizza into the colors of the Italian flag, red

tomatoes, green basil, and white mozzarella cheese. Kings and Queens weren’t expected to frequent the local pizzeria shops, so Esposito took the pizzas to them. This event gets credit for being the first-ever pizza delivery recorded in pizza history. Margherita declared it the best dish she had ever eaten and it gave birth to the authentic Margherita pizza, the pizza that was introduced to America by returning World War II soldiers that were stationed in Italy.

We are not only enjoying the pizza but remarking on the concept of being able to have it delivered.

Before we declare “pizza delivery” to be one of the greatest inventions of all time, we decide to see how it stacks up against some other notable game-changing inventions. So we go back and forth, noting the “other” top inventions that changed the world. In no special order we start with the compass, then the printing press. Since we’re in a garage, we of course throw in the internal combustion engine. We had to include the telephone, it’s how we got the pizza delivered in the first place. We certainly

didn’t forget the light bulb or the internet. My brother throws in the nail (we sweep a lot of them up each weekend). Since both of us come from medical backgrounds, we had to recognize “penicillin” as both a life-changing and lifesaving invention (for our purposes, discoveries are included with inventions). And as much as we were enjoying our “delivered pizza” it was hard to include it with the emerging list of the greatest inventions of all time.

Moments later, almost in synchrony, we both notice and point to the little white plastic gizmo sitting in the center of the pizza. We believe we have identified this small ingenious device as a contender for consideration as an invention that changed civilization.

Casey Chan, writing on “Pizza’s Guardian Angel” sums it up. “A piece of plastic? Yes, that circular plastic thing that goes in the middle of a pie to prevent the pizza from sticking to the top of the pizza box. It’s called a pizza saver. And it was invented over 30 years ago on February 10, 1983, when Carmela Vitale got her patents issued for that piece of plastic.

That little structure prevents the top of the pizza box from caving in onto the hot pizza, rendering it into the realm of unappetizing goo. There is a complex thermody-

namic reaction that takes place in the pizza box involving the heat from the pizza impacting on the corrugation process which acts as a space insulation layer. The design flaw of the pizza box causes the top center of the box to soften and sag and (heaven forbid) attach itself to the cheese topping. Vitale termed the device the “pack-

age saver,” which was an injustice to the device since it was intended to save the pizza and not the package.

Chan provides more information on the “saver” than you probably need to know. “The tripod look was created to keep the footprint of the pizza saver small which

kept the damage to the pizza minimal while also being rock solid in preventing exorcised pizzas. Three dimples on your pizza is much better than splattered guts everywhere. It’s basically every pizza’s guardian angel.”

One could argue that Exceptional Parents have been looking for a similar device to prevent their goals, dreams and aspirations from being crushed from “cardboard thinkers” lurking above. They are constantly looking for allies, legislation, champions, fairness, compassion and sensibilities to prevent the top from caving in on their efforts and energy. Exceptional Parents don’t expect services to be delivered, they are happy to go out to get them.

We finished the pizza and got the part to fit; and so, life is good in the garage. •

“Exceptional Parents have been looking for a similar device – a Guardian Angel – to prevent their goals, dreams and aspirations from being crushed from ‘cardboard thinkers’ lurking above.”

#### ANCORA IMPARO

In his 87th year, the artist Michelangelo (1475 -1564) is believed to have said “Ancora imparo” (I am still learning). Hence, the name for my monthly observations and comments.

— Rick Rader, MD, Editor-in-Chief, EP Magazine  
Director, Morton J. Kent Habilitation Center  
Orange Grove Center, Chattanooga, TN

## CONNECT AND DISCOVER

### Join EP’s Facebook Community



EP’s revamped Facebook page welcomes you to share stories, discover resources and connect with the special needs community.

Parents and families with members with special needs benefit greatly from meaningful interaction with peers facing the same challenges and joys. Facebook has provided the EP readership community with a convenient and effective platform to communicate, ask questions, promote events and share special moments.

Connect, Share and Discover with EP  
[www.facebook.com/exceptionalparentmag](http://www.facebook.com/exceptionalparentmag)

Visitors can access the latest news and articles from recent issues of EP Magazine, and provide feedback and insight of their own.

EP’s Facebook page an open community group for parents, grandparents, family and friends of people with special needs family members. It’s an ideal place for both parents and professionals to share information and resources.

Parents, teachers, academics and professionals that are willing to help each other by sharing knowledge and resources are a vital part of the EP community. Like us today!

# WHAT'S HAPPENING

## 3D PRINTING IS DISRUPTING THE WAY WE PROVIDE PERSONALIZED MEDICINE

**3D printing is disrupting the way we provide personalized medicine, finds IDTechEx Research. From its humble beginnings in the late 1980s, through to the global force that it is today, the capabilities of 3D printing technology have expanded dramatically, to establish itself as an attractive manufacturing solution for prototyping and production.**

Conferring advantages such as shorter lead times, reduced waste and opportunity for mass customization, the potential of 3D printing was quickly realized and has gone from strength to strength since. One of the key industries to have successfully leveraged these advantages is the medical and dental industry. In the IDTechEx Research report, 3D Printing in the Medical and Dental Industry 2019 – 2029, 3D printing in the medical and dental industry is forecast to be worth over \$8.1 billion by 2029. View the report on trends, opportunities and outlook at

[www.idtechex.com/research/reports/3d-printing-in-the-medical-and-dental-industry-2019-2029](http://www.idtechex.com/research/reports/3d-printing-in-the-medical-and-dental-industry-2019-2029)

### 3D PRINTING STREAMLINES THE PRODUCTION OF PERSONALIZED MEDICAL DEVICES

3D printing allows the production of a wide range of devices such as hearing aids to Invisalign® aligners to prosthetic limbs. Use of 3D printing in these applications leverage its ability for mass customization from 3D imaging data. Personalization is particularly important to medical devices designed to be worn by the patient for extended time, as this improves patient comfort, and with that, adherence to the treatment. No manufacturing process in the medical sector has been as disrupted by 3D printing as that of the hearing aid. 3D printed hearing aids are made with digital precision, an improvement over the lengthy hand-crafting process that sometimes resulted in pieces that were not perfectly fitted. This is important where less than a millimeter of difference can lead to discomfort for the wearer. Thus, adoption of 3D printing has not only streamlined but also enhanced the manufacturing process. Given these benefits, 3D printing is gaining popularity in the field of dentistry, and is also emerging as a method of manufacture for several other medical devices where customization is key to improved patient comfort and improved therapeutic outcomes. Compared to traditional manufacturing workflows, 3D printing confers several potential advantages to the dental industry.

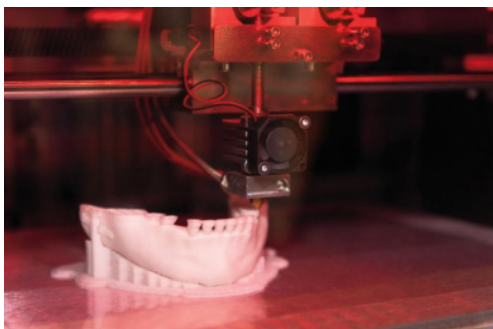
### 3D PRINTING IMPROVES SURGICAL OUTCOMES

The range of applications is not limited to the manufacture of medical devices. 3D printing is also used extensively in surgical procedures, whether in the creation of patient-specific 3D models for teaching, planning and visualization, intraoperative surgical guides, disposable surgical instrumentation, or custom plates, implants, valves, and stents to be implanted into the patient. 3D printing advances surgical standards and improves efficiency, resulting in improved surgical outcomes for the patient. 3D printed implants are durable, lightweight and customized to fit the patient for better functional and aesthetic outcomes.

### 3D PRINTING WILL PROVIDE PERSONALIZED MEDICINE

The range of applications is not limited to medical devices or surgery. 3D printing can be used to manufacture pharmaceuticals, such as patient-specific pills. Personalized medication is especially promising in disrupting the way we treat chronic conditions, by helping patients streamline the number of pills that they

must take, and by creating patient-specific dosages that will limit the unwanted side effects experienced. Moreover, as the development of 3D bioprinting continues to evolve, there is scope for the implantation of personalized organs as part of regenerative medicine.



### 3D PRINTING IN THE MEDICAL AND DENTAL INDUSTRY

IDTechEx's recently published research report, 3D Printing in the Medical and Dental Industry 2019 – 2029 draws from extensive IDTechEx expertise within the field of 3D printing. IDTechEx analysis of 3D printing and 3D bioprinting technologies, as well as 3D printing materials and 3D printing software, is provided in context of medical and dental applications. A 10-year market forecast for 3D printed medical devices and 3D bioprinting is also provided, which is accompanied by IDTechEx market and regulatory outlooks.

The report is organized by the following key topics:

- Surgical tools, guides, and models
- Implantable devices
- Orthoses, prostheses and other medical devices
- Pharmaceuticals
- Dental tools, models, and prosthetics
- Living tissues

Each stand-alone chapter includes the motivations and restraints of adopting 3D printing, analysis of commonly used 3D printing technologies and 3D printing materials, detailed applications and case studies, and a discussion of specific regulatory concerns.

To find out more contact [research@IDTechEx.com](mailto:research@IDTechEx.com) or visit [www.IDTechEx.com/3Dmed](http://www.IDTechEx.com/3Dmed)

# WHAT'S HAPPENING

## AUTISM STUDY FINDS HIGH RATES OF UNMET HEALTHCARE NEEDS

*An Autism Speaks analysis of national survey identifies barriers to care and provides guidance for new programs to address needs across the lifespan.*

A new analysis of the National Survey of Children's Health finds that nearly a fifth of children with autism (18.8 percent) have unmet healthcare needs. This contrasts to 9.6 percent of children with other disabilities and 2.6 percent of children without disabilities.

The analysis also identifies the circumstances most strongly associated with unmet healthcare needs among children with autism. And it provides guidance on how public programs can better address these disparities across the lifespan.

The report, by Autism Speaks science and public policy experts, appears in the *Journal of Autism and Developmental Disorders*. It's based on the 2016 National Survey of Children's Health. This federally funded survey of more than 50,000 parents recently made headlines for its finding that autism rates may be significantly higher than official estimates by the Centers for Disease Control and Prevention.

### COMPLEX HEALTHCARE NEEDS

According to the national survey, 93 percent of children with autism have one or more co-occurring health conditions, compared to 62 percent of children with other disabilities. This finding is backed by considerable research associating autism with high rates of many medical and mental health issues, including seizures (epilepsy), digestive disorders, disrupted sleep, anxiety and depression, among others.

### BARRIERS TO CARE

Yet these complex medical needs were not the sole or even the primary driver



**TOUGH CHALLENGES:** Children with autism face a variety of unmet healthcare needs, including no or low-quality health insurance, no access to family-centered care, adverse childhood conditions and other parental challenges such as financial hardship, difficulties caring for the child, unemployment and being a single parent.

behind the disparities in access to needed services, according to the new analysis.

The circumstances strongly associated with unmet healthcare needs among children with autism were:

- no or low-quality health insurance
- no access to family-centered care (care that includes families as partners in their child's healthcare)
- adverse childhood conditions (family separation, divorce, physical or emotional abuse and domestic violence in the home, etc.) and,
- parental challenges (financial hardship, difficulties caring for the child, unemployment and being a single parent, etc.).

### PROPOSED POLICIES AND PROGRAMS

"These findings make clear that the unmet healthcare needs faced by children with autism are substantially related to factors best addressed through policies and programs that strengthen the ability of

families to care for their children," says study leader Arun Karpur, Autism Speaks director for data science and evaluation research.

"Programs supporting children with autism and their families need to integrate social supports across a broad range of needs including education, workforce development, healthcare and other welfare programs," Dr. Karpur adds. Currently, he says, these types of public programs operate separately, increasing a family's difficulty in accessing them.

*Have concerns or questions about autism? Get personal guidance from Autism Speaks' trained Autism Response Team at 888-AUTISM2 (288-4762); en Español 888-772-9050; or [familyservices@autismspeaks.org](mailto:familyservices@autismspeaks.org). You can also learn about the signs of autism, screening and diagnosis, associated health conditions and autism treatments and more at [www.autismspeaks.org](http://www.autismspeaks.org)*



# ACHIEVE GREATER INDEPENDENCE WITH ABILITIES EXPO!

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# NEW PRODUCTS



## GIANT FISHING 1-20

The Educational Advantage Giant Fishing 1-20 is a product designed for children ages three and up to improve eye-hand coordination and motor skills while learning numbers 1-20. Up to two players hook the fish with their fishing rods. There are 20 brightly colored numbered fish, 2 plastic rods and a net bag for storage. Fish are made from durable plastic and are approximately 9 inches long. The fishing rods are

28 inches long. This Giant Fishing Game can also be used in water. It is suitable for indoor or outdoor use. Suitable for ages three and up.

### AUTISM PRODUCTS

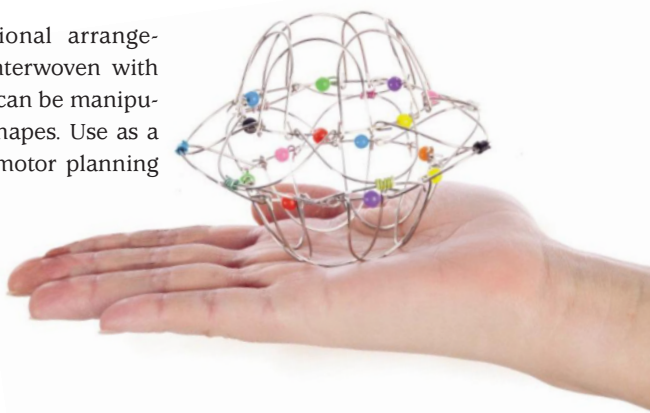
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## MAGIC LOOPS

An attractive 3-dimensional arrangement of fine wire loops interwoven with brightly colored beads that can be manipulated into many different shapes. Use as a fidget activity or work on motor planning skills.

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## SENSORY SHIRT

The JettProof Sensory Long Sleeve Shirt is a calming sensory compression shirt designed for children with autism, Asperger's, sensory processing disorder, dyspraxia, apraxia, Down syndrome, cerebral palsy, ADHD or anxiety. This shirt can be worn as an outer garment or an undergarment, and is manufactured extra-long to provide calming sensory input to the entire torso. It is designed to provide children with gentle pressure and proprioceptive feedback (information received from muscles and tendons concerning body movement and position). This is to help children regulate their body, filter sensory information, remain calm, heighten attention and focus, and become more self-aware. The JettProof Sensory Long Sleeve Shirt has special external stitching for a seamless feel, and stamped labelling for wearers with tactile sensitivity. JettProof is made from Calmtex, a breathable, moisture-wicking sensory fabric designed to help keep the child cool and dry all year round.

### JETTPROOF

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Tools & Technologies to Enhance Life

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The ABLEDATA database of assistive technology and rehabilitation equipment contains information on more than 30,000 products for persons of all ages who have a physical, cognitive, or sensory disability. Products are chosen for these pages by the ABLEDATA staff based on their specific applicability to or design for children who have disabilities. ABLEDATA, operated by New Editions Consulting, Inc., is funded by the National Institute on Disability and Rehabilitation Research (NIDRR) under contract number ED-0SE-13-C-0064. For more information on these and other assistive devices, or to submit product information for the database (and possible inclusion on this page), contact: ABLEDATA, 103 W. Broad Street, Suite 400, Falls Church, VA 22046; phone: 1-800-227-0216; TTY – 703-992-8313; website: [www.abledata.com](http://www.abledata.com); email: [abledata@neweditions.net](mailto:abledata@neweditions.net); twitter: [https://twitter.com/AT\\_Info](https://twitter.com/AT_Info); Facebook: <https://www.facebook.com/abledata>.

# NEW PRODUCTS



## RAINBOW COUNTING BEARS WITH MATCHING SORTING CUPS

The Skoolzy Rainbow Counting Bears with Matching Sorting Cups is a sorting toy designed for children ages two through elementary school age, to introduce color recognition and basic mathematics concepts. The math manipulatives function well as preschool toys with addition and counting by 2s, 3s, 4s and 5s. They also work as fine motor skills toys for occupational therapy. Children can work on matching, sorting, mathematics, dexterity,

hand-eye coordination, and fine motor control as they count, sort, and play. Set includes 60 small bears in 6 colors (1-inch-tall), 6 plastic matching cups (3.5 inches x 3 inches), 1 storage container with lid (7 inches x 3 inches) and 1 Color Bear Dice (1.5 inches).

### SKOOLZY

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## STRESS LESS FIDGET BALLS

The Stress Less Fidget Balls are sensory integration aids designed for children ages three and up with autism, attention deficit-hyperactivity disorder, and sensory processing disorder to stress less and work on fine motor control and intrinsic hand strengthening. Children squeeze these squishy multi-sensory balls and enjoy the feel of the smooth stretchy material. Includes two balls of different weights. Children can squeeze the green ball to hear a "crunchy" sound, like waves crashing on a beach. The blue ball makes no noise, good for when quiet is needed. Children can toss both fidgets in their backpack or purse for any time they need to self-regulate or de-stress. Use with adult supervision.

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## SENSORY LIQUID DROP TIMERS SET

These petite, classic hourglass-shaped timers are just the right size for stacking, games, or handheld visual relaxation. Each set features three chunky timers with colorful bubbles that float to the bottom till time is up. The set is an ideal resource for quiet focus, developing creative language and understanding simple scientific principles. Useful for visual input and quiet focus and can be turned upside down to provide a variety of ways for the bubbles to fall or rise. The set includes 3 transparent timers in the colors of red, green and blue. Contents inside timer contain mineral oil and water.

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# INTRODUCING THE ALL-NEW WWW.EP-MAGAZINE.COM



## EP's Innovative New Digital Strategy

**Exceptional Parent Magazine** is proud to announce the launch of [www.ep-magazine.com](http://www.ep-magazine.com) – our all new website which coincides with our expanding role as a leader in the field of special needs publishing and communications.

[www.ep-magazine.com](http://www.ep-magazine.com) now features a bold new design and intuitive site-wide navigation system with improved menu functionality that directs you to the information most relevant to you. It is also fully responsive with mobile devices, making it easy to navigate on a wide range of web browsers and portable devices.

We've introduced a range of new content to the website, including *In This Issue* that highlights selected content from our latest issue, and

*From Our Contributors*, which features the most recent offerings from regulars such as Genetic Alliance and the AADMD.

Our eNewsletter is the latest innovation in our digital strategy, enabling you to sign up for updates right on the homepage, and access the articles that matter to you each and every week. We also plan to continue adding more video content and product information to provide you with all of the resources you need to care and plan for your loved one with special needs.

We're really proud of the new website and feel it will create the experience you're looking for when you pay us a visit. Check it out here: [www.ep-magazine.com](http://www.ep-magazine.com)



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**CONTACT:** Faye Simon at [fsimon@ep-magazine.com](mailto:fsimon@ep-magazine.com)

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

# Parents of Children with Disabilities in a Single-Parent Family

*“Being a single parent is becoming more and more common, with the US Census Bureau estimating that there are around 12 million single parent families. As relationships change and dissolve, many children are left with a lone parent.”<sup>1</sup>*

*“Rearing a child with disabilities is a challenge, perhaps even more so for single parents who most often are women. Stress and negative psychological effects have been considered likely outcomes for parents of children with disabilities. With the increased family focus in the provision of services for children with disabilities, it becomes even more important to understand the sources of stress and the types of adaptations made in these families...Single mothers of children with disabilities often were younger, had less education, and lower incomes... Findings indicate that gross differences between single- and two-parent mothers tended to become nonsignificant when maternal education and income were taken into account.”<sup>2</sup>*

BY H. BARRY WALDMAN, DDS, MPH, PHD AND STEVEN P. PERLMAN, DDS, MSCD, DHL (HON)

**“C**hildren with a disability are often born into low-income families, and families who care for children with a disability often slide into poverty. According to Census 2000, poverty rates among families caring for children with disabilities are 21% higher than families who do not have children with disabilities.”<sup>3</sup>

## KEEP IN MIND

Medicaid and the Child Health Insurance Plan (CHIP) covered about half (48%) of all children with special health care needs in 2016. Less than one in five (19%) children with disabilities receives Medicaid because they also receive federal Supplemental

Security Income (SSI) benefits. Other Medicaid coverage pathways for children with disabilities are offered at state option. Reflecting different state policy choices, the share of children with special health care needs covered by Medicaid/CHIP varies by state from 23% to 67%.

- Medicaid's benefit package for children, *Early and Periodic Screening Diagnostic and Treatment*, covers physical and behavioral health services as well as long-term care services that enable children with chronic needs to live at home with their families. Medicaid supplements special education services and fills in coverage gaps for privately insured children with special health care needs.



## AMERICAN ACADEMY OF DEVELOPMENTAL MEDICINE AND DENTISTRY

The American Academy of Developmental Medicine and Dentistry (AADMD) was organized in 2002 to provide a forum for healthcare professionals who provide clinical care to people with neurodevelopmental disorders and intellectual disabilities (ND/ID). The mission of the organization is to improve the quality and assure the parity of healthcare for individuals with neurodevelopmental disorders and intellectual disabilities throughout the lifespan.

- Annual per enrollee spending is over seven times higher for Medicaid children who qualify through a disability pathway (\$17,831) compared to those who qualify through another pathway, such as family income (\$2,484) as of 2013. This reflects the greater intensity and variety of needs among most children who qualify based on a disability compared to most children who qualify through another pathway. Legislative proposals that would reduce and cap federal Medicaid funding may pose a particular risk to children with special health care needs.<sup>4</sup>

## IN ADDITION

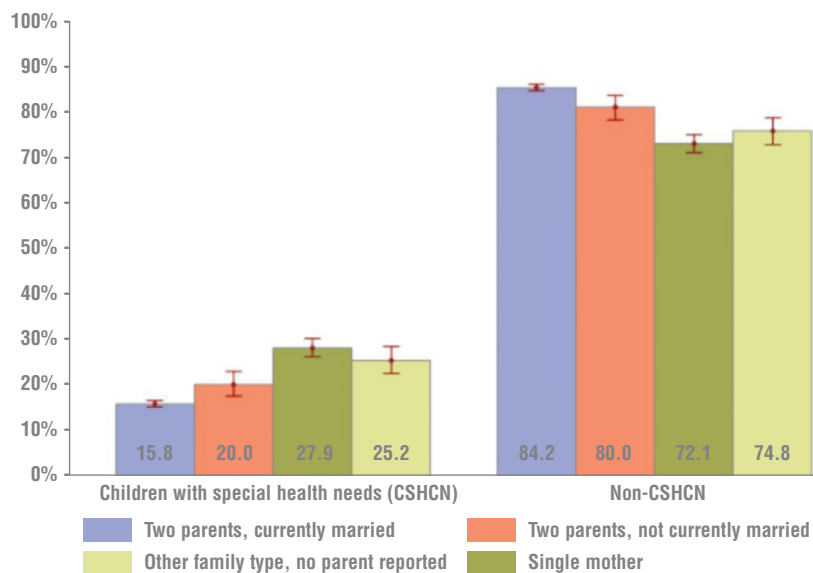
In terms of parental arrangements – **Nationally, (living with two parents currently married)** 15.8% of children have special health care needs; ranging from, 11.4% in California and 11.6% in the District of Columbia to 22.0% in Louisiana and 22.4% in West Virginia.

**Nationally, (living with a single mother)** 25.2% of children have special health needs; ranging from 17.3% in Hawaii to 44.8% in Montana.<sup>5</sup> (See Graph 1)

## REALITIES

“... divorce, particularly with often-attendant drops in income, parental involvement, and access to community resources, diminishes children's chances for wellbeing. It is revealed that children whose parents live apart are twice as likely to drop out of high school as those in two-parent families, one and a half times as likely to be idle in young adulthood, and twice as likely to become single parents themselves.”<sup>6</sup>

**Graph 1. Children with Special Health Care Needs, Aged 0-17 years Nationwide**



“Although much has been written suggesting that stress, grief, and other factors associated with parenting a child with disabilities results in high rates of marital discord, marital dissatisfaction, and divorce, this notion is poorly supported by research. Research demonstrates that parents of children with disabilities have marriages that exhibit the full range of function and dysfunction seen in the general population, most parents of children with disabilities have normal marriages, and the same things that predict healthy and unhealthy marriages in the general population also predict healthy and unhealthy marriages among parents of children with disabilities... (But among single divorced mothers raising) children



**NUMBERS COUNT:** Does undercounting really matter? The reported by Global Burden of Disease Study is more than five times the estimated number reported by the U.S. Census Bureau's annual American Community Survey.



**NEVER DETERRED:** New national policy in the UAE suggests that people with special needs or disabilities should be referred to as “people of determination” to recognise their of Access,” suggests determination, independence and engagement by focusing on the person rather than the wheelchair.

with disabilities, the average income was only 62% of the “minimum subsistence” level.”<sup>7</sup>

“... we found that divorce rates were not elevated, on average, in families with a child with developmental disabilities. However, in small families, emphasis added)there was a significantly higher risk of divorce relative to a normative comparison group.”<sup>8</sup>

Nevertheless, there are over 9 million single mothers in the United States today. On top of demanding work schedules and child care responsibilities, single moms face a higher risk of developing health problems than their married peers. Employed single mothers are 40% more likely to have cardiovascular health problems and 74% more likely to have a stroke compared to married moms who worked. They are also 77% more likely to smoke.

The more time women spend parenting alone, the more likely their health will worsen as they age, affecting their ability to do even the most menial tasks.<sup>9</sup>

## THOUGHTS FOR SINGLE PARENTS OF CHILDREN WITH SPECIAL NEEDS

“Parenting as a single parent is difficult enough in “normal” circumstances, but when your child has special needs, there’s an even greater level of difficulty. The challenges seem to double, and if there is no

support from the other parent, you’re on your own to manage the care of your child with special needs, and sometimes your other children as well.”<sup>10</sup>

- **Create a schedule and try to be consistent.** *A schedule can help reduce many stressors. If your child knows what to expect, he/she will probably have fewer meltdowns, leaving you more time to handle other things, and decreasing your stress.*
- **If your child’s other parent can be involved, work on co-parenting for the best interest of your child.** *Each of you will have ideas about how your child should be raised, but do your best to keep routines consistent in both households.*
- **Network with other single parents who have kids with special needs.** *Many parents feel the need to meet other parents who are going through similar challenges. Lots of parents are now using social media to gather and support each other online. Again, there will be groups that are for all disabilities, and some will be diagnosis specific. No matter how you choose to find support, other parents can be your best resource.*
- **Create opportunities for family time.** *Even with a busy schedule, it is important to spend time together as a family.*

- **Counseling can provide great relief.**
- **If you have other children who are old enough to help, let them help, but not too much.**
- **If you need assistance with housing, food, healthcare, or childcare find assistance from your local social service agencies.**
- **Take some time for yourself.** *As a single parent, this is the most important thing, but also may seem like the most impossible. A good way to get in a few minutes for yourself here and there is by setting strict bedtimes for your children. Of course there will be interruptions to your routine, but generally that time can be yours.*<sup>10</sup>

Are the children worth it? You’re darn right! •

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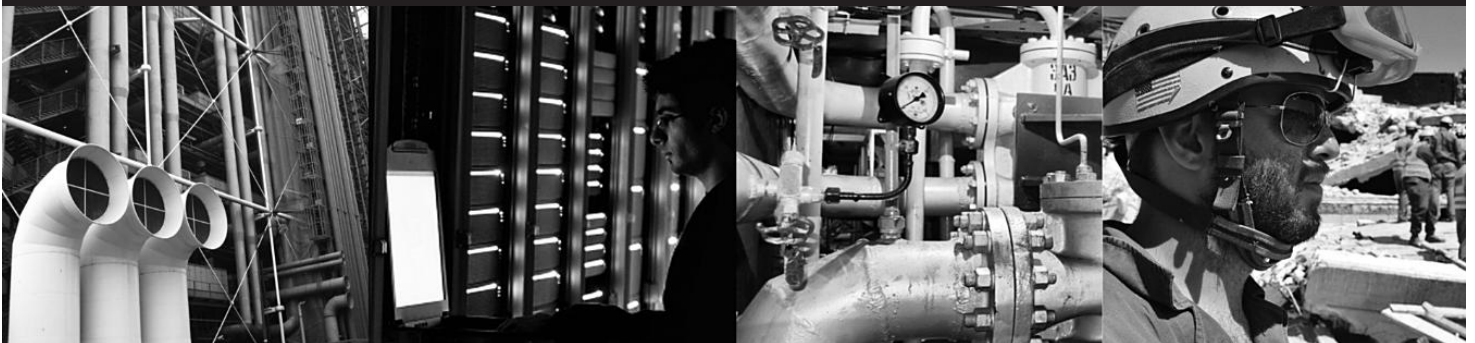
Bring together more than thirty professionals, each a craftsman in his or her former industry, in one organization and no industry, situation, or challenge will be new to us. Not to say that we've seen it all. Technology adds novel challenges daily, making a flexible organization – one willing to grow in those new disciplines – invaluable.

LJS Fac/X, a twenty-two year old company, has undergone its own evolution since the 1990s. Larry Smith began as an individual electrical contractor, founding the company as LJS Electric as his commercial clients grew his business. Larry saw the need to expand his capabilities, and, over the next two decades, he brought talented professionals together to complement each other's unique skill set. Together the staff of LJS Fac/X offers practical, hands-on experience in a broad array of specialties.

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## ORGANIZATION SPOTLIGHT

The cornerstone of CYSHCNet research is multi-site studies that bring together researchers, community partners, and youth/family research partners from universities and communities nationwide.



# CYSHCNet

Changing How Systems of Care Respond to the Needs of CYSHCN

BY CHARLENE SHELTON, RN, MPA, PHD

*Children and youth with special health care needs (CYSHCN) comprise nearly 20 % of children in the U.S., ages 0 to 17. Quality, affordable health care varies from state to state, making the system of health care uneven and difficult to navigate for patients and families.*

**B**ecause of their frequent use of health services, CYSHCN are particularly vulnerable to shortcomings in healthcare delivery, to medical evidence that doesn't address issues of concern to families, and to fragmentation of health-related policies and services across state, county, and city governments.

To respond to these and other concerns, the Maternal and Child Health Bureau of the U.S. Health Resources and Services Administration (HRSA) has funded a new national research network, CYSHCNet (CYSHCNet.org), which is poised to change how systems of care respond to the needs of CYSHCN and their families, by bringing meaningful research projects that educate and inform patients, families, and providers about the needs of CYSHCN and their families. CYSHCNet aims to improve the quality of research for this community by establishing a national network of researchers working with CYSHCN, family caregivers, and family-led organizations. The cornerstone of CYSHCNet research is **multi-site studies** that bring together researchers, community partners, and youth/family research partners from universities and communities nationwide. This approach allows research to reflect the diversity of CYSHCN across the U.S. and address topics of concern to CYSHCN and their families.

Three specific initiatives are at the core of CYSHCNet's work: 1) partnering with youth and family caregivers in every research project; 2) creating a national research agenda; and 3) training emerging investigators through the Guided Research Mentoring Program. **Youth and family partnerships** in every research project ensures that youth and family leaders have a seat at the table from the time a study is first designed, to ensure that studies are relevant and address the concerns of CYSHCN and their families.

Youth and family partners bring a unique

perspective to the research process through their lived experiences along with technical expertise in varied fields that improve the study outcomes, eliminate barriers to study participation, and optimize dissemination of findings. Creating a **national research agenda** will define and prioritize the most important topics as chosen by CYSHCN family leaders and experts in CYSHCN research nationwide. Right now, although the amount of research about CYSHCN is increasing rapidly, there is no coordination or agreement on the most important topics. **Training emerging investigators** through the Guided Research Mentoring Program aims to increase the pool of CYSHCN researchers. There are relatively few experienced CYSHCN researchers, and this is a hurdle to implementing large, rigorous studies at multiple sites that are needed to have lasting impact on the CYSHCN community. Each year, the Network supports three emerging investigators' one-year studies to help them mature into experienced researchers.

CYSHCNet was launched in September 2017. In its second year of operation, CYSHCNet is close to announcing its first major product – the CYSHCN national research agenda - which was crafted with the input of nearly 300 health care systems professionals, youth, and families. The research agenda will provide guidance to researchers through prioritization of the most important and timely health care concerns and increase the number, scope, and quality of research projects that focus on improving health systems for CYSHCN. The goal is to improve health systems and health care delivery, increase access to health care for CYSHCN, and expand services for families and caregivers.

With partner organizations in nine states,

including universities, hospitals, and Family Voices, CYSHCNet has the reach to bring meaningful change to the way health care systems support CYSHCN and their families. The CYSHCNet governing bodies are made up of a who's who of expert CYSHCN researchers, administrators, payment experts, educators, and advocates, many of whom are either parents of CYSHCN or adults with special health care needs. Youth and family leaders are an integral part of the governing committees on equal footing with researchers and other committee members.

Currently there are 10 studies in progress throughout the Network. Studies focus on telehealth, emergency department admissions, transition to adult health care, and the use of multiple medications. The first paper to come out of the Network focuses on opioid prescribing for CYSHCN. Published in the peer-reviewed journal *Pediatrics*, the study shows that it is common for doctors and dentists to prescribe opioids to CYSHCN, especially when they have more than one disease or condition or take more than one medication. While much of this may be appropriate,

this paper sheds light on what is currently happening so that future work can look more closely at what might need to change.



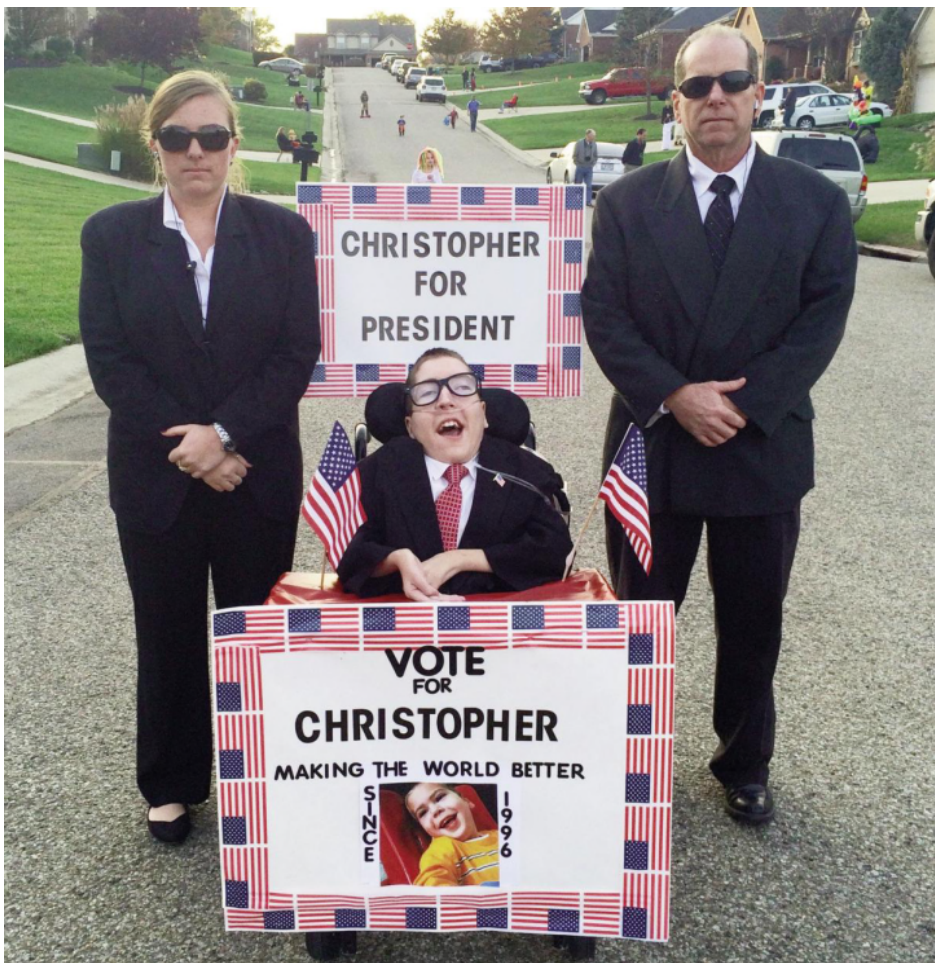
CYSHCNet is a network of committed researchers, families, clinicians, and administrative and policy partners who work together strategically to accelerate the generation and application of knowledge needed to best help CYSHCN and their families. We strive to not only conduct nationally-relevant health systems research, but also to increase research capacity by training emerging CYSHCN investigators.

## LEARNING FROM FAMILY STORIES

Among the many tasks that governing committee members perform, an important charge is to help in the collection of family stories. Family stories illustrate the richness of the experience of living with special health care needs and caring for CYSHCN. Through their stories, CYSHCN and their families tell of the challenges of living with special needs as well as the rewards,

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**SNEAK PREVIEW:** Christopher is a 22-year old who has been cared for by physicians at a children's hospital for his entire lifetime, but that care is at risk now that he is an "adult" who weighs 75 lbs. He is also a big sneaker fan.



**MAN OF THE PEOPLE:** Christopher's parents express frustration with systems of medical care that become disjointed once a young adult with special health care needs has to transition to adult services.

resilience, and love. Stories are unique to each family, showing how they cope with the health care system, deal with diagnoses, connect with other families, and transition their children to adult services and adult responsibilities. Through an understanding of families' daily struggles, researchers in CYSHCNet see the full picture of how health care impacts CYSHCN and their families on a daily basis. Stories keep us engaged and guard against seeing this research as a purely academic endeavor. Stories also help to connect families with researchers and increase the pool of youth and family leaders who are interested in participating in research activities.

The following are examples of stories that families have written to us.

Christopher is a 22 year old with an extremely rare degenerative disease that leaves him a spastic quadriplegic who is oxygen dependent, nonverbal, and g-tube fed. He has been cared for by physicians at a children's hospital for his entire lifetime.

Christopher is followed by 10+ subspecialists, with a history of multiple long inpatient stays. His parents have built relationships with many physicians over the years and this consistency of care has been a lifesaver, quite literally. However, Christopher's streamlined care is at risk now that he is an "adult" who weighs 75 lbs., uses equipment/interventions not commonly used in adult medicine, and needs a Complex Care Clinic to coordinate his care.

Allison Loechtenfeldt, Christopher's mother, wrote his story: one of frustration with systems of medical care that become disjointed once a young adult with special health care needs has to transition to adult services.

Of course, not all CYSHCN have the level of medical complexity that Christopher has. Serena (not her real name) is on the spectrum and generally in good health; however, she receives assistance with her social skills. She sees a therapist and plays body language recognition games at home.

Dealing with the school is a problem because Serena is bullied and has a hard time understanding how to "fit in" better with her peers. The school personnel do not really know how to help Serena, even though they have written recommendations from her therapist and parents. Because Serena is a good student and quite capable of excelling in the classroom, there is a perception that her social skills are a result of her personality or a level of arrogance.

**C**hristopher and Serena's stories illustrate the diversity of the experiences of CYSHCN and demonstrate that CYSHCN frequently encounter issues that aren't addressed by existing evidence and standards. By working in partnership with CYSHCN and their families, CYSHCNet projects can identify issues that have fallen through the divides that exist between the reality of families' experiences and what providers and policy makers understand.

Youth and family partners shape research in three basic ways: **planning**, **implementation**, and **dissemination**. By partnering in planning, youth and family partners help research projects start off on the right foot. Youth and family partners help researchers focus on questions that will have a real impact for CYSHCN and their families. By partnering in **implementation**, youth and family partners help make research safe, comfortable, and rewarding for research participants as well as helping ensure that research participants represent diversity, spreading the benefits of research findings more evenly through society. By partnering in **dissemination**, youth and family partners tackle one of the toughest issues facing researchers today: making sure that research findings are applied in practice.

Through collaboration with other research networks, youth, families, funders, and health care providers, studying topics such as those mentioned above, CYSHCNet's reach can extend to all aspects of health care systems. CYSHCNet's focus on multi-site studies and youth and family partnerships will create a better health care landscape for CYSHCN and their families and will help to focus scarce research dollars on the most important topics facing CYSHCN, their families, and clinicians. CYSHCNet brings together top researchers,

## SPREADING THE WORD : CYSHCNet SEEKS STORIES

We invite youth and families to contribute their stories and consider being a co-investigator on our research projects. If you have a story to contribute about yourself, your child or youth, or your family, please send it to the National Coordinating Center Program Manager at [Charlene.Shelton@UCDenver.edu](mailto:Charlene.Shelton@UCDenver.edu). Stories should be about 250 words and may include photos. Stories are used in articles like this one and in internal communications, brochures, and the CYSHCNet web site ([CYSHCNet.org](http://CYSHCNet.org)). A photo release form and/or permission form will be sent to authors who grant permission to use their real names and photographs.



partners with youth and families, and prioritizes concerns based on the input of CYSHCN, their families, and health care providers in a way that is sure to improve health systems.

*This project is supported by the Health Resources and Services Administration (HRSA) of the U.S. Department of Health and Human Services (HHS) under UA6MC31101 Children and Youth with Special Health Care Needs Research Network. This information or content and conclusions are those of the author and should not be construed as the official position or policy of, nor should any endorsements be inferred by HRSA, HHS, and the U.S. Government. •*

### ABOUT THE AUTHOR:

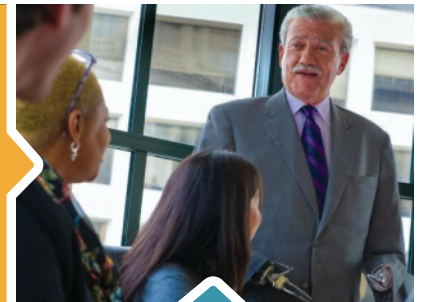
Charlene Shelton, RN, MPA, PhD is the program manager of the CYSHCNet National Research Network and the parent of 2 CYSHCN. She is a medical sociologist and former critical care nurse with master's degrees in policy/nonprofit management and sociology. Her PhD is in Health & Behavioral Sciences from the University of Colorado Denver. All four of her children are grown, so she has spare time to teach medical sociology at Metropolitan State University of Denver, garden, and ski.



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## Pay Attention to Nutrition

Studies have shown that people with disabilities are more likely to be overweight, and also obese. Carrying extra weight not only increases your risk for health complications such as heart disease and diabetes, but it can impact your mobility.

When you have a disability, you may be prone to having increased inflammation in your system. This impacts your digestion and can contribute to a number of secondary conditions. Many people then take more medications to address the symptoms from these other complications.

The good news is that the way we eat can address this increased inflammation naturally! Nutrition is using food to nourish your body with the essential elements it needs to live, grow and heal.

People who have disabilities commonly have poor diets, for a number of reasons. It may seem like a healthy diet is more expensive than eating junk food. We will address this in future articles to show how you can eat healthy foods on a budget. Getting to the super market may be difficult. If you don't drive, and rely on a family member or friend to drive you, you may not go as often as necessary to have



fresh food. It may also be inconvenient to take a dial-a-ride service, especially if you live in a more rural area. If this sounds like your situation, consider a delivery service that can bring you good, healthy foods.

Your disability may also make it difficult to prepare healthy meals. I often hear people who have limited tolerance to standing say this gets in the way of cook-



**NOW YOU'RE COOKING:** "Your disability may make it difficult to prepare healthy meals. However, it is better to take longer to prepare your meals because you have to adjust to a different way of doing it, than to deal with the complications brought on by an unhealthy diet."

- Digestive dysfunction • Constipation
- Diarrhea • UTI's • Obesity
- Osteoporosis • Arthritis
- Type II diabetes • Heart disease
- Pain • Sleep disorders • Skin issues

By improving your diet to have better nutrition, you can improve sleep and increase your energy! Everyone can use this. It will also help to maintain weight. While losing weight is a nice goal, assuring you do not put on more weight is a good first step. This can be challenging, and losing weight could be a bonus benefit.

You could have improved skin health. Many people do not equate skin issues with diet, but skin is the largest organ we have. Protecting it is important!

Improved diet can improve your bowel function. If you have loose stools, or go

frequently, your intestines may not have the time to absorb nutrients. A good diet will help to slow this process. On the flip side, if you experience constipation, which is a common side effect of many medications, this can increase the number of toxins in your body. Stool carries all of the toxins out of the body, and letting it sit in the colon can affect your body negatively. It is healthy to move that along regularly.

A good diet can improve your mood, as well as decrease pain that you experience. An improved mood, and also improved nutrition, can decrease the pain experienced, especially if you are decreasing inflammation. By decreasing pain, you may be able to lower the amount of pain medication you take. These medications also carry a number of uncomfortable side effects. Decreasing the amount of medication you take is always a good goal. Our bodies were not designed to have all of those chemicals pumping through the body.

Studies have shown that people with dis-

abilities are more likely to be overweight, and also obese. Carrying extra weight not only increases your risk for health complications such as heart disease and diabetes, but it can impact your mobility. It is difficult to move more weight, especially if you have weakness or impaired functional mobility, added weight could even impact your independence. Additionally, it has been shown that people with disabilities have higher percentages of body fat.

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**"A good diet can improve your mood, as well as decrease pain that you experience, especially if you are reducing inflammation. By decreasing pain, you may be able to lower the amount of pain medication you take."**

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Why is weight gain more common in people with mobility impairments? There are a number of reasons. First, having that increased percentage of body fat, and lower lean body mass, means that your metabolism slows down. Metabolism is the number of calories that your body needs to function.

Remember that weight maintenance is having a balance between calories out and calories in. A higher fat percentage means less calories out. Remember that a disability also means that you are burning less calories from moving around less to complete basic activities. You will need to adjust your intake from pre-disability days. Exercise will help increase the calories out! While a good diet is important, it only works with consistent exercise. There are plenty of previous posts about the importance and benefits of exercise.

Medications can contribute to weight gain. There can be multiple reasons as to why this is, and you should not stop any medications without consulting your physician. However, if you are able to safely decrease any medications, that will help your overall health. Because of this side effect, understand that medications may make weight loss more difficult, or slow it down. Do not get frustrated! The weight gain did not come on over night, so be patient and keep up the hard work!

ing. You can certainly prepare food sitting down! You can cut up foods, you can mix bowls, you can even (carefully) cook on a stove! It is better to take longer to prepare your meals because you have to adjust to a different way of doing it, than to deal with the complications brought on by an unhealthy diet.

A poor diet can lead to nutritional deficiencies. Depending on your primary condition, there may be other reasons why your body is not absorbing all of the good nutrients from food. Or you may be on medications that impact the absorption of nutrients in the digestive tract. All of these reasons are why you should consider following a better diet.

There are a number of complications that are associated with disability, but many can be prevented with a good diet. Common complications include:

## PAYING ATTENTION : MAKING SIMPLE CHANGES

Do not think about dieting. That often fails because you feel like you are depriving yourself and then you return to your normal eating habits, if not worse, and gain back any lost weight. Try to make simple changes. Here are a couple to start with:

### 1. Restrict fruit intake to only 1 per day.

This does not sound like a common recommendation, however, while fruit has a number of good nutrients, it also has fructose. This is a natural sugar, and high amounts have been shown to increase inflammation in the system. The best fruits to have for your one serving are berries, orchid fruits, and citrus fruits.



### 2. Consume lots of vegetables!

Veggies help to slow the release of glucose, and decrease the risk of insulin resistance. They are low in calorie and high in fiber, which will help you feel fuller faster. Vegetables are also high in vitamins and minerals, which, as mentioned previously, are important due to the impaired nutrient absorption. They also help to rid the body of toxins. It is recommended that you eat at least 8 servings a day! So if you need a snack, consider some cucumber slices.



**3. Reduce sugars.** Sugar is linked to a number of health complications, and really offers no benefit. It leads to increased obesity, inflammation, hormone imbalances, insulin resistance, and higher cholesterol. Skip dessert, but also limit sugar containing products such as cereals, cookies, muffins, and white rice/pasta/bread.



**4. Avoid artificial sweeteners!** Just because something says “diet” does not mean it is healthy! It often means that it has artificial sweetener in it, and these compounds have been shown to actually stimulate appetite. Artificial sweeteners also increases the cravings for carbohydrates and stimulate fat storage. This can all contribute to weight gain even when you think you are choosing healthy alternatives.



**5. Eat good fats.** Fat got a bad reputation over the years because each gram has higher calories than each gram of carbohydrate or protein. However, fat helps suppress appetite and curb cravings. By limiting fat in your food, you'll likely be more hungry more often. Fat also adds taste – we want to enjoy the food we eat or we won't eat it, right? Good fat is in fish, nuts, olives and avocado. Oils from these foods are also healthier than butter or lard for cooking.



You may notice that your finances are tighter when you have a disability. This is unfortunately common. This is also a reason many give for following a poor diet and not exercising. While it may seem pricy to lead a healthy lifestyle, it does not need to be. It may take more planning and more time, but that will contribute to less illness and less hospitalizations. That time is invaluable, right? Put in that extra time and effort now to earn it back later.

As mentioned earlier, a disability may predispose you to having more inflammation in your system. This can contribute to weight gain. Additionally, you may have hormonal changes that can make weight loss more difficult. Again, do not get discouraged. Forgive your body, and continue the hard work. It will pay off!

You may also have poor carbohydrate metabolism, and insulin resistance. This can lead to diabetes, or make diabetes more difficult to control. This can be dangerous. Diabetes can affect your whole body, and lead to a plethora of additional complications. Prevent it if you can! Good diet and regular exercise are key.

*This information, and information about an anti-inflammatory diet, can be found in **Eat Well, Live Well with SCI** by Kylie James and Joanne Smith. •*

## THE FITNESS PRIORITY

My name is Kristin McNealus, DPT, MBA, and I received my Masters in Physical Therapy from Boston University and went on to earn my Doctorate in Physical Therapy from MGH Institute of Health Professions. I received my MBA from Pepperdine University in 2016. I started Every Body Fitness, an online fitness program for people with physical limitations to workout anywhere. We have a video-on-demand program that offers cardiovascular workouts, boot camp style strengthening workouts, balance classes, and adapted yoga programs. I started this because I know that it is important to get exercise, but there can be challenges getting out to some of the activities discussed in this article. I wanted to design an option with as few barriers as possible. This can be a primary workout program, or complement any other activities. You can check this program out at [www.ebfitnessonline.com](http://www.ebfitnessonline.com)

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# ADHD and a WHOLE FOOD PLANT-BASED DIET

*What role does nutrition play for children with ADHD? This is a controversial subject and, because we often have an emotional attachment to food, we are reluctant to look at this as an adjunct treatment. The studies that have been done do not provide consistent results. It is suggested, however, that the “Western” way of eating (the Standard American Diet) plays a role and this is especially true for boys.*

BY TERI YUNUS

When my son's preschool teacher called me and said that my three-year-old was so fidgety he kept falling off his chair, I felt like this was another level of challenge for this little one. He had been in the program for deaf children just a few weeks when I got the call. In the 1980s, attention disorders were becoming more prominent and teachers were often at their wit's end with how to manage these kids.

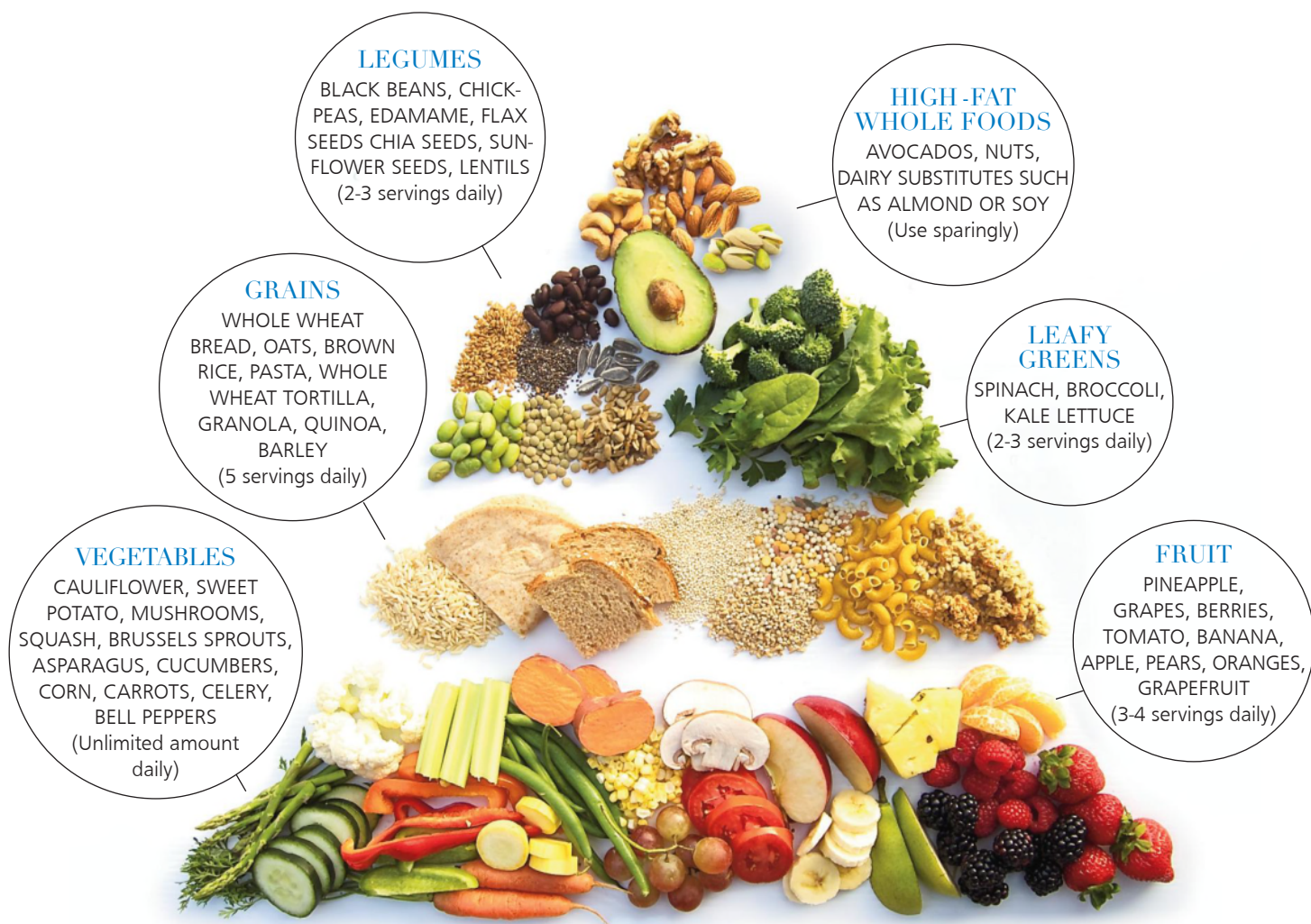
At that time, I was a single mom with three little boys and two jobs and convenience was top priority for me. My boys ate Fruit Loops and Cap'n Crunch, Spaghetti O's, boxed macaroni and cheese, along with lunchmeat and canned tuna. My youngest son was born deaf (to the best of our knowledge) and was a very picky eater. He was offered fruits and vegetables and was so tactically defensive that he gagged on anything with texture. He would only tolerate soft foods. Bologna and pancakes became his favorites.

By age four, my son was being prescribed stimulants to control his hyperactive tendencies. This was over 30 years ago, and I remember it as being stressful for my son, who was the most loving little boy, and our entire family. His symptoms became center stage and that environment was hard on all of us. The double disability demanded a lot of attention and the entire family felt it. The medications required multiple doctor visits for adjustments

and we tried them all. None of these drugs gave him significant relief and the investment in managing this disorder was an added stressor.

Attention deficit hyperactivity disorder (ADHD) affects approximately 11% of US children aged 4-17. The Centers for Disease Control estimates that 2.7 million children in the U.S. are currently taking medication for ADHD. The disorder can disrupt cognitive, academic, behavioral, emotional and social functioning. It may be associated with other conditions, such as learning disabilities, anxiety, depression and conduct disorders. The cause is unknown and thought to be a combination of genetic and environmental factors. It is characterized by inattention and impulsivity and may present as disorganization, forgetfulness, poor concentration, academic underachievement, inability to follow instructions or finish tasks, risky activities without consideration of consequences, disruptive behavior, interrupting others, impatience. Hyperactivity can be seen as fidgeting, difficulty remaining seated, inability to remain quiet, or restlessness.

The disorder is seen more frequently in boys and there seems to be a genetic propensity among siblings with the disorder. Early lead exposure is one of the environmental risk factors known. There are diagnostic criteria that must be met prior to diagnosis as



**GREAT PYRAMID:** A whole food plant-based diet is based on whole foods that have minimal to no processing. Beans, legumes, vegetables, whole grains, fruit, nuts and seeds provide the macro and micronutrients that promote health. These foods also contain hundreds of naturally-occurring phytonutrients that may protect against cancer, heart disease, osteoporosis, and other chronic health conditions.

not all children with these symptoms have the disorder.

Standard management for ADHD often focuses on pharmacologic treatments with stimulants and other prescription medications. These drugs can be helpful in many cases but the side effect profile for most of the treatments can be problematic. Behavioral interventions are often recommended as the initial treatment for children with ADHD and are often used in combinations with medications. We know that physical activity is critical for growth and development and may help reduce the symptoms for kids with ADHD.

What role does nutrition play for children with ADHD? This is a controversial subject and, because we often have an emotional attachment to food, we are reluctant to look at this as an adjunct treatment. The studies that have been done do not provide consistent results. It is suggested, however, that the “Western” way of eating (the Standard American Diet) plays a role and this is especially true for boys. High intakes of sugar, salt, fat with minimal consumption of whole grains, fruits, and vegetables may be an associated risk of ADHD.

Some of the nutritional factors that are currently under study include artificial food colorings and common allergens. It is likely that artificial food colorings play a role in the development of

symptoms in some with ADHD. Some children with ADHD may also be sensitive to foods such as milk, chocolate, eggs, soy, wheat, corn and legumes, along with salicylate-containing foods such as grapes, tomatoes and oranges. Inadequate vitamin and mineral intake may play a role in ADHD. Iron, copper, zinc, magnesium and calcium deficiencies are common in those with ADHD and it is theorized that this may affect the central nervous system. Nutrient poor meals and snacks are implicated as contributory for those with ADHD. Those with ADHD may also have lower levels of omega-3 fatty acids and higher levels of omega-6 that may lead to inflammation and oxidative stress.

**T**hey say hindsight is 20/20 and looking back, I would have done things much differently if I knew then what I know now. As parents, we do the best we can with the information and experience we have. This is the motivation for this article. There is information that you may not be aware of and your family may be struggling like mine did. Most of us turn to our doctors for nutritional advice, not knowing that physicians get little to no nutritional education. No medical professional ever talked to me about diet when I was seeking treatment for my son’s ADHD. What I know now came many years later.

Most of us believe that we are eating and feeding our children a healthy diet. It is difficult to know what a healthy diet is given all the conflicting information we are exposed to on a daily basis. The food industry promotes food products not based on health, but based on sales and demand. Food that is advertised is typically highly processed. These items lack adequate nutrients yet taste so amazing we go back for more (earning the industry more dollars). Highly processed foods often contain artificial food colorings, flavorings,

fruits, beans and whole grains. We know that the gut microbiome plays an important role in overall health and may be strongly associated with ADHD. We know that children lead more sedentary lives than their parents did. Lack of physical activity has a role in ADHD. We know that environmental exposures to toxins has been linked to ADHD.

One treatment that may help in all these areas is a whole food plant-based (WFPB) diet. This style of eating is based on whole foods that have minimal to no processing.



**ROUNDING INTO SHAPE :** Diet may be that added tool that can make a difference with your child today and in his future. Eating a whole food plant-based diet can help prevent obesity, diabetes, high blood pressure, cancer, heart disease and many other chronic illnesses. Setting our children up for the best adult life is part of our jobs as parents.

and preservatives and do not have the micronutrients that are essential for good health. Fast foods and foods high in sugar, salt and fat light up all the dopamine receptors in the brain and can be soothing to those with attention disorders.

What we know is that there is little good science consistently connecting diet with ADHD. We know that there is concern about food additives, preservatives and flavorings, along with other toxins and chemicals found in our food supply. We know that most children with ADHD eat the Standard American Diet (SAD). This way of eating is associated with multiple disease processes and not optimal for health. We know that most children do not eat the recommended amount of vegetables,

Beans, legumes, vegetables, whole grains, fruit, nuts and seeds are the foods that provide the macro and micronutrients that promote health. Dr. Michael Greger, nutritional expert, researcher and founder of [www.nutritionfacts.org](http://www.nutritionfacts.org) states these foods contain not only the essential vitamins and minerals, but also hundreds of naturally-occurring phytonutrients that may protect against cancer, heart disease, osteoporosis, and other chronic health conditions.

Meat has become the “main dish” in the SAD and many people wonder what plant-based eaters actually eat. A WFPB diet does not need to be complicated. There are recipes available online to satisfy the needs of most families. There are soups, casseroles, salads, side dishes, pasta dishes,

comfort foods, amazing desserts, and so much more. Some WFPB eaters are starch based, others based on greens and beans. The possibilities are endless.

Foods that are excluded from this way of eating include added oils, added sugar, all animal products including meat (includes chicken and turkey), fish, dairy (yes, cheese, too) and eggs along with processed foods. These foods are often very high in saturated fat, trans fat, salt and other additives. “Junk” foods are also excluded from this lifestyle as they do not promote healing but can diminish our health. It is important to know that not all “health” foods are healthy.

Growing up, most of us heard repeatedly, “eat your vegetables”... many of us may use these words with our own children. Most of us know that vegetables are one of the healthiest foods we can eat. Many plant-based doctors and nutritionists agree that the more veggies we eat, the healthier we will be.

Foods common in the WFPB diet feed the gut microbiome (the good bacteria in our digestion tract). You may have heard the old adage, “you are what you eat”... this one, too, is very true. What we eat determines what gut bacteria are in our intestines and this plays an important role in our ability to fight disease and our overall well-being. Preliminary human studies have demonstrated the likelihood of a connection between the gut microbiota and ADHD and overall brain health. Eating a WFPB diet improves gut health and consequently reduces inflammation.

**T**he bottom line is this... there is not ONE right way to treat this complex condition. Often, ADHD is best managed by multiple modalities. Medication is one, behavior therapy is another, diet may be that added tool that can make a difference with your child today and in his/her future. Eating a whole food plant-based diet can help prevent obesity, diabetes, high blood pressure, cancer, heart disease and many other chronic illnesses. Setting our children up for the best adult life is part of our jobs as parents. Your family may consider experimenting with adding more plant-based foods and reducing animal products to see what improvements may be seen. Using dietary intervention does not mean abandoning

medications. Nutrients are compatible with drugs to a greater degree than the medications that are common to ADHD are compatible with other drugs.

Dr. Joel Fuhrman, Dr. Neal Barnard and Dr. Michael Greger offer information on what this lifestyle can do for your child and your family. These physicians, and others, are reputable and base their recommendations on the best research available. ADHD management can be easier when offering the healthiest foods. The bonus is that typical chronic illnesses that so many Americans are experiencing now can be prevented when the illness-causing foods are eliminated and replaced with the most nutritious options. Many cities and town have organized groups for plant-based eating support. If your town doesn't have one, consider working with other parents to create one in your community. You are not alone. Many parents are searching for better answers, just like you. •

#### ABOUT THE AUTHOR:



Teri Yunus is a Family Nurse Practitioner and Nationally Board-Certified Health & Wellness Coach with Health Up with Teri! She recently retired from her work as a nurse practitioner and devotes her time to coaching with emphasis on transitioning to a whole food plant-based lifestyle. She empowers her clients to take their power back and the results she sees with her clients is transformative! [www.healthupwithteri.com](http://www.healthupwithteri.com) Contact Teri at [healthupwithteri@gmail.com](mailto:healthupwithteri@gmail.com)

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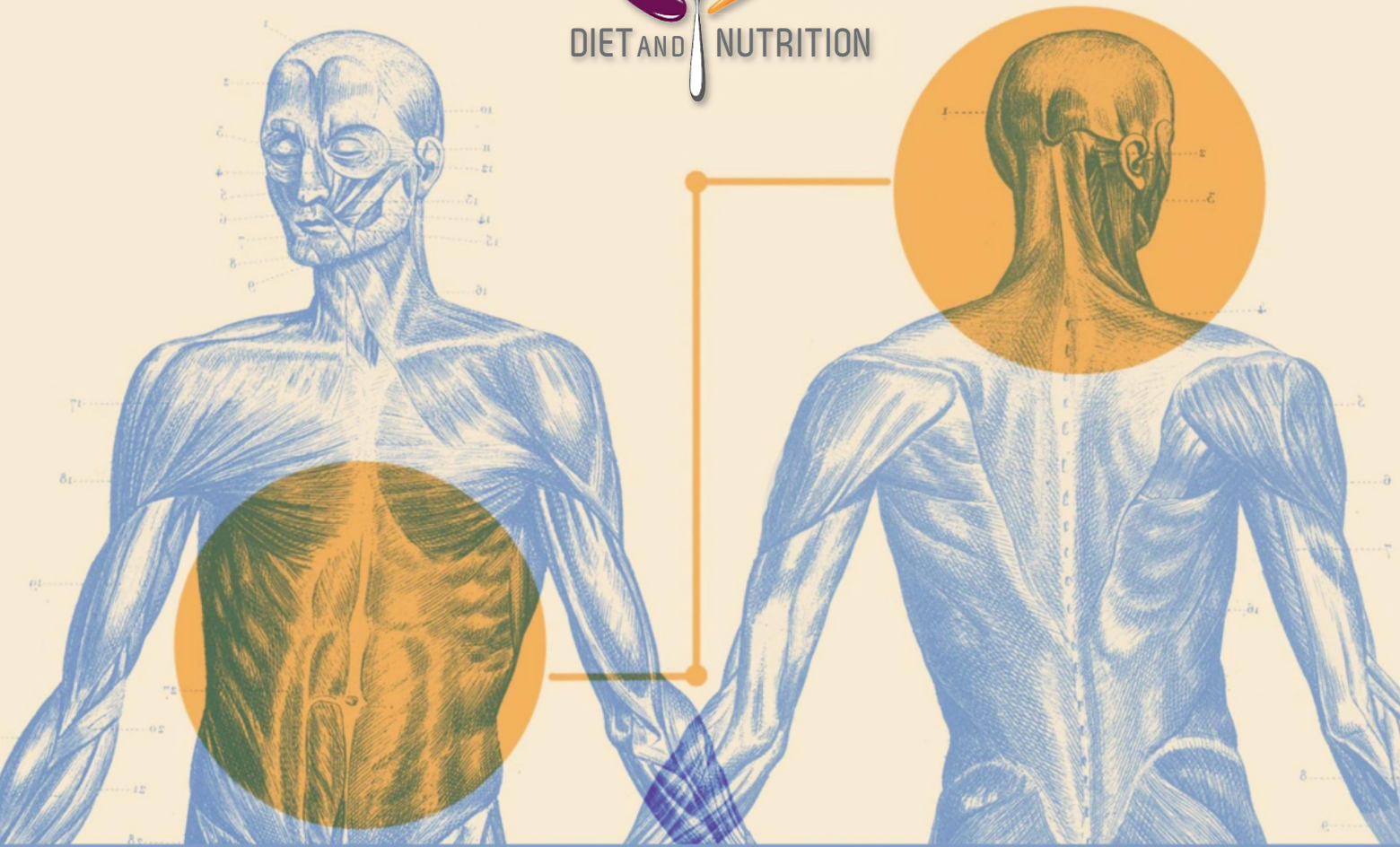
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# THE GUT-BRAIN

## RELATIONSHIP AND ROLE IN HEALTH AND WELL-BEING

*Since a healthy brain promotes a healthy gut, and a dysfunctional gut will hurt the brain, this brain-gut interdependence often becomes a vicious cycle. In people with special needs, all the issues become compounded, since they already have some nervous system impairment in addition to this scenario.*

BY DR. STEN EKBERG

# WE ALL KNOW THAT THE BRAIN REGULATES EVERY FUNCTION IN THE BODY, AND RECENTLY THERE HAS BEEN A LOT OF ATTENTION ON THE GUT-BRAIN RELATIONSHIP AND INTERDEPENDENCE. IN THIS ARTICLE I WILL DISCUSS SOME OF THE BASIC PROPERTIES OF GUT AND BRAIN, HOW THEY RELATE TO EACH OTHER, AND THE TYPES OF FOODS THAT CAN CREATE PROBLEMS OR PROVIDE SOLUTIONS.

**W**hen we understand the underlying principles and mechanisms, rather than just learn a laundry list of what-to-do's, I believe we will make long term changes which can have a profound, positive impact on our own well-being, as well as that of our loved ones.

The brain is a very active organ. It makes up about 2% of your body weight, but it uses 20% of your energy, 20% of your calories and 20% of your oxygen. So what that means is that the brain's job of processing signals is really hard work, and the brain is very "hungry" and demanding of resources.

Muscles perform mechanical work, whereas the brain performs electrical work. Its job is to manage the electrical state of membranes by shuffling sodium, potassium and calcium ions back and forth across those cell membranes. The ability to shuffle minerals, and to keep the membranes in good repair, is what determines the quality of our thoughts, focus, digestion, health and everything else about us.

A cell membrane is a barrier that is very selective about what it lets through. This ability to selectively determine what is allowed to enter, and what is left outside, is the key to all life as well as the key to all brain and immune function.

The brain needs two things to perform well - quality signals and quality nutrients. The brain receives signals from our senses and translates that information into a picture of what the world looks like through a process called perception. Lots of accurate signals equals a precise, high resolution picture from which the brain can make correct decisions. Incomplete, distorted signals mean that the brain has an incomplete, fuzzy picture and will have a hard time making the right choices. Garbage in - garbage out.

Signals also provide activation for the brain cells. Just like muscles grow stronger from resistance exercise, and shrink from disuse, brain cells grow stronger from more signals and shrink from the lack of them. This is the mechanism behind neuroplasticity. Signals, therefore, is the "juice" that keeps the brain alive. Use it or lose it.

**A**ll life forms are able to make decisions and respond to their environment. What allows them to do that is selective cell membranes acting as barriers. In humans there are two barriers that are especially important. The first barrier is the gut lining. It serves as a barrier between the environment and our blood stream. When we put things in our mouths, it contains all sorts of things that we do not want in our blood stream. Food is not

technically "inside" our bodies until it has entered our blood and our cells, and it is up to the gut barrier to decide if it belongs inside or not.

Only very specific, very small things should be allowed to get inside. Food consists of large particles, cells, proteins, fiber, bacteria, etc. All of these are very large particles. Much too large to be allowed through. That's why we have a digestive system, with hydrochloric acid in the stomach and enzymes in the intestines.

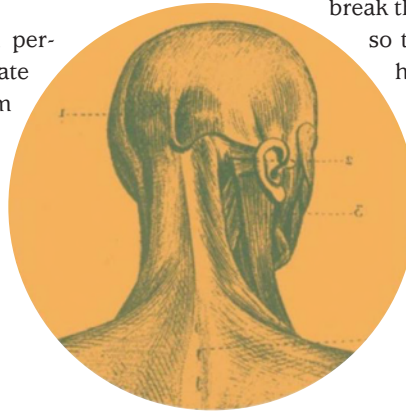
The purpose of the first half of the digestive tract is to break the food down into very small particles so that it can be absorbed in the second half.

In an ideal scenario, food is ultimately broken down into individual amino acids, fatty acids and single carbohydrate molecules called sugar. These very small particles can safely enter through the gut barrier, because they are too small to cause an allergic reaction. They are the fundamental units from which the body can make energy and building blocks for healing and repair.

A healthy gut flora, or biome, is a mix of bacteria dominated by friendly bacteria which keep the unfriendly, or pathogenic (disease causing), bacteria in check. When we take antibiotics, we kill off whole colonies of bacteria, good and bad. The pathogenic bacteria however, tend to thrive on our modern diet of sugar, grain and

processed food, so the pathogenic bacteria recover faster, become dominant and create dysbiosis (unbalanced gut flora), the impact of which we are only beginning to grasp.

The combination of toxins from pathogenic bacteria, sugar, grain and stress create irritation and inflammation, which increases wear and tear on the stomach lining. In an effort to control the situation, immune cells move in to try to clean up the mess, and in the general chaos, there will be some casualties. The immune system produces antibodies, some of which may start attacking the tight junctions, which is like the "cement" that hold the cells together. When the tight junctions are attacked, the gaps increase and the gut becomes leaky.



**"THE BRAIN NEEDS TWO THINGS TO PERFORM WELL - QUALITY SIGNALS AND QUALITY NUTRIENTS."**

When the lining is damaged and the bacteria are out of balance, enzyme production suffers, the digestion of food becomes even more incomplete, and the gut barrier has openings large enough for undigested particles to pass through, causing further immune reactions and inflammation.

The pathogenic bacteria, thriving on sugar and grain, produce toxins which now leak into the bloodstream.

What does this do to the brain? Well, the other important barrier we want to mention is the blood brain barrier (BBB), which protects the delicate brain cells from toxins in the blood. This barrier also has tight junctions which can get attacked by the same antibodies that attacked the tight junctions in the gut. The result is that when you have a leaky gut, you are almost guaranteed to have a leaky brain as well.

Remember those toxins produced by the pathogenic bacteria in the gut that got into the blood? They will now get into the brain as well and basically poison the brain. This mechanism has been linked to a lot of mental disorders as well as developmental problems like the autism spectrum. Many cases have been improved or even reversed by restoring gut function and bacterial flora.

Since a healthy brain promotes a healthy gut, and a dysfunctional gut will hurt the brain, this brain-gut interdependence often becomes a vicious cycle. In people with special needs, all the issues discussed above become compounded, since they already have some nervous system impairment in addition to this scenario. On a positive note, it also means that there is great potential for improvement by understanding and taking some effort to correct the situation.

When it comes to health, I believe the key is to look at the big picture. To understand that our diet and environment have changed more in the last 50 years than it has in the previous 250,000 years, and that most disease can be explained by those changes.

While there are several contributing factors, I believe the most important one, and one that we can influence, is the quality of our food. Too much discussion is wasted on details such as meat vs vegetables or carbohydrates vs fat, rather than stepping back and looking at the big picture. What has changed? We don't need more details, we want a whole new outlook on food.

The type of food that is innately right for humans ultimately comes down to the properties of our digestive tract and the type of enzymes and stomach acid we can produce to digest and process food. The type enzymes you are capable of producing depends on your DNA, which is essentially identical to that of early Homo Sapiens,

250,000 year ago. In other words; the DNA in your body today is adapted to the food we have eaten for the last 250,000 years.

This is the philosophy behind the Paleo diet which says that we would do best to only eat the type of foods that were available to our ancestors. Anything else would be foreign to our DNA, or in my opinion, at least a gamble. That excludes modern grain, sugar, pasteurized dairy, and all processed food, food additives and chemicals. I don't promote or think that we should be slaves to any particular diet, but I think the Paleo diet is a great starting point to understand food.

In this short article, I am not able to discuss in detail how to heal leaky gut, but a great resource is the website

<http://www.gapsdiet.com/>. The short version is: eliminate all sugar, grain and processed food, and introduce natural, fermented and healing foods like sauerkraut, yogurt, and bone broth. Eat whole food and allow the gut to recover.

The brain is made up of about 70% fat, so high quality fats in the diet is crucial for a healthy brain. DHA, which makes up about 40% of the fat in the brain is critically important, but almost universally deficient. It is a very long, and squiggly molecule found in fish oil. DHA makes the cell membranes more flexible, and is very important for cell membranes properties.

**F**ew topics are plagued with more controversy and misinformation than that of food. We tend to get caught up in the details. We can't see the forest for the trees. I believe the answers are in plain view if we only look at the foundations of human physiology and understand the historical perspective. Up to 70% of calories consumed in this country are from sugar, refined grain and highly processed vegetable, seed and grain oils. Foods that are not only devoid of nutrients, but also inflammatory, allergenic and often toxic. We don't need to sift the details. We need a whole new outlook on food.

There are two questions we want to ask ourselves. 1) Was this food around 50,000 years ago? And, 2) Has it been altered by man? The key to understand is that for eons, humans, like all other animals, have lived on whole food provided for us by the planet. A fact that has only changed in the last century; a mere blink relative to the age of your DNA.

Start making food as important as it is. Learn enough to make good choices. You and your loved ones are worth it. •

#### ABOUT THE AUTHOR:



Dr. Sten Ekberg D.C. is a Holistic Doctor, Clinical Nutritionist, and former Olympic decathlete. As the founder of the healing center Wellness for Life (WFL), Dr Ekberg is a pioneer in the field of integrative health care and all-natural health restoration. Many last resort

cases have had their health restored when Dr. Ekberg was able to identify the root cause others had missed. He has a very popular YouTube channel providing free information on all topics relating to holistic health.



**“THERE IS GREAT  
POTENTIAL FOR  
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# THE POSITIVE INTENTION OF ANXIETY

BY JACKIE SCHWABE



*How do you know if your child's behavior is anxiety or bad behavior? What is anxiety? What is the positive intention of anxiety? How can we tell whether or not a behavior is related to an existing diagnosis or to anxiety? What are the potential symptoms of anxiety? What kinds of natural supports can you provide for your children if they do struggle with anxiety? This article seeks to answer all of these questions and help you find natural supports for your child with special needs who also experiences anxiety.*

## HOW DO YOU KNOW IF YOUR CHILD'S BEHAVIOR IS ANXIETY?

We were getting our four children ready for school and our daughter burst into what seemed like an unprovoked hysterical

crying tantrum. These outbursts had started to become a regular occurrence over the last year. Honestly, we thought that she was attention seeking because her younger sister got a lot of one-on-one time from her therapists as a result of her in-home therapy, her brother was getting extra attention at school in reading to help with his dyslexia, and her baby brother just got a lot of attention because he was an adorable baby.

The outbursts seemed to be isolated to occurring at home most days before school. Then, what seemed like all of a sudden, the outbursts started happening in school right before she had to take a test; test anxiety didn't make sense because she was a straight A student.

How do any of us know if these types of outbursts are more than just attention-seeking behavior? Well, if the behaviors persist despite supports you put in place and/or start to interfere with their daily life, it might be more than just a tantrum, it could be anxiety.

## WHAT IS ANXIETY?

According to ChildTrends.org, anxiety disorders are one of the most common health problems of childhood and adolescents. According to kidshealth.org and the national alliance on mental illness, NAMI.org, anxiety disorders can cause people to feel excessively frightened, distressed, or uneasy during situations



where many others would not feel afraid. There are several types of anxiety you might hear: generalized anxiety, OCD, phobias, social anxiety, panic attacks, and PTSD. Regardless of the type of anxiety, there is a positive intention from the body in causing anxiety. The body's job is to protect itself. Therefore, anxiety is a result of the body itself trying to protect itself; anxiety is not a willful negative behavior your child is using to get something they want, or as a desperate plea for attention.

If you can change your frame of mind to consider that the body is causing the anxiety as a physiological response to stress with the intent to protect the body, you can fathom that your child is not trying to act out in a negative way. Your child is most likely just as confused as you are by their behavior. If you can consider that behavior is a form of the body's non-verbal communication, perhaps you can reconsider how you might handle the situation.

### CAN YOU TELL WHETHER OR NOT A BEHAVIOR IS RELATED TO AN EXISTING DIAGNOSIS?

Even if you accept the idea that behavior is communication and it is essentially a cry for assistance or intervention, how do you know if your child's special needs diagnosis is the reason for the behavior or if the reason is anxiety? While you cannot always tell if the behavior is related to an autism diagnosis or a social anxiety disorder, you can consider that the condition might contribute to the anxiety or the anxiety might present itself uniquely due to other disorders. For example, if your child has an autism diagnosis and is nonverbal, your child may not be able to tell you their stomach hurts due to anxiety, but they may start or increase their self-injurious behavior.

The key take-away here is to consider if your child's existing diagnosis might have communication, sensory, focus, learning, or unique processing considerations that can make it more difficult to see patterns, triggers, physical signs, or behaviors. The potential symptoms of anxiety are important to understand so you can use this information to determine if you have more going on than the existing diagnosis.

### WHAT ARE THE POTENTIAL SYMPTOMS OF ANXIETY?

If we are not always able to determine whether or not the behavior is related to an existing diagnosis or if it is anxiety, what are some potential symptoms and how might they present themselves differently if your child has another diagnosis? Anxiety potential symptoms include physical signs like stomach aches, headaches, or muscle tension. If you have a nonverbal child with an autism diagnosis, they might increase head banging activities. Other anxiety symptoms include excessive behavior, complaining, crying, tantrums, bad moods, behavior progressions, clingy behavior, or manipulative behaviors like aggression or self-harm. All of these symptoms might show up in a unique way depending on your child's initial diagnosis. So, what do you do?

### WHAT KIND OF SUPPORT CAN YOU PROVIDE FOR YOUR CHILDREN IF THEY DO STRUGGLE WITH ANXIETY?

If you identify behaviors or symptoms that seem like they might be related to an anxiety disorder, it is always best to seek a

medical professional's input. However, if you either have a diagnosis of anxiety already or you want to support your child with behaviors that could be related to anxiety, here are a few tips.

There are a few strategies for supporting children with anxiety with special needs. The first step is to closely observe your child and see if you can identify triggers, changes in their behaviors, or clues that they are having physical symptoms. If you are able to

**"ANXIETY, IF IT PERSISTS, CAN INTERFERE WITH YOUR CHILD'S DAILY LIFE. HOWEVER, WHATEVER BEHAVIORS THEY ARE EXHIBITING ARE NOT BAD OR NAUGHTY."**

notice any of these behaviors before they have an anxiety attack, you can encourage them to attempt self-soothing techniques like counting, taking deep breaths, meditation, or visualization. Try techniques informed by your awareness of your child's abilities.

If you are not able to prevent the behaviors using observation, you can try to be proactive and help them avoid triggers, use social stories to prepare them, create visual activity boards so they are aware of what is happening next. You can also create an anxiety toolbox, including things like a security item, fidget toys, eye masks, weighted lap blankets, headphones, or other items that can

help support their need to reduce the potentially negative external stimuli. You can also assist your child by rewarding good choices, so they have models for appropriate behaviors. You can work to anchor positive thoughts and experiences to the location that is causing them the anxiety.

If you are unable to help with any of the above strategies, consider physically removing your child from the area that seems to be causing the anxiety. Give them a quiet place to decompress or a safe place to reset or rest.

### THE POSITIVE INTENTION OF ANXIETY: RECAP

It was hard to see our daughter's anxious behavior as a positive intention when we were trying to calm her down. However, we found that we often needed to use the same techniques for ourselves before we attempted any interventions. While our daughter didn't have an additional diagnosis, we often had to consider whether our child with an autism diagnosis was dealing with a typical social avoidance behavior common with her diagnosis or if it was an escalating social anxiety disorder. Either way, if we

took the time to calm ourselves with a few deep breaths, then observed the behavior of our daughters to see if we could pinpoint what the behavior was trying to communicate to us, we were better able to use trial and error to help support our girls.

Our oldest daughter still has struggles with some obsessive behaviors, some phobias of things like bugs, and some generalized anxiety. However, we are content to say that for the most part she is using her own natural supports to keep her anxiety under control. Our daughter with the autism diagnosis still struggles with things that seem to be typical for both autism and for anxiety. We provide her more natural supports, like time to take a break and lowering the lights, than our oldest daughter. It has been a five-year journey with the two of them, but they are both coming along well.

**A**nxiety, if it persists, can interfere with your child's daily life. However, whatever behaviors they are exhibiting are not bad or naughty; that is a judgement of a physiological response. Physiological responses are neither good or bad, they just are. As with all behaviors, they are the body's way of communicating a message that there is something wrong and it requires our help and assistance to address. Anxiety is essentially the body's flight and fight response kicked into overdrive and it is trying to help your child feel better. Our job as parents is to see the signs that our children might miss and try to help them uncover the solution to the body's problem.

Whether or not a child has a special need can complicate or make observing behaviors and identifying their source more challenging at times. Yet, if we are observant and look for



**THE PARENT'S PART:** Anxiety is essentially the body's flight and fight response, and it is trying to help your child feel better. Our job as parents is to see the signs that our children might miss and try to help them uncover the solution to the body's problem.

changes in behavior patterns, repeated triggers to behaviors, physical signs or symptoms, or increases in seemingly excessive behaviors it can be a sign that our child needs more natural supports. Effective supports might differ based on your child's abilities. For example, you might not use counting to ten with a child that is non-verbal or is unable to count. As with many behavioral interventions, assisting with anxiety is often a result of trial and error.

One final thought. Anxiety is a serious disorder. If you feel you need assistance in identifying if your child has anxiety, always seek appropriate medical attention. If you feel you are not able to provide

the natural supports needed, always seek appropriate medical attention. While this article offers some natural support solutions, there are pharmacologic solutions as well as other holistic options. Whatever method you take to assist your child, just know there is often trial and error in the process of finding support. •

#### **ABOUT THE AUTHOR:**

Jackie Schwabe is CEO of Mindlight, LLC. She is a Certified Caregiving Consultant and Certified Caregiving Educator. She received her BA in Management Computer Systems from the University of Wisconsin -Whitewater and her MBA in Technology Project Management from the University of Phoenix. She has been active in the area of healthcare integration, healthcare IT, telemedicine, product development, and product management for over 20 years. She has been a cross-sector, cross-discipline leadership practitioner her entire career. Jackie wakes up motivated to help others. Her mission, to provide the tools, opportunities, and connections people need to be their best self. A mother of four children — one with autism — she often says different is not less and communication happens in more ways than verbally. She co-founded MindLight, LLC as a way to technologically help caregivers.

**“ANXIETY IS A SERIOUS DISORDER. IF YOU ARE NOT ABLE TO PROVIDE NEEDED SUPPORT, SEEK MEDICAL ATTENTION.”**

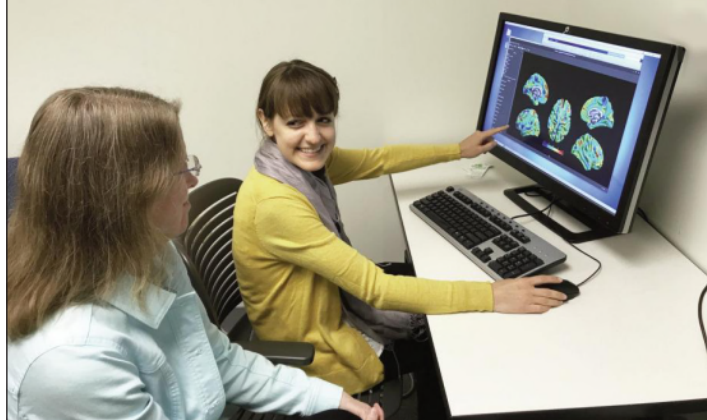


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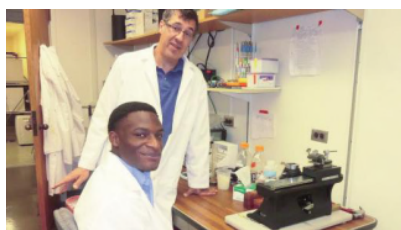
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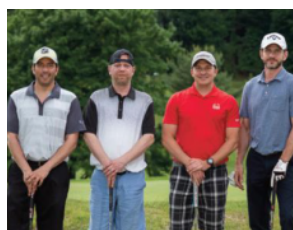
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NAMI (The National Alliance on Mental Illness), the nation's largest grassroots mental health organization, has developed a program called **Ending the Silence**. The goal is to raise awareness and change perceptions about mental health and to start that conversation with middle school and high school students.

# MINDING YOUTH MENTAL HEALTH



BY JANET HAAG

*Every good parent wants their child – their children – to be healthy and happy. We go to great lengths to find the right pediatricians, to make sure our kids' immunizations are up to date, that we get them the right care when they are sick, and sometimes we forget that what is going on in their minds is as important to their health as what goes on in their bodies. Mental health and physical health go hand in hand.*

Let's start by looking at a few statistics, according to the Substance Abuse and Mental Health Administration (SAMSHA), 1 in 5 Americans has a diagnosable mental health condition. 50% of these conditions show up by age 14; 75% by age 24, so it should come as no surprise that 1 in 5 youth ages 13-18 lives with significant mental health challenges, depression and anxiety topping this list. The

statistic, however, that should be of greatest concern to us is that less than 20% get the help they need.

Often, the reason why treatment is not adequately pursued can be attributed to the shame, blame, silence, and misunderstanding that surrounds mental health challenges. This is particularly problematic because early intervention is critical—the earlier treatment is received, the better the outcome. In the absence of treatment, we see more acute and prolonged illnesses, increased substance abuse, higher school dropout rates, greater involvement in the criminal justice system, and higher rates of suicide.

It is normal for children and teens to experience various types of emotional distress as they grow and develop, and the truth is that it can be hard to know when certain behaviors are cause for concern and when they are simply part of normal phases of development. However, when the emotions are **extreme** and/or the distress is **persistent**, significantly interfering with daily activities – these **CAN BE** signs children are struggling with their mental health. Not all of these struggles will lead to a diagnosable mental health condition, but we need to pay attention, talk to our kids about how they are feeling and what they are thinking, and provide the support and assistance they need. Creating “space” for children and teens to express their feelings and concerns helps



**HEALTHCARE PATIENCE:** Mental health treatment is a process, so it takes time, and trial and error are to be expected. Patience is essential. We might see ten steps forward and nine steps backward, but even small improvements suggest progress.

them develop emotional intelligence and strengthen their mental health.

Mental health challenges are not anyone's fault. Abnormalities or injury to the brain, as well as chemical imbalances can be the root cause. Genes, passed from one generation to the next, and family history can interact with other factors and increase susceptibility to specific mental health conditions. In addition, poverty, social isolation, abuse and loss influence one's ability to cope. Often, we underestimate the effect that upsetting social/cultural/historical experiences can have on kids. Some prime examples are 9/11, war, or gun violence. The latter is an issue that we are grappling with in our schools in a BIG way right now.

Because no two people experience an event or situation in exactly the same way, what is traumatic for one child may not be for another. Trauma is, in fact, more common than we might think and often misunderstood. It can happen like a "bolt out of the blue," triggered by an unexpected death

in the family, a sudden injury—or it can develop over time through intense pressure precipitated by living in a crime-ridden neighborhood, ongoing neglect or abuse, or encountering a series of losses. The common denominator in any traumatic experience is the feeling of utter helplessness that it generates. When any of us are triggered, we experience a rush of adrenaline that can set off a chain reaction of emotions and behaviors that may seem out of proportion to the situation.

Trauma can be at the root of certain mental health struggles and If we suspect a child has been traumatized, the first thing we want to do is to let him/her know he/she is not to blame, either for the trauma, or his/her response to it. If childhood trauma goes untreated, it can carry over to adulthood and set the stage for further trauma.

It is important for us to remember that children need time to work through their emotions – some children may want to talk, others may not talk but might express themselves in other ways such as drawing or engaging in physical activity. No matter what, children need a calming presence.

Sometimes, the best we can do is to be that presence and wait until later to figure out what actually happened. Sometimes, asking children how they think a sibling or friend is handling a particular situation can help to relieve the pressure they are feeling and encourage them to open up. Most of all, we need to reassure them that we can work through problems and issues. There are solutions and alternatives and ultimately, we'll work things out. We will be OK.

Talking with a child's pediatrician can be a start on the path to seeking mental health treatment but we have to remember he/she is not a mental health specialist. Putting together the right team of mental health professionals will not be quick or easy. The most effective treatment usually involves a team, and a combination of treatment

modalities. This may include finding the right medication or combination of medications, therapy, and home and school behavioral plans. The goal is to put together a plan that works well for everyone. Children, parents, school personnel, and mental health professionals should all be active participants in setting treatment goals.

Medication is not magic. There are many different kinds and dosages and it can be challenging "to get it right." Prior to taking medication to treat a mental health condition, there should be an evaluation that includes a description of presenting concerns and symptoms, health history, information about the child's development, education, social interactions and possibly laboratory studies (like blood tests, x-rays etc.) Because medication is involved –medical

training and expertise is needed –hence the need for a psychiatrist or advanced practice nurse and ongoing medication monitoring. Lots of people are confused by a psychiatrist's role in treatment because they are not always as involved in therapy as people expect them to be. However, it is actually a therapist's primary job to build rapport with a child

**"It is normal for children and teens to experience various types of emotional distress as they grow and develop. However, when the emotions are extreme and/or the distress is persistent, significantly interfering with daily activities – these CAN BE signs children are struggling with their mental health."**

and help them find healthy ways to cope. We have to remember that if, over time, a particular mode of treatment isn't working, or a particular therapist isn't connecting with our child, it is perfectly OK to make a change. We also need to work closely with the school. Teachers spend a lot of time with our children. We want to partner with them and take advantage of whatever school services are available.

**M**ental health treatment is a process, so it takes time, and trial and error are to be expected. Patience is essential. We might see ten steps forward and nine steps backward, but even small improvements suggest progress. As parents/caregivers, we should not underes-

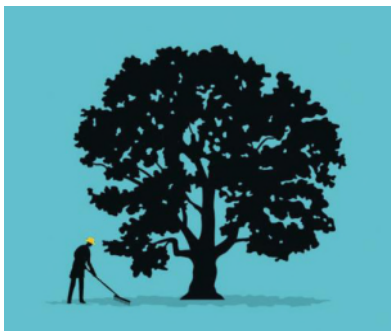
timate the importance of finding other people who can understand what we are going through, with whom we can share our frustrations and hopes. There is something to be said for collective wisdom. We also need to take care of ourselves by eating healthy, getting enough sleep, exercising, and managing our own stress. Effectively modeling self-care tells our children what they should be doing, louder than our words ever can.

Finally, what can we do about stigma to promote earlier intervention and treatment? Often, people, including kids, look at those with mental health challenges and that's all they see. They label them and treat them unfairly as a result. If we are going to change this for the better, we have to change people's minds and hearts. We have to start with a conversation.

We have to recognize that mental health challenges are no different than any other challenge. We have to see people for who they are – with all their strengths and hopes and dreams, as well as their challenges.

NAMI (The National Alliance on Mental Illness), the nation's largest grassroots mental health organization, has developed a program called **Ending the Silence**. The goal is to raise awareness and change perceptions about mental health and to start that conversation with middle school and high school students. NAMI Mercer, a robust local affiliate of NAMI ([www.namimercer.org](http://www.namimercer.org)) is offering this program throughout the greater Mercer County area. **Ending the Silence**, presentations include a lead presenter who provides gen-

eral information about mental health, a young adult who shares their journey of recovery, and an opportunity for interaction. There are three tracks – one for School Staff, one for Families and one for Students. Those who have experienced the program have said it made a real difference. **Ending the Silence**, can be booked by contacting NAMI Mercer.



**WAYS OF SEEING:** We have to see people for who they are as well as their challenges.

For parents/caregivers who are interested in connecting with others who share their experiences and concerns around their kids' mental health, check out the **Parent Support Network of Central New Jersey**, a collaborative venture between The Youth Mental Health Project ([www.ymhproject.org](http://www.ymhproject.org)) and NAMI Mercer. This is a group for caregivers of children under the age of 24 to help each other find better resources, and better understand and advocate for their children's mental health.

If we ever get over the stigma associated with mental health conditions—we might start to talk more freely about what works and doesn't work, where we can find help, and how much hope we can have for a happy, healthy future for all our kids! •

*Acknowledgements: Special thanks to NAMI ([www.nami.org](http://www.nami.org)) and to the Youth Mental Health Project ([www.ymhproject.org](http://www.ymhproject.org)) for providing substantive content for this article.*

#### ABOUT THE AUTHOR:

Janet Haag is Executive Director, NAMI (The National Alliance on Mental Illness) Mercer.

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# DEVELOPING APPROPRIATE IEPs FOR STUDENTS WITH ANXIETY OR DEPRESSION



LAUREN AGORATUS, M.A.

*According to the National Alliance on Mental Illness, 1 in 5 students have a mental health condition. The most common is anxiety, followed by depression.<sup>1</sup> Students with disabilities, including students with mental health disabilities, must have an appropriate Individualized Education Program (IEP) in order to be supported and successful in school. Some students may be eligible for a 504 plan instead of an IEP. Both can help support students with special mental health needs.*

## ANXIETY

In addition to anxiety, other considerations must be given to school refusal which could be anxiety related to trauma at school, or bullying. Parents should make sure that all incidents are reported to the teacher and principal, and that effective bullying prevention and resolution techniques are used to investigate the cause and intervene, including appropriately dealing with the bully(ies). Other families may find that a child with intellectual/developmental disabilities has severe separation anxiety. This can be addressed by allowing the child/parent to visit the school before the child will attend. Also, the parent could gradually increase the time away from the child. Sometimes this is best accomplished using a behaviorist.

School accommodations for anxiety can range from calming techniques, teaching strategies, class environment, and testing situations. For calming, students may try relaxation techniques, classroom breaks, or even calling a parent, but only if the parent agrees this helps. Teaching/ environmental strategies could include giving advance notice before transitioning to a new activity, giving extra time, or letting the student know about changes, such as substitute teachers. For testing, again providing extra time or a quiet area, and letting the student know about upcoming exams, helps ease anxiety. (See Resources section).

According to Kids Health,<sup>2</sup> teachers can help students with anxiety by:

- finding out which techniques work at home

- giving students extra time
- letting students know what to expect
- providing structure in the school day
- modifying assignments and reducing workloads when necessary
- giving the students breaks when needed possibly modifying the school day or shortening classes

## DEPRESSION

Many of the same techniques can be used for children with depression. It is vital to employ positive reinforcement and avoid any negative approaches such as punishment, or shame and blame. Children with depression may already experience low self-esteem. Positive strategies could include:

- allowing more time
- breaking down assignments into smaller tasks
- offering extra help such as tutoring
- offering counseling at school

## BASIC PROTECTIONS FOR STUDENTS WITH MENTAL HEALTH CHALLENGES

IEPs can include emotional supports, such as goals/objectives in the social/emotional section of the IEP. Counseling or social skills can be related services on an IEP. Or a 504 Plan could have accommodations such as coming into the classroom after the class has settled down to reduce anxiety due to noise or using seating preferences.

Besides goals/objectives and appropriate supports and services, other safeguards include functional behavioral assessments, positive behavioral interventions and supports, behavioral intervention plans, and manifestation determinations. A Functional Behavioral Assessment (FBA) determines the function of the behavior; for example, is the student seeking attention, resorting to escape/avoidance of demands, etc. Positive Behavioral Interventions and Supports (PBIS) are then put into place (see [www.pbis.org](http://www.pbis.org)). This means that the IEP now includes a Behavioral Intervention Plan (BIP). A manifestation determination decides if the behavior is the result of the child's disability prior to deciding on a change in placement. Children with special needs have the right to a free, appropriate public education (FAPE) in the



## COLLABORATIVE PROBLEM SOLVING : A PHILOSOPHY

- ❑ "If kids could do well they would do well." If the kid had the skills to exhibit adaptive behavior, he wouldn't be exhibiting challenging behavior.
- ❑ "Behind every challenge behavior is an unsolved problem and a lagging skill."

least restrictive environment (LRE). This means that the student has the right to attend the school s/he would have attended if s/he didn't have a disability.

Children with challenging behaviors are often disproportionately segregated from their peers. They are often disciplined differently as well, sometimes not getting early intervening services for as long, or as much as, other children. Included in discipline may be the inappropriate use of restraints or seclusion, often resulting in injury or even death. The NAMI National Restraints Committee noted that restraints are ineffective at behavioral management and experienced as trauma by students subjected to them. NAMI addresses restraints in schools in their policy platform "Services and Supports for Children, Adolescents, Young Adults and Families".<sup>3</sup>

It is beyond the scope of this article to document the entire IEP or 504 processes. For a good overview, see "Putting a Plan in Place

to Help Your Child Succeed in School" in Resources. If families need help in developing an appropriate IEP or 504 Plan for their child with mental illness, they can contact their Parent Training and Information (PTI) Center to explain the process. PTIs can also help parents with discipline issues, including eliminating restraints which should never be included in IEPs. The Center for Parent Information and Resources also has a resource collection on Positive Behavior Supports and on Mental Health Resources (*see Resources, below*).

Students with anxiety or depression make up the majority of mental health conditions to be addressed at school. However, IEPs are individualized and students with other mental health conditions can also benefit from these accommodations as well as appropriate supports and services under an IEP or 504 Plan. •

### ABOUT THE AUTHOR:

Lauren Agoratus, M.A. is the parent of a child with multiple disabilities who serves as the Coordinator for Family Voices-NJ and as the central/southern coordinator in her state's Family-to-Family Health Information Center, both housed at SPAN, found at [www.spanadvocacy.org](http://www.spanadvocacy.org)

### References

1. <https://www.nami.org/Blogs/NAMI-Blog/May-2018/Ensuring-Your-Child-is-Supported-at-School>
2. <https://kidshealth.org/en/parents/anxiety-factsheet.html>
3. <https://www.nami.org/About-NAMI/Policy-Platform/4-Services-and-Supports-for-Children-Adolescents>

## RIISING ABOVE : RESOURCES FOR STUDENTS WITH ANXIETY OR DEPRESSION



### NATIONAL ALLIANCE ON MENTAL ILLNESS

Ending the Silence - for Families, Professionals, & Students

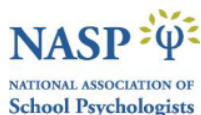
[www.nami.org/Find-Support/NAMI-Programs/NAMI-Ending-the-Silence](http://www.nami.org/Find-Support/NAMI-Programs/NAMI-Ending-the-Silence)

Putting a Plan in Place to Help Your Child Succeed at School  
(IEP Basics)

[www.nami.org/blogs/nami-blog/september-2015/putting-a-plan-in-place-to-help-your-child-succeed](http://www.nami.org/blogs/nami-blog/september-2015/putting-a-plan-in-place-to-help-your-child-succeed)

Services/Supports for Students

[www.nami.org/About-NAMI/Policy-Platform/4-Services-and-Supports-for-Children-Adolescents](http://www.nami.org/About-NAMI/Policy-Platform/4-Services-and-Supports-for-Children-Adolescents)



### NATIONAL ASSOCIATION OF SCHOOL PSYCHOLOGISTS

"Depression: Supporting Students at School"

[www.nasponline.org/Documents/Resources%20and%20Publications/Handouts/Families%20and%20Educators/Depression\\_Supporting\\_Students\\_at\\_School.pdf](http://www.nasponline.org/Documents/Resources%20and%20Publications/Handouts/Families%20and%20Educators/Depression_Supporting_Students_at_School.pdf)



### HOW THE ALSUP (ASSESSMENT OF LAGGING SKILLS AND UNSOLVED PROBLEMS) WRITES YOUR IEP FOR YOU

Dr. Ross Greene of Collaborative and Proactive Solutions  
(CPS) podcast

[www.blogtalkradio.com/drrossgreene/2017/10/10/the-alsup-writes-your-iep-for-you](http://www.blogtalkradio.com/drrossgreene/2017/10/10/the-alsup-writes-your-iep-for-you)



### PARENT TRAINING AND INFORMATION CENTERS

[www.parentcenterhub.org/find-your-center](http://www.parentcenterhub.org/find-your-center)

Positive Behavior Supports Resource Collection

[www.parentcenterhub.org/pbs-resources](http://www.parentcenterhub.org/pbs-resources)

Mental Health Resources

[www.pathlms.com/naccho/courses/5037](http://www.pathlms.com/naccho/courses/5037)



### POSITIVE BEHAVIORAL INTERVENTIONS AND SUPPORTS

"Unfair Access to Healthcare Affects Our Families" blog

[www.pbis.org](http://www.pbis.org)



### UNDERSTOOD.ORG

"Can an IEP or 504 Plan Include Something About Getting Emotional Support at School?"

[www.understood.org/en/school-learning/special-services/ieps/can-an-iep-or-504-plan-include-something-about-getting-emotional-support-at-school](http://www.understood.org/en/school-learning/special-services/ieps/can-an-iep-or-504-plan-include-something-about-getting-emotional-support-at-school)

"At a Glance: Classroom Accommodations for Anxiety"

[www.understood.org/en/school-learning/partnering-with-childrens-school/instructional-strategies/at-a-glance-classroom-accommodations-for-anxiety](http://www.understood.org/en/school-learning/partnering-with-childrens-school/instructional-strategies/at-a-glance-classroom-accommodations-for-anxiety)

# LET'S TALK ABOUT DEPRESSION AND ENERGY MANAGEMENT



BY CLARISSA G. HOOVER, MPH

*If you're seriously bummed out over some bad news or some hard times, you may find that it is lack of energy, not lack of time, that keeps you from getting things done. If you're having trouble doing everything you need to do for your family (no matter how bad you want to), staring at a stack of dirty dishes thinking carryout sounds good tonight (too often), or struggling to build up your nerve to go to work in the morning (yes, I've been there), maybe you need to start thinking about **energy management** instead of time management.*

When I was laid off a month after my daughter's third hospitalization, it hit me much harder than previous lay-offs that I'd gone through. (Yes, I consulted a lawyer – it didn't help me, but I'd like to think that we did enough to help others down the line.) We were less than a year out from my daughter's diagnosis with cystic fibrosis, and I wasn't exactly Miss Congeniality before the lay-off. However, the lay-off sparked a turn for the worse. Since I wasn't working, I had nothing but time, but I just didn't have the energy to put my life and my career back together again.

Around this time, I ran across one of the teaching tales that makes the rounds of the disability community: the Spoon Theory. A woman with lupus explains her life to a friend by handing her a fistful of spoons and translating the energy cost of each activity into its cost in spoons. Her friend starts the day with 12 spoons, and is staggered to learn that getting dressed will cost her two spoons – one to get dressed, and one to get ready to get dressed, which she hadn't even thought of as a task. I don't have lupus, so I was really surprised by how much this story resonated for me. When I thought about it, I realized there was one main difference between me and the Spoon Theory. I didn't start every day with 12 spoons – I could have a lot more (or less!) depending on the choices that I made. I didn't call it this at first, but I guess that I've been working on my own theory of energy management ever since that day.

My first rule of energy management is to invest energy to produce or save energy. My second rule is to treat myself as kindly as I would treat someone else I saw in a situation like mine. Everything else springs from these two rules and, really, the sec-

ond rule springs from the first – because it wastes a LOT of energy to be unkind to myself.

Let's pause a moment to be clear about this – what I'm talking about here is a prescription for depression and anxiety. I haven't used those words yet because I didn't think of myself that way at that time in my life. Didn't think of myself that way when I started therapy. Didn't think of myself that way (don't ask me how I got away with it) when I was on anti-depressant medication for six months. I didn't really start to think of myself that way until

I started to get better. These days, when I'm feeling pretty good most of the time and depression or anxiety are occasional interludes, it's pretty obvious what they are. Because I know what I'm like when I'm feeling good, and anything that changes me that much deserves a name, a diagnosis, and (very important!) a wealth of resources available on the internet when I type the right keywords into my favorite search engine.



Is energy like a pie, that's gone once it's cut and served? Or is it like a plant, that grows if it's cared for? (Don't throw any Laws of Thermodynamics at me here – they apply, but they aren't as helpful a way of thinking about life force, the energy that drives the human body.) Many people with disabilities, including the woman who authored the Spoon Theory, face tough limitations on the amount of physical energy they have to get through the day – every activity must be chosen with care, every priority carefully weighed. Even so, I believe that energy is more like the plant than the pie.

*Below are some of my suggestions for how to grow your energy by investing limited energy in ways that produce or save energy down the line.*

## FUEL THE BODY

Like all energy, your body's energy starts with fuel, mainly oxygen and food. This is especially important if you (like my daughter) can't take breathing or digestion for granted – but really, should any of us be taking them for granted? You can't grow your energy if you don't have it to begin with, so breathing well and eating well are top priorities for energy management. Exercise is also important, to keep your heart and lungs in good shape to supply you with energy, and your muscles in good shape to use it.

## SLEEP

Depression and anxiety can wreak merry havoc with sleep patterns – sleeping all the time when you're not tired; can't sleep no matter how tired you are; sleeping all day and can't sleep at night. So, without being too glib about the size of the challenge, I have to mention the importance of getting a good amount of sleep (probably around eight hours) every night. It seems kind of silly, but it was actually my phone that finally got through to me on this, when it prompted me to set a bedtime based on when I was getting up in the morning. I haven't

got this one completely nailed down yet, but I've gotten close enough that I know it's going to be good for me, and I'll keep after it until I get there.

## LINE 'EM UP AND KNOCK 'EM DOWN

Did you see how I did that, just then? *I'm not there yet, but I'll get there.* This is part of "line 'em up and knock 'em down," which has been one of my favorite mottos since shortly after my daughter's diagnosis. It's gotten me farther than I ever imagined back when the next big challenge was eating off of real plates instead of paper. The point of this is to keep focused on one challenge at a time, rather than looking at everything that needs to change and getting overwhelmed into a state of emotional paralysis. It would fit in nicely with my overall message if I claimed that I always focus first on the things that would increase my energy reserves most, but that's just not true. It almost doesn't matter how I decide what to focus on as long as I *have* a focus. As long as I am making progress, it helps my energy levels and helps me feel better about myself and about my situation.

## EXERCISE, AGAIN

Exercise is so effective against anxiety and depression that it is worth a double mention here. I was once privileged to interview a number of breast cancer survivors who had been cancer-free for up to ten years, and I learned a lot from what they told me when I asked about exercise: "I dance"; "I walk with my mom"; "I work in the yard every day." These women did not limit themselves to jogging and gym memberships – they understood that the essential feature of exercise is movement, and celebrated opportunities to blend exercise with other things that they enjoyed.

## DO SOMETHING THAT SEEMS OUT OF REACH

Sometimes the things that we think are impossible or not worth the effort turn out to be the best, most worthwhile things that we can do. This can include day-to-day things like taking the kids to the playground, or more adventurous activities, like going to an amusement park. Maybe it can't happen often, maybe it takes extra preparation or extra time, maybe you'll need special equipment – whatever it takes, it may be worth the energy tradeoff, because nothing recharges those energy stores like VICTORY.

**POWERED UP:** Exercise keeps your heart and lungs in good shape to supply you with energy and your muscles in good shape to use it. Don't limit yourself to jogging and gym memberships – the essential feature of exercise is movement. Celebrate opportunities to blend exercise with other things that you enjoy.

## IS ANGER GETTING THE JOB DONE, OR IS IT DRIVING YOU INTO THE GROUND?

It isn't recognized in depression stereotypes, but depression often takes the form of anger rather than malaise. This kind of anger tends to find targets that have nothing to do with where the anger is really coming from, and it is a huge energy drain for you and other people around you. If you're struggling with anger that seems out of proportion to whatever the immediate triggers are, try to let go of it rather than letting it drive you. As with malaise-type depression, you may find some relief from some of the other suggestions on this list, particularly the quiet powerhouse in the anchor position, "Get Grounded."

## IS REST RESTORING YOUR ENERGY RESERVES, OR DRAINING THEM?

This is an issue with depression and anxiety that can be tricky, particularly if it's combined with physical problems that limit energy reserves and truly require increased rest. You feel exhausted, so you watch TV, mess around on the computer, or take a nap... and when you get up, you feel worse than ever. So, if rest doesn't help you when you're tired, what will? The answer is, anything else on this list, anything else you can think of, text a friend, exercise (did I mention exercise?), but first and foremost, recognize that if rest isn't helping you, rest isn't what you need – or in any case, it isn't all that you need.

## GET HELP REFRAMING YOUR PROBLEMS

This is the point where a lot of people would talk about the importance of a good therapist, but since I know that isn't an option for everyone, I want to back up a step and talk about what that means. A good therapist (or friend, or cleric, or whatever) isn't going to solve your problems for you, and they aren't (God forbid) going to create new ones out of thin air. What they will do is help you reframe problems so that they are easier to solve

(which is where the energy savings come in). "What would happen if you had that conversation?" "What was it about that that you liked?" "What do you want to see happen next with this?" Everyone gets stuck sometimes, but when you're depressed or anxious, being stuck may cost more energy than you can afford. It can be a huge help to have someone else pointing out things that you're making harder than they have to be.

## GET GROUNDED

Getting grounded is about getting more connected with yourself. Journaling, making art, making music, meditating, and (surprise, surprise) exercise are all strategies that can help you get grounded. It's surprisingly common, even encouraged in our society, to spend large amounts of energy trying to escape ourselves. It's a little challenging to explain the energy savings from getting grounded until you've experienced them yourself, but they can be profound. Whether you're trying to block out past trauma or current pain, or simply never really had a strong sense of yourself in the first place, grounding activities help you create a safe space to come to terms with things that you've been trying to avoid.

I don't know how well the energy management strategies that worked for me will work for you, but I hope that they at least give you some ideas. I also hope that this is a chance to think about the value of activities that invest your energy to end up with more energy, and the value of investing in yourself. •

### ABOUT THE AUTHOR:

Clarissa G. Hoover, MPH, started advocating for patients, families, and quality healthcare shortly after her daughter's diagnosis with cystic fibrosis in 2005. She is currently a project director for Family Voices ([www.familyvoices.org](http://www.familyvoices.org)), a national, nonprofit, family-led organization promoting quality health care for all children and youth, particularly those with special health care needs.



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# *In Praise of* **Autism Surfing** *Organizations*

BY MICHAEL JOHN CARLEY

*There's a folktale somewhere about a wave that became increasingly upset as it came closer to shore because it didn't want to die. The wave behind it reassured it that yes, it would die, but that it would then go back into the greater ocean and somehow create more continuous waves. It's an allegory that resonates no differently than similar lessons told to us by major religions that guarantee afterlife; and therein, it's not a very unique story. Yet unlike the fables within sacred texts, and barring the implied consciousness within a moving curl, the story of the dying wave is rooted in secular knowledge.*



*Call it neo-paganism, tree-hugging, or whatever you wish, but the comparison of natural forces as a substitute for written doctrine has been weighed by spectrumites and neurotypicals alike long before the Polynesians carved the first surf boards from sacred trees. It's a lovely, natural exercise. And this particular tale of the dying wave alludes heavily towards a belonging to life itself, rather than to limited, individual lives.*

It's also a theoretical contest about an earth – not a heaven – that attracts our curiosity. For it's the oceans of this planet – not the terrain – that we still underestimate, even if by comparison we own less than half the globe's mass. Nothing in nature is a partisan world that screams for us, or our communities to “be” one way or another. Instead, all nature seeks balance – a word not to be confused with “moderation” (the latter concept having revealed itself as a more and more contrarian, if not cowardly, fallback). But while our forests and mountains give awe, they do not move, or intimidate our imagination as does the sea. This mammoth force, whose underwater pressure, if harnessed, could fuel cities (if not continents), is still one we fear admiring, if not also embracing. With so much of it still unexplored it is arguably our last frontier. Like love, the ocean is unstable, not stable, and dangerous. We who subscribe to no religious influence whatsoever can take comfort in our capacity, however unrealized, to employ the ocean's potential as a healing strategy. And in spectrumfolk run parallels herein such as the accumulated traumas that are often there, within us, deep, in ways in which no one understands. We have fears that are visible, and some that are not. It's hard on our side, as spectrumfolk, to even see this; and it's an even harder concept for the neurotypical world to swallow. A bridge is needed.

Cue the Ocean Heroes.

For many people on the spectrum, the enthusiasm of these autism surf people might initially feel threatening. At the starting gate, spectrumites, both non- and über-verbal, may find it impossible to rely on these sun-bleached salespeople, mouths curved upwards. For too often in our pasts, unconscious purveyors of snake oil remedies have asked for our trust, only to betray it through well-intentioned ignorance. These resentfully-named “beautiful people” may have invalidated the seriousness of what someone went through, causing that person, as time wore on, to shut off, and trigger more distrust whenever a new opportunity arose (to gain trust). Numerous times throughout our lives we may have faced such literal or figurative cheerleaders; those self-

**GOOD VIBRATIONS:** The author (*third from left*) with Ocean Heroes volunteers Stephanie Hudson, Sam Moyle and Luke Hallam; “These wonderful people are not “beautiful” by birthright. They have trusted/allowed the sea to change them, and so it is the sea that has made them that way.”

anointed instructors who do not believe that we should be allowed to refuse their happy medicine, or who would wish to deny us the right... to not smile back. We sense superficiality. Somewhere, we also know that real depression, real anxiety, real anger, or real trauma can't be remedied by a makeover.

But the surfers are different. They just are. They, and the product/remedy/medicine they sell, are true, and brave, and powerful, and good. Our skepticism is thankfully no match for a persuasiveness so rooted in truth.

Recently in Perth to keynote the wonderful [Autism West's wonderful 10th anniversary conference](#), I was given an offer I couldn't refuse. Western Australia's version of [Surfer's Healing](#) (CA), [Surfer's Way](#) (NY), and [Surfers for Autism](#) (FL) is called “[Ocean's Heroes](#).” They work closely with Autism West and they invited me out for a day. They knew from my writing both that I love surfing, and that I not-so-paradoxically stink at it. And with nothing asked in return, Ocean's Heroes were committed to making me better.

Background: I've actually gotten to try surfing in some gorgeous spots: Costa Rica; Todos Santos, Mexico; Morocco (where, in one of my few lifetime successes in standing on the board, I realized [right before wiping out] that I needed to leave GRASP), and Kauai, where I was almost decimated when a current sent me hurtling towards jagged rocks. In Taghazout, I once had private lessons; but despite instruction to the contrary, I still grab inappropriate-sized boards for my skill level, and head for the big waves, hoping to hit the lottery. I once half-joked to my wife that it was nice to know how I was going to meet my maker...



Ocean Heroes is a charity set up by local West Australian surfers that aims to enhance the lives of those living with autism, through active involvement in the sport of surfing. Ocean Heroes combines compassion, skill and professionalism to provide children with a unique opportunity to experience the thrill of catching a wave. Visit [www.oceanheroes.com.au](http://www.oceanheroes.com.au)

you'd gag. The point herein is that these people, in *all* these locales that perform this work, are special, special folks, and that their work is wonderful. The feedback I've always gotten from parents who've attended the seminars of all the orgs who provide this service – either on both coasts or abroad – has never been short of “my kid's addicted,” “my non-verbal son learned how to trust,” “my daughter who has crippling anxiety was liberated.” I have never heard a negative experience with an autism surfing organization.

Look – long story short before I dissolve into poetica, is that *of course* Ocean's Heroes made me better that day. The board they trained me on felt as big as a cruise ship (easy to control), the waves were safe and easy, and they are fantastic teachers. I doubled my life's output in standing successfully, and for the first time reached shore by stepping off the board onto actual sand. But if my being a good student was the point of this article, I'd gag, and

That's not to say complaints aren't out there, but please...can we fund this stuff rather than spend another five million on serotonin levels?

And the stories of kids who arrived at the beach untrusting, yet who quickly fell in love with surfing? Those narratives now seem countless.

Luke Hallam is 28, a Perth native, and by trade, a personal trainer who works with people with disabilities. *"I just started working with this 8-year-old girl on the spectrum when I was younger and had a lot of success with her. Well, her mum was a powerful autism mum here in Perth..."* so Hallam soon had a lot of clients.

He thought about starting a non-profit, and contacted Israel "Izzy" Paskowitz at Surfer's Healing in California, who was

Hallam added, *"And seeing the excitement on your face when you catch that wave."*

There's also cases like the girl we'll call Jane, who as Luke relayed, went through a period where she'd *"been suicidal for weeks. The day after our event she went back to school for the first time in months. She's never missed an event since."*

**R**ight when the concept of autism surfing clinics was introduced over a decade ago, it was a no-brainer in my mind – on only a theoretical level – before the first outing even occurred. The overwhelmingly positive feedback that would come from the first trials were mere confirmation. Why? Because we spectrumfolk love the water. Not only



**DREAM TEAM:** (Left to right) Hallam, Hudson and Moyle. Over the last three years, they have served 700-800 autistic kids via over 30 events. They have even expanded from Perth to include other parts of Western Australia. "Surfing's a really selfish sport. This way we give back," says Moyle.

immensely unselfish with his time and gave Hallam the pointers he needed. Hallam then hooked up with marine biologist, Sam Moyle, also 28 (and a third person, Tom Johnson, whom I did not meet) and soon they were off doing fundraisers like 20 km ocean swims (swim, tread water to vomit, swim, repeat...), paddling 250 km from Hawaiian island to Hawaiian island, as well as getting the Australian lottery to fund their equipment (van, boards, wet-suits). Now joined by Stephanie Hudson, 26, a physical therapist at a local hospital, they participate in whatever events they can: The local RotoSwim, or "Run for a Reason," among others. At it now for three years they have served 700-800 autistic kids via over 30 events. They have even expanded from Perth to include other parts of Western Australia.

After our day, and over coffee, I asked "Why?"

"Surfing's a really selfish sport," said a smiling Moyle. *"This way we give back."*

is it an arena where those of us with motor skills issues can actually feel graceful, but you could write multiple articles on how the bubbles created in the foam provide a sensory joy, how the

force of the waves act like a deep-tissue hug, how the unexpected tugs at our legs create suspenseful surprise; and on a sadder note, that there's a reason why so many significantly-challenged spectrumites are attracted to, but often drown in, swimming pools. The more time we spend in it, the more we seem to trust this "wrong planet."

Back in the summer, I wrote [an article](#) on the subject of autism and travel. In it, I questioned if the sickness permeating modern-day Midwestern Americans was-

n't due in part to not having an ocean nearby. Well, during our post-surf conversation Hudson chimed in that *"If I'm having a (crappy) day, I'll go to the beach – Even if it's just a dunk in the water."* The problems she brings to the coastline don't disappear, she said, but they're mitigated by the greater power. The excess

*"The stories of kids who arrived at the beach untrusting, yet who quickly fell in love with surfing? Those narratives now seem countless."*



**SITTIN' ON TOP OF THE WORLD:** "I've actually gotten to try surfing in some gorgeous spots. Despite instruction to the contrary, I still grab inappropriate-sized boards for my skill level, and head for the big waves, hoping to hit the lottery. I once half-joked to my wife that it was nice to know how I was going to meet my maker."

frustration that blocks our problem-solving skills is gone, to reveal only the core sadness or dilemma, if not also the capacity and confidence to resolve them. That may be true for any great act of nature, but all three of these St. Peter's, these gatekeepers and guardians, agreed that on a bad day they know they need to go to the beach. Forests do this too, but to a lesser degree (they're too small).

These wonderful people all over the world – not just my three heroes – aren't inherently better than you or I, nor are they better than anyone who "gives back" in whatever manner. They too have great diversity in educational opportunities, culture, politics, economics, and mental health – I would even bet that they have just as many relationships end as all of us. But I'd also bet that those aforementioned breakups are implemented with far more emotional health than what we usually muster. That's the ocean's influence on *them*. They are not "beautiful" by birthright. They have trusted/allowed the sea to change them, and so it is the sea that has made them that way.

**T**he faith discovered will always resonate more than the faith inherited. But with surfing, the parallel, as a belief system, has one tricky nuance. When in need, we instinctively look above, yet this massive energy is not above you. It's something you feel underneath you; a near-Wiccan force (not too unlike George Lucas' fiction) that you *have* to respond to whether you believe it to contain that consciousness or not. The scriptures of major religions, while sometimes beautiful, can also reveal bigotry and make demands that con-

trast science, if not knowledge itself. The ocean, however, has made no such mistake.

Later, back on shore and exhausted (you are having too much fun to notice what a fantastic workout surfing is), you may hear the words "It's not worth it" regarding a present torment. Petty insecurities may have just disappeared and yet you don't know where they went. You are therein freed to question once-rigidly-held, absolutist notions.

Take me for example: I'm normally someone who wants the kids he works with as a school consultant to always become grownups who understand what they have, and disclose their autism to others with confidence. Jane, though, through her suicidal tough spot, was able to say "I have autism," and yet it wasn't enough. And so I am hypocritically just fine that she has abandoned that introduction. These days, a happier Jane greets others with the words "*I'm a surfer.*" •

#### ABOUT THE AUTHOR:



Michael John Carley is the Founder of GRASP, a school consultant, and the author of *Asperger's From the Inside-Out* (Penguin/Perigee 2008), *Unemployed on the Autism Spectrum*, (Jessica Kingsley Publishers 2016), the upcoming *Book of Happy, Positive, and Confident Sex for Adults on the Autism Spectrum... and Beyond!*, and the column, "Autism Without Fear," which for four years ran with the Huffington Post but is now ecstatic to be at home with Sinkhole. Dozens of past columns can be found at [www.michaeljohncarley.com/index.php/articles.html](http://www.michaeljohncarley.com/index.php/articles.html).

And for more information on Michael John, or to subscribe to his updates, you can go to [www.michaeljohncarley.com](http://www.michaeljohncarley.com)



BY RENEE DEASE AND STEPHANIE CORKETT

*Tyler Wigington, a Special Olympics athlete from Wisconsin, races around a bend in Coimbra, Portugal. Tyler has been running non-stop for more than an hour and 30 minutes. He is competing with Colton Lohrenz, another Special Olympics athlete from Wisconsin, in the INAS World Half Marathon Championships for individuals with an Intellectual Disability.*

**T** Tyler hopes to break his all-time best record of 1 hour 36 minutes but comes short with a finishing time of 1 hour and 41 minutes. Tyler loves the thrill of long-distance running. “This was a hard race, the temperature was high. We got to run from the city into the country,” said Tyler.

Tyler was introduced to Special Olympics when he was eight years old. He participated in bowling, and then progressed to track and field. From an early age, it was apparent to Don, Tyler’s father, that Tyler had real talent in running. Tyler competed with Special Olympics Wisconsin in athletics, but the state didn’t offer any running events longer than two miles.

Don and the rest of the Wigington family is very proud of Tyler and his accomplishments. Don is the Vice President of Sport for Special Olympics Wisconsin and his wife and children have volunteered as chaperones and coaches throughout Tyler’s career in Special Olympics. “I’m impressed with the friends Tyler has made and the positive social impact which Tyler and the other athletes

encounter with Special Olympics,” explained Don. “With the support from Special Olympics, Tyler has been able to branch off to more competitive races, which is how Tyler now competes in more elite competitions.”

Tyler began running longer and longer races outside of Special Olympics. After he graduated high school, Tyler wanted to do a half marathon. “I wanted to push myself more in longer races,” said Tyler. Don and his wife were nervous before Tyler ran his first half marathon. “It’s a long race, we were worried Tyler would miss a turn and get lost, or not stop for water breaks,” said Don. For Tyler’s first long race, a law enforcement officer rode a bike through the race with him to make sure he stayed on track. As Tyler grew comfortable with this pattern, he was soon ready to run alone. At the International Federation for Athletes with Intellectual Impairments (INAS) U.S. Championship in Long Island, Tyler ran the race alone and achieved his personal best record of 1 hour and 36 minutes.

As Tyler grew in self-confidence and built leadership skills through Special Olympics, he applied to be considered as a Special Olympics Health Messenger. Health Messengers are Special Olympics athletes who have been trained to serve as health and wellness leaders, educators, advocates and role models within their Special Olympics communities, and the community at large. They are critical to ensuring Special Olympics achieves its goal of equitable health for all people with ID. Tyler submitted a video nomination explaining why he’d be a good fit for the position and was accepted for training in 2018. “I was very excited when I heard I had been selected to become a Health Messenger. I wasn’t chosen the year before, so being selected this year was very special,” said Tyler.



**HAVE SNEAKS, WILL TRAVEL:** (Opposite page) Tyler mid-race in Portugal; (above, clockwise from top) with fellow Special Olympics Wisconsin athlete Colton as they prepare for the race in Portugal; at Health Messenger Training in Washington, DC; and with his family visiting the Grand Canyon after one of his races.



Tyler, along with other Special Olympics athletes from around the United States learned about how to motivate themselves and others to live healthier lives, and received important health tips including personal hygiene, nutrition, and others. Tyler will complete a project this year based on his learnings. He will work with his community and a local state program in Wisconsin to promote the Fit 5 exercise booklets that Special Olympics has made to educate athletes about fitness and safely

working out. He will be working with an intern at Special Olympics Wisconsin to set up sessions with Wisconsin athletes. "I'm excited to start this project and teach others about Fit5," said Tyler.


Tyler is already looking forward to his next competitive race. He, along with his family, will travel to Australia in October of 2019. Tyler will compete in a Track & Field competition at the 2019 Global Games with his USA team Athletes without Limits. Tyler is taking the winter season off to be fully

rested before he starts to train again in the spring. "I can't wait for this next race and to have my family there with me to support me," exclaimed Tyler. •

#### ABOUT THE AUTHORS:

Renee Dease is Coordinator, Healthy Athletes, Health Programs at Special Olympics International. Renee has been with Special Olympics for 36 years. Stephanie Corkett is External Health Communications manager with Special Olympics, based in Washington, DC.

# WOMEN VETERANS HEALTH CARE

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FROM OUR FAMILIES... TO YOUR FAMILIES

# MILITARY MAGAZINE

## MILITARY LIFE

54 HOW TO COPE WITH A TRAUMATIC  
EVENT

56 HOW TO DEAL WITH COMBAT  
STRESS

57 HELPING FAMILY MEMBERS WITH  
SPECIAL NEEDS MEET THEIR  
FITNESS GOALS

## PUZZLES & CAMO

58 WORDS OF WISDOM

By Shelly Huhtanen



ARMY  
NAVY  
AIR FORCE  
MARINES



## HOW TO COPE WITH A TRAUMATIC EVENT

*A violent act, catastrophic accident, or sudden loss can leave you feeling anxious and fearful, which are normal reactions. But if anxiety and fears are taking over your or a loved one's life, you may want to consider professional help.*

Military OneSource offers confidential, non-medical counseling - face to face, online, by phone or video - along with the Military Crisis Line at 800-273-TALK (8255), and resources for post-traumatic stress disorder. All are available for free.

Reminders and events can trigger post-traumatic stress disorder, bringing back painful memories and emotions for months or even years after the trauma. Learn about common reactions to trauma, some coping mechanisms and ways to help others, along with resources for more information and help.

### COMMON FEELINGS AND REACTIONS FOLLOWING A TRAUMA

Traumatic events may cause you or someone you love to experience a range of feelings and reactions, such as:

- Sadness
- Fear
- Anxiety
- Anger
- Irritability
- Inability to concentrate
- Disruption of sleep patterns
- Eating problems increase or decrease

Although these feelings and reactions are normal, you can help yourself or your loved one manage and cope with them so they don't become overpowering.

### POSSIBLE COPING MECHANISMS

Coping strategies like these may help you or your loved one recover from anxiety, depression or other post-trauma feelings and reactions that may be impacting your life. Strategies may include the following:

- **Spend time talking and sharing your feelings with people you love.** Doing so can put things in perspective,

which may make your day-to-day life more manageable. It can also help you focus on positive relationships instead of the traumatic event.

- **Take care of yourself.** If you feel well physically, you might manage your feelings and reactions better. Eat healthy foods, exercise moderately, get enough sleep, and take any medications prescribed for you. Avoid using drugs or alcohol to cope – this may lead to you feeling worse over time.
- **Try to stick to your typical, day-to-day routine.** It can be a healthy distraction from feelings after a traumatic event. Going back to your home and work responsibilities can renew a sense of purpose and lessen feelings of isolation.
- **Practice stress-relieving techniques.** Exercise, journaling, meditation, listening to music and deep breathing techniques are just a few activities that can help relieve stress by focusing your mind on something other than the traumatic event. Try these to find what works best for you.
- **Avoid media coverage of the event for a while.** Too many reminders or fixating on the event may heighten your anxiety. If it's unavoidable, try to watch any news coverage with a friend or supporter and discuss the event or your feelings if you feel comfortable.
- **Don't be afraid to seek support from friends, family and professionals.** Many people also find comfort in their religious beliefs and faith communities during difficult times.

### EXTENDING HELP IN TIMES OF CRISIS

If a friend or relative is deeply affected by a trauma, there are ways you can help. People who go through a traumatic event may not get a chance to talk about their feelings and experiences. They might think they don't need to share their feelings, or they think something's wrong with them because they're having trouble coping. Here's how you can help:

- **Reassure him or her the emotions they're feeling are a normal reaction to a traumatic event.** Remind them fear, anger, hopelessness and shock are common feelings others – possibly even you - have had.
- **Share your feelings.** If you experienced a similar event, your insight could be comforting.
- **Invite your co-worker, friend or relative to a ceremony, vigil, religious service or fundraising event.** Taking part in efforts to remember or help the victims of a tragedy and their families can bring comfort and a sense of community. Sometimes just being with other people who experienced trauma can help with emotional isolation.

- **Include him or her in your family events and normal daily routines.** This can help relieve feelings of isolation.

Each person reacts differently to trauma, so be patient when offering help, and expect a range of emotions and reactions. Check in periodically and let him or her know you're available for support throughout the coping process.



**ENLISTING HELP:** No one has to struggle alone; in fact, asking for help is a sign of strength. Friends and family can provide a lot of support, but you may also consider seeking help from a counselor or professional therapist.

### RESOURCES AND SUPPORT

No one has to struggle alone; in fact, asking for help is a sign of strength. Friends and family can provide a lot of support, but you may also consider seeking help from a counselor or professional therapist.

Free, confidential, non-medical counseling is available 24/7 from Military OneSource, whose consultants can refer service members and their families to services in their local community. Non-medical counseling services are also available face to face, online, by phone or video by calling 800-342-9647. OCONUS/International? Visit [www.militaryonesource.mil/international-calling-options](http://www.militaryonesource.mil/international-calling-options) for calling options. Your installation's Family Support Center can also provide confidential, non-medical counseling with Military and Family Life Counselors ([www.militaryonesource.mil/confidential-help/non-medical-counseling/military-and-family-life-counseling](http://www.militaryonesource.mil/confidential-help/non-medical-counseling/military-and-family-life-counseling)). Find out how Children and Youth Behavioral Military and Family Life Counselors ([www.militaryonesource.mil/confidential-help/non-medical-counseling/military-and-family-life-counseling/military-and-family-life-counseling-the-essentials](http://www.militaryonesource.mil/confidential-help/non-medical-counseling/military-and-family-life-counseling/military-and-family-life-counseling-the-essentials)) can help your child cope.

Coping with a traumatic event can be complicated and can take time for you and those you love. You're not alone. Use your available resources to help you manage and cope with your feelings.

– Military One Source

# HOW TO DEAL WITH COMBAT STRESS

**C**ombat stress reactions are natural responses of the body and brain to the extreme stress of combat. Sometimes a threat is so prolonged or intense that it causes a "stress injury." In these cases, the body and brain continue to maintain that state of high alert long after the danger has passed. Combat stress is not a sign of weakness — it affects many exceptionally strong service members and here's how you can learn the signs and manage it in a healthy way.

## RECOGNIZE THE SIGNS AND SYMPTOMS OF COMBAT STRESS

Although there are many signs and causes of combat stress, there are certain key symptoms common in most cases:

- *Problems sleeping*
- *Feeling anxious*
- *Uncharacteristic irritability or angry outbursts*
- *Withdrawal from others*
- *Other changes in behavior, personality or thinking.*

Combat stress sometimes leads to stress injuries, which cause physical changes to the brain that alter the way it processes information and handles stress. Be aware of the following when dealing with a stress injury:

- *Stress injuries can change the way a person functions mentally, emotionally, behaviorally and physically.*
- *The likelihood of having a combat stress injury rises as combat exposure increases.*
- *The earlier you identify the signs of a stress injury, the faster a full recovery can occur.*
- *If left untreated, a stress injury may develop into more chronic and hard-to-treat problems such as post-traumatic stress disorder, or PTSD.*
- *There is no guaranteed way to prevent or protect yourself from a stress injury, but there are things you can do to help yourself and others recover.*



## DEAL WITH COMBAT STRESS FOR A HEALTHY RECOVERY

There is no guaranteed way to protect yourself from a stress injury, but there are things you can do to help yourself and others recover:

- **Return to a routine as soon as possible** with regular meals, sleep and exercise.
- **Maintain your health.** Drink plenty of water, eat nutritious meals, exercise and get enough sleep. Rest and recuperate after stressful events and practice relaxation techniques before, during and after stressful events.
- **Reach out to others with similar experiences.** They are probably having many of the same feelings, so you'll see you

are not alone. Participate in your unit's after-action reviews and work to build trust with your unit.

- **Use your sense of humor.** Sometimes humor can help you look at stressful situations from a different perspective. Laugh often — it is a great stress reliever.
- **Address your spiritual needs.** Some people find strength in some form of prayer or by discussing their concerns with a chaplain.
- **Ask for help in managing problems at home** while you are away. It is hard to keep your head in the game if you're worried about issues back home.

## FIND HELP FOR COMBAT STRESS INJURY

If you or someone you know is suffering from a combat stress injury, it is important to get professional help as soon as possible. The earlier you identify the signs of a stress injury, the faster a full recovery can be. The following resources can help:

- **Combat stress control teams:** Combat stress control teams include mental health professionals who support service members on-site during deployment.
- **Your unit's chaplain:** Military chaplains provide counseling, guidance and referral on many issues affecting deployed or returning service members and their families.
- **Department of Veterans Affairs:** These counselors who are also veterans provide readjustment counseling at no cost to combat veterans and their families, including those still on active duty. About 300 community-based Vet Centers ([www.vetcenter.va.gov](http://www.vetcenter.va.gov)) provide these services.

- **TRICARE:** Therapy services may be available at your nearest military treatment facility or a local network provider. Your primary care manager can refer you to appropriate counseling, or you may contact your regional TRICARE office ([www.tricare.mil](http://www.tricare.mil)).
- **Defense Centers of Excellence for Psychological Health and Traumatic Brain Injury Outreach Center:** This Department of Defense call center is available 24/7 to provide information and local resources to service members with questions or concerns about psychological health issues and traumatic brain injury. Call 866-966-1020.
- **Outside military support channels:** In some cases, service members choose to find help outside military support channels. If you do, be sure you understand the costs before you begin a treatment program.

If you need immediate help or are experiencing a crisis, contact the Military Crisis Line at 1-800-273-8255 and press 1, or visit [www.veteranscrisisline.net/ActiveDuty.aspx](http://www.veteranscrisisline.net/ActiveDuty.aspx)

— Military One Source

# HELPING FAMILY MEMBERS WITH SPECIAL NEEDS MEET THEIR FITNESS GOALS



*Getting in shape, eating better and exercising regularly helps us lower stress, improve self-esteem and our general well-being. Individuals with special needs share these same goals and can achieve their health and fitness goals with the help of an adaptive fitness and nutrition plan.*

Here are some tips to help family members with a disability meet their fitness goals:

- **Meet with a doctor or health care professional** to develop a program that combines safety considerations with realistic goals. Fitness comes in all forms, and a doctor can recommend modifications for physical activities and traditional exercises to make activities more inclusive. Always follow up on a regular basis with any suggestions or concerns or to adjust the program if necessary.
- **Eat a healthy diet.** The U.S. Department of Agriculture ([www.nal.usda.gov/fnic/dietary-guidance-0](http://www.nal.usda.gov/fnic/dietary-guidance-0)) has useful information and motivational messages to keep the whole family on the path to healthy eating. If your family member has special dietary restrictions, coordinate with the doctor or nutritionist to develop a plan. The Food and Drug Administration's "Food Allergies: What You Need to Know" ([www.fda.gov/Food/ResourcesForYou/Consumers/ucm079311.htm](http://www.fda.gov/Food/ResourcesForYou/Consumers/ucm079311.htm)) can help

you identify common food allergies, learn the symptoms of an allergic reaction and understand food labels to avoid potential allergens.

Take advantage of the tools and resources to track progress to achieve fitness goals.

- **SuperTracker** from USDA can combine healthy eating goals and physical activity in one place. List your top five personal goals with feedback from a virtual coach, track food intake and physical activity; receive weight management guidance and more. Create a personalized nutrition and activity plan and keep a record of achievements. [www.supertracker.usda.gov/default.aspx](http://www.supertracker.usda.gov/default.aspx)
- **The Morale, Welfare and Recreation Program** (<http://download.militaryonesource.mil/12038/MOS/Factsheets/FactSheet-InclusiveCustomerService.pdf>) offers inclusive recreation opportunities. In the last few years, there has been a push to further extend services to members of the military community with various disabilities. Check out the MWR fitness, aquatics, sports programs and more. [www.militaryonesource.mil/health-wellness/healthy-living/fitness-nutrition-active-living/fitness-classes-with-morale-welfare-and-recreation](http://www.militaryonesource.mil/health-wellness/healthy-living/fitness-nutrition-active-living/fitness-classes-with-morale-welfare-and-recreation)
- **The Exceptional Family Member Program** offers tips and support available to you on and off military installations. [www.militaryonesource.mil/family-relationships/special-needs/exceptional-family-member/exceptional-family-member-program-the-essentials](http://www.militaryonesource.mil/family-relationships/special-needs/exceptional-family-member/exceptional-family-member-program-the-essentials) •

– Military One Source

# Words of Wisdom

Stop worrying about the future and stop replaying what happened in the past. Listen to the words of Roosevelt, "Do what you can with what you have where you are."

As I reminisced about the last year and identified the hopes I had for the coming year, I thought back on what our family has endured over the years past. I wish I could have gone back into time to tell myself to worry less and take time to enjoy the little things because time has a way of getting away from us if we let it. Still, to this day, my husband and I say that the moment our son was diagnosed with autism was one of the scariest and most life changing times of our lives because it affected every person we cared about. Most of all, our immediate circle of trust and love that included Hayden and Broden.

I told Mark that I wish I could go back during that time that I was alone in the bathroom stall, crying in the medical center about 30 minutes after hearing the diagnosis of autism. I was there in the bathroom stall, thinking that the diagnosis must have been some sort of mistake and that my family was not supposed to be the ones chosen for this life. A life with autism that I still couldn't understand.

If I could go back and have a few minutes I would validate fears of my younger self, but I would remind her that Broden was still the same boy he was before she brought him to the medical center for testing. I would tell her to listen, listen to a voice of one who's been there and walked in her exact shoes. I would say something like this...

"I know you're scared and I know you're mad. I know you need someone to blame. This will pass in due time. You will learn that being scared is a feeling that you'll need to identify and work through, but being mad and trying to find someone to blame will be time wasted. You only have so much energy, so make it worthwhile. You will hear that Broden is a gift and, at first, you will not understand, because you will be overrun by grief and unsure on how to help him. I guarantee you if you open your heart and

see all of Broden as he truly is, you will love harder, work harder, and fight harder for him than you ever thought you could.

You will soon realize that you will not care anymore what people think. You will learn to pause and let your son teach you that happiness and success may not be the same definition of what others see as happi-



struggling to connect with Broden.

Stop worrying about the future and

stop replaying what happened in the past. Listen to the words of Roosevelt, 'Do what you can with what you have where you are.' It will be enough. It will always be enough if you work with your partner, Mark. Give Mark a chance. This is one of many situations to come that is impossible to handle by yourself. I will say this again because I know you're stubborn. You cannot do this yourself. Broden's diagnosis of autism is not your fault. It's not Mark's fault. Once you realize that Mark is on your team, both of you will learn to lean on each other and become a unified front. As a team, you will accomplish more that will benefit your son's quality



**HINDSIGHT:** I wish I could have gone back into time to tell myself to worry less and take time to enjoy the little things because time has a way of getting away from us if we let it.

ness and success. Your son will always surprise you, so don't ever assume what he will or won't do. He hears what you

of life because, in the end, that is what matters.

I challenge you not to fight where the

journey takes you. Where you are is where you're supposed to be. Wherever you are on your journey is an opportunity for you to reflect and learn to grow a little wiser. If you live in the present and appreciate it, this will only benefit you as time passes. You will be scared quite often and will try to find ways to avoid hurt. In order to avoid hurt, you will try to shelter Broden and in turn, this may stifle his growth and independence. Be careful. This will be an ongoing challenge for you, so you need to identify it and modify your plan for him because he deserves to be challenged.

You will learn the meaning of trust as you realize that it will take a village to raise your son. Always be grateful and appreciate those who have been brought into your family's life to help Broden grow and learn. Learn to identify those who are not and minimize the footprint they will have on your journey. Lastly, enjoy your life with your son and see how he enriches your family's lives. You will soon learn that your life is full. Don't avoid experiences to avoid hurt. Sometimes you need to hurt in order to grow. Broden was gifted to your family to

grow you."

My heart swelled as I wrote these words. If only I could share these sentiments with my younger self a little over a decade ago. Looking back, our journey has been a long and winding trail with our share of pot holes and rickety bridges, but as I look back and reminisce, the journey has left me with a beautiful view. •

**"Where you are is where you're supposed to be. Wherever you are on your journey is an opportunity for you to reflect and learn to grow a little wiser. If you live in the present and appreciate it, this will only benefit you as time passes."**

#### PUZZLES & CAMO

Shelly Huhtanen is an Army wife stationed at Fort Benning, GA who has a child with autism. She enjoys sharing her experiences of day-to-day life caring for her son with autism while serving as an Army spouse. She authored *"Giving a Voice to the Silent Many"* that encompasses many stories of raising a child with autism in the military. Shelly is passionate about autism advocacy for our military and works to bring awareness to our local legislators and command about providing better support for our military autism community, such as better health care and education.



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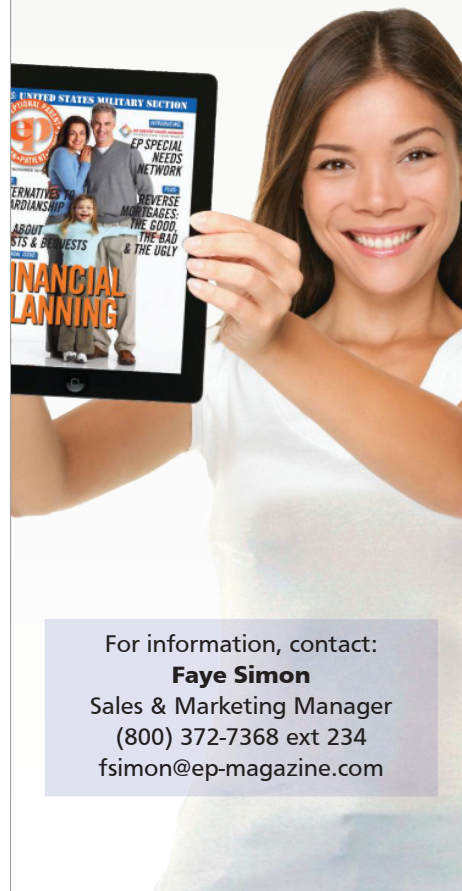
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