PLUS: UNITED STATES MILITARY SECTION

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EXCEPTIONAL PARENT
MAGAZINE
FEBRUARY 2020
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INSIDE THIS ISSUE:

THE ROLE OF NUTRITION & WELLNESS in HEALTHY SCHOOLS

NEUROMUSCULAR DISORDERS:

PRACTICAL FEEDING TIPS

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EP EXPLORES MENTAL HEALTH:

GETTING HELP for A CHILD WITH A DD

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Information and Support for the Special Needs Community

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Note from the Editor-in-chief: EP World, Inc. advocates for the dignity of all citizens with disabilities including the use of "people first language" where possible. We do not normally edit articles and submissions that do not reflect this language, therefore, at times, readers might see alternative nomenclature.
— Rick Rader, MD

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STEP FORWARD: A Soviet soldier waving his country's flag over the central plaza of Stalingrad in January 1943. Nazi forces from the Battle of Stalingrad surrendered on February 2, thereby ending one of the bloodiest battles in the history of war.

PHOTO COURTESY GEORGY ZELMA/WIKIMEDIA COMMONS

Order 227: "Not a Step Back"

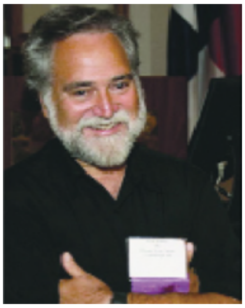
The goal of this article is certainly not to provide any positivity to the cruel regime of Stalin, but to remind the current crop of disability rights activists that the world is watching and waiting to see if you understand, respect and acknowledge your role in the "ongoing" movement.

My maternal grandfather, Morris, was an army deserter. A proud army deserter.

He was conscripted into the Russian army and, realizing the growing unrest would eventually lead to the creation of the world's first socialist state, he fled at the outbreak of the Russian Revolution of 1917. He loved, flourished, and embraced the American democratic way of life while agonizing over the terror that the dictator Joseph Stalin brought to the Russian people.

Stalin offered, "The death of one man is a tragedy. The death of millions is a statistic." While it can be considered an astute observation, bringing the stark reality of personalizing tragedy, it is also reflective of someone who knew a thing or two about statistics. Estimates of the number of deaths attributable to Stalin vary widely, but historians estimated that the numbers killed by Stalin's regime reached 20 million or higher. These reflected executions, assassinations, Gulag deaths and labor colonies, deportations, the famines of 1932-33 and 1946-47, forced settlements, and massacres.

I shiver at the tales of how Stalin's cruelty impacted on the lives of millions of Soviet citizens and how entire families never recovered from his reign of terror.



With all the champions that have actually impacted on the disability rights movement, why on earth would I select this despot to "inspire" a message that I think is noteworthy and applicable to moving forward with inclusion, acceptance, and an appreciation for neurodiversity?

Like most dictators, Stalin ruled by issuing thousands of orders. These orders dictated behaviors, expectations, rules, regulations, mandates, consequences, codes, prohibitions, and ordinances.

In 1943, Stalin issues Order No. 227, an order that, with some explanations, could serve as a reminder to the disability community.

Order No. 227 came to be known as the "Not one step backward" order.

During World War II, early German successes against Russia had emboldened Hitler in his goal of taking control of two of Russia's most significant strongholds, the cities of Leningrad and Stalingrad. Things looked bleak for Soviet survival. Stalin needed to remind the Soviet citizens, their military and indeed the soul of the country what was expected of them.

Basically, Stalin wrote that retreat is defeat. He announced that the enemy had already taken most of Russia's strategic regions and cities. He cited that, in some instances, the Soviet troops had given into panic and abandoned several cities without offering any serious defense and without waiting for Moscow's orders. Part of Order No. 227 issued the following "Every officer, every soldier and political worker must understand that our resources are not limitless. The territory of the Soviet state is not just desert, it is people – workers, peasants, intellectuals, our fathers, mothers, wives, brothers, and children."

Historian Catherine Merridale, writing in The History Reader adds, Stalin's remedy was embodied in a new slogan, "Not a step back!" which became the army's watchword. Every man was told to fight until his final drop of blood.

Of particular interest is the fact that at Stalin's insistence, Order No. 227 was never printed for general distribution. The order was conveyed by word of mouth to every man and woman in the army. Stalin instructed that "your reports must be pithy, brief, clear, and concrete. There must not be a single person in the armed forces who is not familiar with Comrade Stalin's order."

> "Pioneers of the disability rights movement understood the consequences of retreating and relinquishing the ground they heroically fought for."

Order No. 227 was not made public until 1988, when it was printed as part of the policy of "glasnost," or openness.

And while you might think this was a draconian threat to punish soldiers who abandoned their position, most of the rules for military conduct are abundantly clear regarding the consequences for soldiers who retreat without or against orders from their commanders. In fact, Order No. 227 was simply a re-statement of what had been an accepted part of military decorum since ancient warfare principles were established by the Greek and Roman empires.

Order No. 227 resonated with the Soviet troops. Most of them reported that it was a needed and important reminder. It was found that it provided a welcome relief and helped to fortify their resolve.

The Soviet Union played an instrumental part in defeating the Germans and ending the War in 1945.

Order No. 227 provides a message for the ongoing disability rights movement. *"Ongoing"* is the key and operative word. While the world for people with disabilities has reached major milestones, and opportunities have been provided for individuals against the backdrop of complex, lifelong and once-thought insurmountable challenges, we are still in the "ongoing" phase.

Unfortunately, many of the pioneers and champions of the disability rights movement are no longer at their posts. They lived with Order No. 227 and understood the consequences of retreating and relinquishing the ground they heroically fought for. They woke up every day understanding what "Not a step back!" meant to them, the people they represented, and the increasing number of future generations who needed them on the front lines.

The goal of this article is certainly not to provide any positivity to the cruel regime of Stalin, but to remind the current crop of disability rights activists that the world is watching and waiting to see if you understand, respect and acknowledge your role in the "ongoing" movement.

From time to time, we all need a reminder of why we are here and what still needs to be done. The troops need to be reminded of our history, our goals, and the consequences of not observing Order No. 227.•

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.

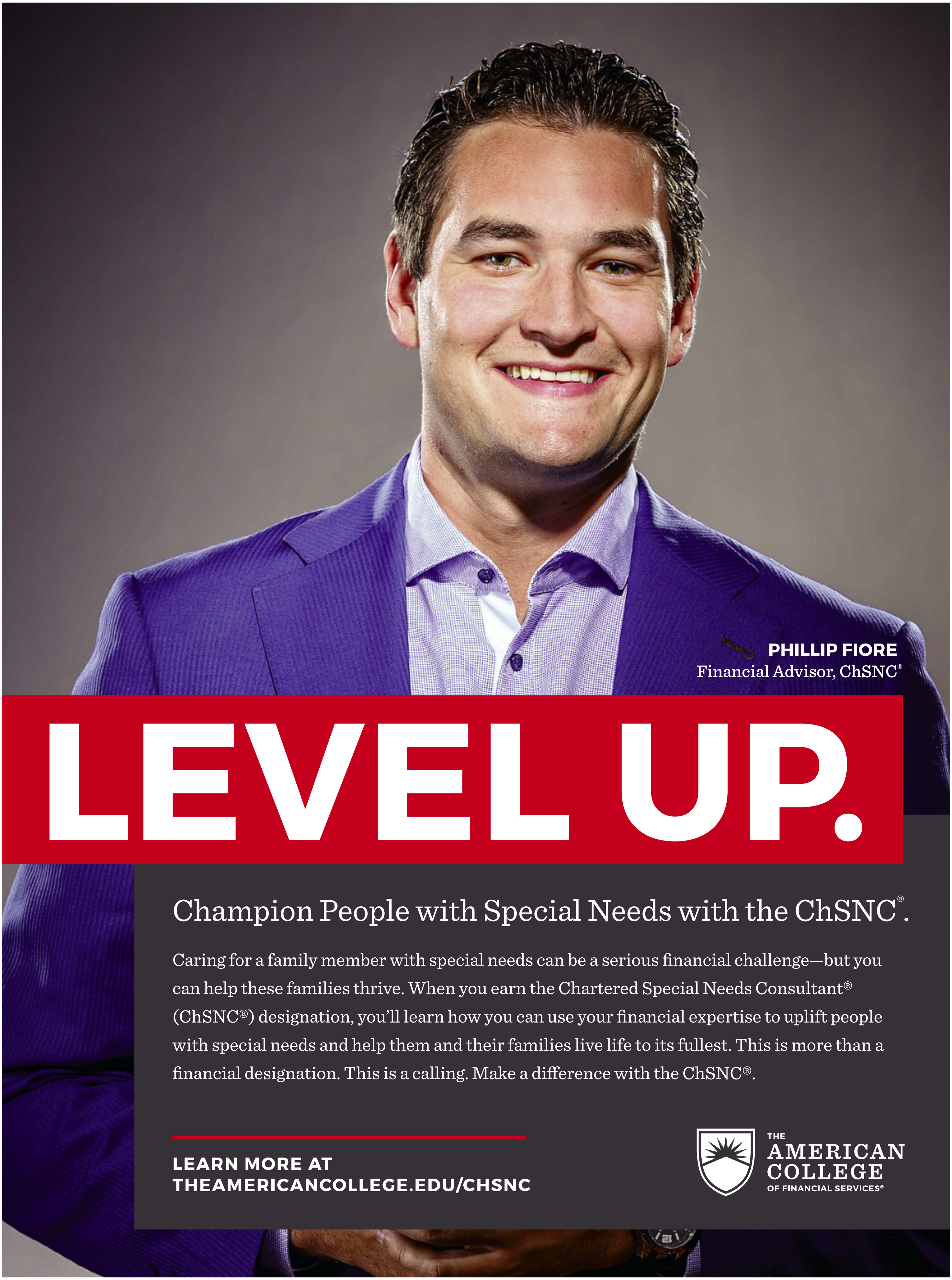
Parents and families with members with special needs benefit greatly from meaningful interaction with peers facing the same challenges and joys. Facebook has provided the EP readership community with a convenient and effective platform to communicate, ask questions, promote events and share special moments.

Connect, Share and Discover with EP
www.facebook.com/exceptionalparentmag

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

DR. VINCENT SIASOCO EARNS THE 2019 SPECIAL OLYMPICS NEW YORK GOLISANO HEALTH LEADERSHIP AWARD

Special Olympics New York's preeminent recognition for health partners and individuals was recently awarded to Dr. Vincent Siasoco, Metro Community Health Center's Chief Medical Officer. The Golisano Health Leadership Award recognizes deserving individuals and/or organizations that make significant contributions to both Special Olympics Health Programs, and the promotion of healthcare, wellness, and fitness for people with intellectual disabilities.

Dr. Siasoco

"Vincent is one of our athletes' greatest advocates and champions for health equality in New York State," said Stacey Hengsterman, President and CEO of Special Olympics New York. "His skill, dedication, and commitment set the highest possible bar for medical professionals working to improve healthcare policy and practice for people with intellectual differences."

Dr. Siasoco has been a leader in Special Olympics Healthy Athletes programming since 2016. He leads two to three health screenings each year. He has recruited numerous colleagues and health professionals from his professional network, providing an increase in trained Clinical Directors throughout New York State. Dr. Siasoco has also eased athletes' access to quality follow-up health care and increased their participation in year-round wellness and fitness programs. As the newly appointed Chair of the SONY Health Advisory Council, Vincent will be leading chosen clinical and community health leaders in New York to further the health vision and objectives of Special Olympics New York.

Dr. Siasoco not only leads the Special Olympics Healthy Athletes Health Promotion (screening annually at the Winter Classic Floor Hockey Tournament at the Javits Center in New York City), but he plans MedFest events throughout the year to provide Special Olympics athletes with an opportunity to receive a sports physical in order to participate in Special Olympics programs and competitions. Dr. Siasoco hopes to lead MedFest events twice a year in different locations across the five boroughs to give NYC Special Olympics athletes the opportunity to receive a free medical screening in order to participate in Special Olympics programming.

"I'm honored to receive this award," said Dr. Siasoco. "I first started out as a volunteer coach at Special Olympics during college and I am proud to continue to be involved today with such an extraordinary organization. I feel very fortunate that I'm able to support, advocate, and work with others dedicated to ensuring our athletes receive the quality care they so deserve. Thank you to Special Olympics New York and the Golisano Foundation for this recognition."

Special Olympics New York is the largest state chapter in the country, serving more than 67,000 athletes across New York, with year-round sports training, athletic competition, and health screenings. The organization also partners with more than 170 schools statewide to offer Unified Sports. All Special Olympics New York programs are offered at no cost to athletes, their families or caregivers. For additional information about Special Olympics New York, to learn more about getting involved, or to make a donation, visit **www.specialolympicsNY.org**

PHOTO COURTESY SPECIALOLYMPICS-NY.ORG

WHAT'S HAPPENING

REGISTRATION NOW OPEN FOR THE ANNUAL EASTERSEALS DISABILITY FILM CHALLENGE

Easterseals Southern California, a leading disability services organization, announced recently at the Sundance Film Festival that registration is now open for its annual Easterseals Disability Film Challenge.

COMING ATTRACTIONS: Each production must include at least one person with a disability onscreen or behind the camera as teams write, shoot and edit their films.

The Easterseals Disability Film Challenge is the entertainment industry's premiere disability inclusion competition. Interested filmmakers and participants can register at **DisabilityFilmChallenge.com** now through Friday, March 13th for regular deadline and Tuesday, March 31st for late registration.

"The entertainment industry is notoriously difficult to break into, regardless of your ability. And, as a person with a disability, I know the odds are stacked against people with disabilities to build careers in entertainment," says Nic Novicki, actor and founder, Easterseals Disability Film Challenge. "I set out to change this, giving filmmakers and actors tangible work experiences and a chance to tell more diverse and varied stories that better represent the real world. Through the Challenge, and thanks to Easterseals' year-round efforts to expand the diversity conversation, disability is gaining representation in front of and behind the camera."

The Easterseals Disability Film Challenge, now in its seventh year, gives filmmakers the opportunity to collaborate and tell unique stories that showcase disability in its many forms. The film competition is open to anyone, with or without disabilities, and will take place over the weekend of April 3-5. Participants will have roughly 55 hours to write, shoot and edit a three-to-five-minute short film based on an assigned genre. While the filmmakers are not necessarily required to include disability in the storyline, each team must include at least one person with a disability in front of or behind the camera.

"Because we rarely see characters with disabilities in storylines, it's easier for society to stereotype and marginalize," said Mark Whitley, CEO, Easterseals Southern California. "Hollywood is galvanizing around the Easterseals Disability Film Challenge to embrace disability inclusion and better reflect the nation's largest minority population, 61 million strong. Together we can shift perceptions, tackle stigmas and advance social change. And, while we're beginning to see bright spots and progress, we still have work to do."

The genre, locations and themes for the 2020 Challenge will be released Tuesday, March 31, 2020, with the remainder of the assignment released Friday, April 3, 2020. Submitted films are judged in five award categories – Best Film, Best Director, Best Actor, Best Screenplay and Best Awareness Campaign – and judged by a diverse group of entertainment industry professionals. Since the Challenge launched, filmmakers from around the world have created more than 200 films that have been viewed online and at festivals such as the HollyShorts Film Festival, Heartland Film Festival and Bentonville Film Festival.

ABOUT EASTERSEALS:

For more than 100 years, Easterseals has been an indispensable resource for individuals with developmental disabilities or other special needs and their families. The services provided by Easterseals Southern California (ESSC) – in Los Angeles, Orange, San Diego, Imperial, Kern, San Bernardino, Riverside and Ventura counties – make profound and positive differences in people's lives every day, helping them address life's challenges and achieve personal goals so that they can live, learn, work and play in our communities. With 2,800+ employees, 60+ service sites and hundreds of community partnership locations, ESSC assists more than 13,000 people, providing adult/senior day services; autism therapy; child development/early education; employment services, veteran employment support; independent living options; and more. At Easterseals, 88% of our income is spent on services. Join in changing the way the world defines and views disabilities at www.easterseals.com/southerncal.

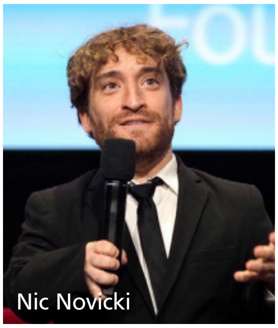
PHOTOS COURTESY EASTERSEALS

WHAT'S HAPPENING

KEY EASTERSEALS DISABILITY FILM CHALLENGE DATES

April 3rd-5th: 2020 Easterseals Disability Film Challenge
Thursday, May 7: Awards Reception Event at Sony Pictures Studios (Invitation Only)

Since the Challenge launched in 2013, there have been several success stories resulting from support received as a part of the Challenge. Jamie Brewer, who won Best Actor in the 2017 Challenge for *Whitney's Wedding,* has been acclaimed for her role on *American Horror Story,* and was the first model with Down syndrome to walk the runway at New York Fashion Week. Dickie Hearts, the Challenge's Best Filmmaker winner in 2015, went on to win a HBO Project Greenlight digital series competition. Jenna Kanell, winner of Best Film in 2015, went on to give a TEDx Talk about her experience. Sofiya Cheyenne was cast in *Loudermilk* after writer-director Peter Farrelly saw her 2018 Challenge entry, *You're Up.* 2019 Best Film nominee Santina Muha has a comedy in development at CBS and 2019 Best Actor winner Nicole Lynn Evans appears in a recurring role on Freeform's *Good Trouble.*


Nic Novicki

Sony Pictures Entertainment, as the official Red Carpet Sponsor, will host the Awards Ceremony. Based on the category, winners have the opportunity to receive the latest in computer technology from Dell, the opportunity to screen their film at the HollyShorts Film Festival, mentorship opportunities and cash prizes.

Registration for the 2020 Easterseals Disability Film Challenge is now open. To sign-up, view the official rules, or for more information, please visit **DisabilityFilmChallenge.com**

Easterseals
Disability Film
Challenge

ABOUT THE DISABILITY FILM CHALLENGE:

As someone with a disability, actor, comedian and producer Nic Novicki launched the Disability Film Challenge in 2013 in response to the under-representation of talent with disabilities both in front of and behind the camera. Novicki created the challenge to give aspiring filmmakers the opportunity to showcase their work and provide them with meaningful exposure. In 2017, Novicki joined forces with Easterseals Southern California – the nation's leading nonprofit supporting people and families with disabilities – to expand the event, now known as the Easterseals Disability Film Challenge. Visit https://disabilityfilmchallenge.com and join the conversation at Facebook.com/DisabilityFilmChallenge

TELEMEDICINE-AIDED THERAPY HELPS PARENTS OF KIDS WITH DEVELOPMENTAL DISORDERS, INCLUDING AUTISM

For families of children with developmental disorders, access to early intervention programs can make a huge difference in their overall development. However, many families in smaller cities or rural areas do not have convenient access to such programs, often located at larger universities in big cities.

To address that need, researchers at UCLA are using telemedicine to remotely help families learn skills that let them work at home with their children to gain essential social skills. One such study involves children with tuberous sclerosis, a rare genetic disorder that often causes development issues. Scientists found early signs of autism in this group of infants who, until now, would never have received crucial early intervention.


NO PLACE LIKE HOME: The trial allows Mary Crawford to implement John Michael's therapy at their home in Arkansas while working with therapists at UCLA.

"The earlier you can intervene and enrich the child's environment, the more likely you are to actually exact change in brain development," said Shafali Jeste, MD, a pediatric neurologist and an associate professor of psychiatry, neurology and pediatrics in the David Geffen School of Medicine at UCLA and a principal investigator at the UCLA Center for Autism Research and Treatment. "Our unique remote delivery allows families to begin that early intervention from their home, which is really important for those who live far away from major academic research centers."

The therapy – called JASPER – is a science-backed technique that uses play-based therapy to enhance children's development and behavior. "We do a very careful assessment of where children are, developmentally, and then train parents to implement this method into their everyday interactions," said Connie Kasari, PhD, professor of human development and psychology and a co-founder of the Center for Autism Research and Treatment at UCLA's Semel Institute for Neuroscience and Human Behavior.

Mary and Brandon Crawford are participating in the UCLA study from their home in Arkansas with their son John Michael, 3. "We've seen huge improvements in John Michael's language skills and his ability to interact and tell us what he wants and how he's feeling," Mary Crawford said. "Seeing that growth and advancement makes our hearts soar because, as parents, we want to do whatever we can to help our son. This trial empowers us to do that, even if we are thousands of miles away from the therapists we're working with." •

PHOTOS COURTESY DISABILITYFILMCHALLENGE; UCLA.MULTIMEDIA-NEWSROOM

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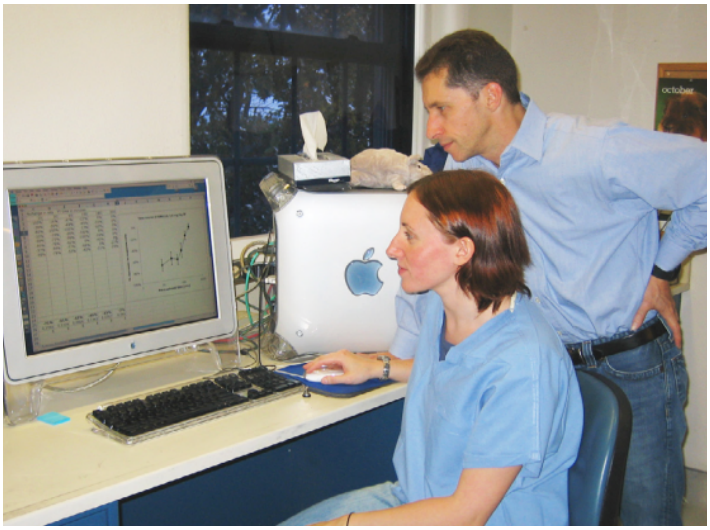

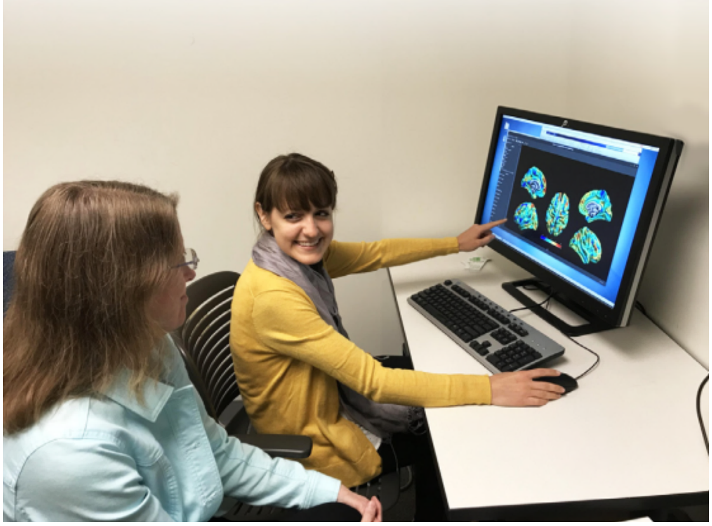

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IES Brain Research Foundation thanks everyone who has participated & donated and wishes everyone a happy, healthy 2020.

NEW PRODUCTS

FUN FEBRUARY FINDS

SUCTION KUPZ

Suction Kupz are colorful silicone cups that feature suction cups on the bottom to encourage fine motor skills, spatial reasoning, creativitiy, exploration, and experimentation. In addition to a suction cup on the bottom, they feature a suctioning brim at the top. They can be used in the tub for scooping, pouring, and floating. They stick to windows, walls, tables, and floors for whatever creative endeavors the child's imagination can conjure. They can also be used as drinking cups. Made of food-safe silicone, they are BPA-free, and dishwasher safe. Each cup measures 2.5 x 2.5 x 2.5 inches. Includes set of 6.

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ABLEDATA

The ABLEDATA database of assistive technology (AT) and rehabilitation equipment contains information on more than 50,000 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, Independent Living, and Rehabilitation Research (NIDILRR).

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: https://abledata.acl.gov/; email: abledata@neweditions.net; Twitter: www.twitter.com/AT_Info; Facebook: www.facebook.com/abledata; Pinterest: www.pinterest.com/AT_Info/

NEW PRODUCTS

WOODEN MAKE-A-CAKE MIXER SET

The Wooden Make-a-Cake Mixer Set is an 11-piece wooden hand-crank mixer set that encourages creative thinking and imaginative play and promotes memory and number skills. Children can mix some delicious pretend-play fun with the wooden mixer. Children can turn the dials to “adjust speed” and use the crank to turn the bowl that fits the mixer. Wooden ingredients include 2 pats of butter and two-part egg, both of which have self-stick tabs that can be sliced through the child-friendly wooden knife. Children can follow the directions on the recipe card to make a pound cake. The set includes a pound cake mix box, pretend pound cake loaf, and a cake pan. Children will enjoy cracking, slicing, blending, and serving up pretend baked treats. Suitable for children 3 and older. Package measures 13.75 inches X 10 inches X 5 inches. Product measures 13.5 inches x 10" inches x 5 inches, and weighs 2.45 pounds.

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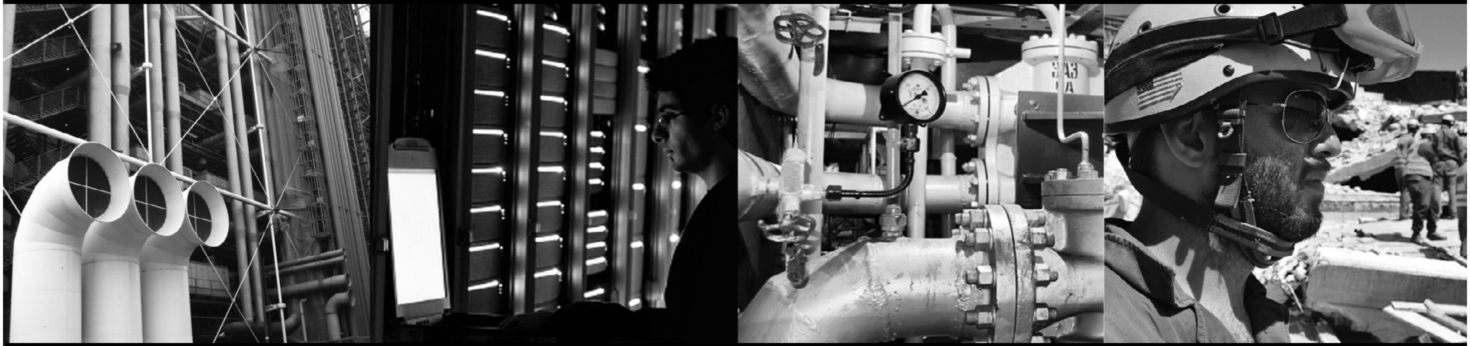

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Why is it essential that each person be counted, beyond the need to determine representation in the Congress? Because the distributions of government federal funds often are based on population numbers in individual states, locales and desperate circumstances (e.g. weather disasters and medical emergencies) and yes, the health circumstances of individuals of all ages.

Undercounting Young Children with Severe Disabilities: A Need for Change

BY H. BARRY WALDMAN, DDS, MPH, PHD, RICK RADER, MD, DHL (HON), ALICIA BAZZANO MD, PHD, MPH AND STEVEN P. PERLMAN, DDS, MSCD, DHL (HON)

A previous article in *Exceptional Parent Magazine* reviewed the U.S. Census Bureau annual American Community Survey demographic findings that an estimated **155,000 children less than five years of age** among the civilian noninstitutionalized population had one or more severe disability. The survey reports estimated data for six disability categories (hearing, vision, cognitive, ambulatory, self-care and independent living difficulties) for individuals five years and older. However, for children less than five years, the report sought information only for hearing and sight difficulties.[1] By contrast, the Global Burden of Disease Study reported that **almost 810,000 U.S. children,** less than five years of age, had developmental disabilities in 2016.[2]

"Does the repeated published undercount of the number of children less than age five with disabilities really matter? That is like asking whether it matters that hundreds or thousands (even more) of eligible residents do not vote in a particular election. Numbers do count, in terms of efforts to bring about change, and how to plan for the results of needed change… Adding to difficulties in accurately determining the full extent of children with varying types of disabilities among children less than five years of age, is the reality of the Census Snafu (i.e. situation normal, all fouled up). Nearly one in four children under the age of five years in the U.S. lives in areas at risk of being missed by census employees in 2020." [1,3]

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.

WHO'S COUNTING: The distributions of government federal funds often are based on population numbers in individual states, locales and desperate circumstances (e.g. weather disasters and medical emergencies) and yes, the health circumstances of individuals of all ages.

A more recent in-depth report by members of the National Center for Health Statistics adds a further dimension in determining the number of children with disabilities less than five years of age between the periods of 2009-2011 and 2015-2017. The review considers the prevalence and trends of developmental disabilities among U.S. children between 3 and 17 years. While children three to five years are not considered separately, the study does demonstrate that this younger age group can (**and should be**) included in a wider review of disabilities (than just hearing and vision disabilities) that affect very young children.

FINDINGS FROM THE REPORT BY NATIONAL CENTER FOR HEALTH STATISTICS

- There were overall significant increases in the prevalence of any developmental disability (including attention-deficit/ hyperactive disorder, autism spectrum disorder and intellectual disability) but a significant decrease for any other developmental delay.
- The prevalence of any developmental disability increased among boys, older children, non-Hispanic white and Hispanic children, children with private insurance only, children with birth weight, equal or greater than 2500 grams (5.5 pounds), and children living in urban areas and with less educated mothers.
- "The prevalence of developmental disability among US children aged 3 to 17 years increased between 2009 and 2017. However, changes by demographic and socioeconomic subgroups may be related to improvements in screening and access to health care." [4]
- "Developmental disabilities are a group of lifelong conditions due to an impairment in physical, learning, language, or behavior areas. Children diagnosed with developmental disabilities typically require services to address behavior and development challenges. Measuring the prevalence of developmental disabilities in the population helps gauge the adequacy of available services and interventions." [4]

SO WHAT IF VERY YOUNG CHILDREN WITH DISABILITIES ARE NOT COUNTED BY THE CENSUS BUREAU?

> *"The U.S. Constitution empowers the Congress to carry out the census in 'such manner as they shall by Law direct' (Article I, Section 2). The Founders of our fledgling nation had a bold and ambitious plan to empower the people over their new government. The plan was to count every person living in the newly created United States of America, and to use that count to determine representation in the Congress.*
>
> *Enshrining this invention in our Constitution marked a turning point in world history. Previously censuses had been used mainly to tax or confiscate property or to conscript youth into military service. The genius of the Founders was taking a tool of government and making it a tool of political empowerment for the governed over their government…"* [5]
>
> *"On numerous occasions, the courts have said the Constitution gives Congress the authority to collect statistics in the census… The degree to which the information is needed for the promotion of legitimate governmental interests has been found to be significant."* [5]

Why is it essential that each person be counted, beyond the need to *determine representation in the Congress?* Because the distributions of government federal funds often are based on population numbers in individual states, locales and desperate circumstances (e.g. weather disasters and medical emergencies) and yes, the health circumstances of **individuals of all ages.**

Medicaid (a federal and state financed program) provides a lifeline for children with disabilities and their families. More than half of all children with a disability or other special health care needs rely on public insurance coverage for a wide range of services and supports. Because Medicaid extends eligibility in multiple ways to children with disabilities, it reaches a broad range of families and children with disabilities. "Compared to other children, youngsters with disabilities are more likely to live in low-income households. Many qualify for Medicaid based on their families' income alone – without it, they would likely have no other affordable insurance options.

For many of these families, Medicaid is the difference between being able to comfortably access comprehensive care for their child and falling into debt due to medical expenses."[6] *(It is because of this reality that determining the extent of needed financial support, that the number of all children with disabilities in a state becomes critical!)*

ADDITIONAL FINDINGS FROM THE REPORT BY THE NATIONAL CENTER FOR HEALTH STATISTICS CENTER FOR HEALTH STATISTICS

- Non-Hispanic white children were most likely to be diagnosed with attention-deficit/hyperactive disorder (ADHD) than non-Hispanic black or Hispanic children.
- Children receiving any form of public health insurance are more likely to be diagnosed with any and each of the individual developmental disabilities when compared with children receiving only private health insurance and uninsured children with the exception of blindness among uninsured children.[4]

YES, IT IS DIFFICULT TO DETERMINE THE TYPE AND DEGREE OF DISABILITY AMONG VERY YOUNG CHILDREN

However, the need is to establish a methodology which would permit the Census Bureau to adopt a more realistic approximation of future numbers and costs for the support of very young children with disabilities who will impact on the health, education and social systems as they get older.

One approach would be to assign three categories for children under five years of age with disabilities: 1) Hearing limitations, 2) Sight limitations, and 3) Other disabilities.*

A more realistic approach for determining population numbers and potential future costs for essential health, education and social services is critical. **Recording only sight and hearing disabilities for children under five years of age is an unrealistic solution.** •

* *Type and severity to be determined at an older age.*

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HEARTSIGHT CHRISTINA LLANES MABALOT

Random Thoughts for the Young Year

Time is a gift. How many people have not lived long enough to flaunt grey hair? Youthfulness is in the heart and my own secret elixir is laughter. I laugh too loud and often.

I always start a new year by reflecting on my life. Rather than restate resolutions that I didn't do last year, which I should have done in the preceding one, this time, I am choosing to count my blessings.

A new year, a gift of time to make sense of my millennial children's mindset so I can appreciate and write about it, another shot at dropping the "age" in "marriage," a new chance to try to become a blind Wonder Woman, or a stand-up comedian – and a fresh occasion to mature and not just age. Events in 2019 that didn't kill me have made me older. What's weird is, I don't feel any older. Perhaps not being able to see one's self is like enjoying the fountain of youth.

Carl Jung aptly described the stage I'm in as the "afternoon of life," a time when people are more inclined to flex their mental biceps than the physical. In the afternoon of life, most people slow down their game. Not me. In fact, this crazy woman recently upped hers. I feel I can still run with my children when they train. I didn't say I finish strong, but I hope it won't ever get so bad where I'm carried home with a sign that says, "Found on the road dead." Need I say more?

The Bible says, "Count the cost before you do something," but I usually end up paying the price for making a foolish decision. Not too long ago, I decided to Wrestle my 57-pound English bulldog. I bent down at his level and gave him the "let's play" signal. He jumped on me, and I crashed on my left knee with a heavy thud. Of course, I bounced back on my feet; I'm not a wuss! But to this day, I'm still suffering from the lingering pain of that injury.

Oh, there's more. About two months ago, I challenged myself to increase my high-intensity interval training to level 10 on the treadmill. I enjoyed the dopamine boost for a few days. One day, as I was relishing the high of running while listening to an audiobook, my wisdom decided to take a break. Forgetting I was blind, I let go of my grip on the treadmill handlebars. You guessed right; I fell off. I wasn't smiling, but the massive cut on my shin was. The wound hurt so bad

I was quiet for about the longest time ever in my life. My son, familiar with my M.O., wasn't sympathetic. He shrugged his shoulders and said, "Stupid decisions, stupid results." Case closed.

Why do I often forget I'm blind? I honestly don't know. I run around the house like a headless chicken as I do my chores. Often, I get attacked by the belligerent walls that are always in my way. I fared better when I was working at a call center. Whenever I went to the restroom, I'd trail along the wall that led to the break area. While doing so one time, I collided with a co-worker oblivious to imminent danger. Thank God, the poor girl was more frightened than hurt. That never happened again, for, after that incident, I received the scarlet letter – "A," the label for "Avoid." Since then, everyone gave way whenever they saw me running.

Please don't ask how many battle scars I've earned over the years. My family wonders why, unlike people who are blind and sensible, I don't hold my hand out to protect my head and face to prevent such mishaps. That's my problem; I forget I cannot see. And, I also overlook that I'm up in age too. Last summer, I joined my kids trekking the Stone Mountain and the Amicalola Falls State Park in Atlanta. After hyperventilating and almost fainting every ten steps, I finally reached the peak. This accomplishment was my very first mountain-top experience, so I asked the kids to hold me up for a picture.

I still pull all-nighters, working and sometimes just hanging out with family, especially on vacations and holidays. I go with my children to the gym whenever they're around and enjoy pumping weights with them. Before my knee injury, I'd work out until exhaustion to be able to sleep better. I sometimes eat like my kids too, like college students living in the dorms, deprived of good food. I often feel that I'm overweight. This perception is why I'm on a perpetual diet, yet, it's just an illusion since I always break the diet. Call it the "make-believe diet" all you want, but I describe it as the "I eat everything I don't see." I stick to these bad habits, rationalizing (wink-wink) that hot flashes make me feel entitled to poor decisions.

What am I thinking? The truth is, I've never lost my 20-year-old mind, or perhaps I'm regressing back to 20? Or maybe, I'm headed to my second childhood? Well, I acknowledge beautiful senior moments when I commit the unpardonable. For example, I once stuck my cell phone in the microwave. Thank God I caught myself, or my phone would've exploded in the oven! On another occasion, I woke up with a foggy brain. I stumbled to the vanity to wash my face. To my horror, I almost stuck my dental retainer in my eye socket and my prosthetic eye in my mouth.

> "My heart had been badly broken on several occasions, but allowing my heart to heal only made me 'whole' and stronger. As a result, I now possess a treasure trove of life lessons I can bequeath to my children. I have learned to be a friend to myself."

Please don't judge me. Blame it on my grey hair. The good news is, I have learned to laugh at myself, which, by the way, explains the laugh lines engraved on my face.

Other than these imperfections, I agree with Jason Mraz that life is lovely. I will never swap my fun-loving family and caring friends for winning the lottery. They are my wealth. For me, happiness is the slurpy-kisses of my dog, devouring a whole bag of Lindor chocolates in one sitting, playing pranks on people (especially on my pastor), finishing a 54-hour audiobook on a marathon weekend, hiding my son's gym gloves, scaring my daughter out of her wits, annoying my husband, sleeping through a storm, believing that I'd fit my size-4 jeans one day, not caring about the effect of gravity on my body, forgetting the bad, remembering when I was glad, and looking ahead for the best that's yet to come.

Indeed, my heart had been badly broken on several occasions, but allowing my heart to heal only made me "whole" and stronger. As a result, I now possess a treasure trove of life lessons I can bequeath to my children. I have learned to be a friend to myself.

I refuse to waste my time daydreaming about what-ifs at the expense of my joy today. Neither would I stress about what-will-be, for God has been by my side over the years, He has proven enough. I believe that God has preserved my health in the past year. I've never been seriously ill that I needed to use my sick time at work (which I enjoyed at the end of 2019).

Time is a gift. How many people have not lived long enough to flaunt grey hair? Youthfulness is in the heart and my own secret elixir is laughter. I laugh too loud and often.

People say that success is elusive, but for me, success is the confidence that tomorrow will be better. Michael Josephson of the Character Counts! project always says, "success is significance." Let me share my last quote for today. "The best things in life are unseen; that's why we close our eyes when we kiss, laugh, and dream."

May you all have a joyful 2020! •

HEARTSIGHT

Christina Llanes Mabalot is physically blind from aniridia, but has a vision. She enjoys touching people's lives to bring out the best in them. "Heartsight" explains her ability to see with her heart. Christina earned her B.A. degree and Masters in Education from the University of the Philippines, Diliman, specializing in Early Intervention for the Blind. She later received Educational Leadership training through the Hilton-Perkins International Program in Massachusetts, then worked as consultant for programs for the VI Helen Keller International. She has championed Inclusive Education, Early Intervention, Capability Building and Disability Sensitivity programs. She was twice a winner in the International Speech contests of the Toastmasters International (District 75) and has been a professional inspirational and motivational speaker. Christina is blissfully married to Silver Mabalot, also physically impaired, her partner in advancing noble causes. Their children are Paulo and Jem, who has aniridia. Visit leadershiptovision.com

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ROBERT K. ROSS ED.D., BCBA-D, LBA

Reducing the Stress of Mealtimes for Picky Eaters

Diet & Nutrition

As a behavior analyst, I learned a long time ago, that fixing "bad" or ineffective routines was extremely difficult. However, creating new routines was always much easier.

THE REALITY VERSUS THE DREAM

For so many parents (with or without children on the autism spectrum), difficulties at mealtime are a daily reality and these struggles can make mealtimes one of the least preferred parts of their lives. Anticipating another *battle royale* over eating can often lead to anxiety and dread. For too many parents, mealtime is a daily ritual of unpleasant time with their children. This is simply not what we hoped and dreamed that raising children would be like. We never envisioned having to nag, beg, cajole and threaten our children into eating food. We want them to be a happy, well-nourished child, yet they often seem bound and determined to resist our efforts and eat only the things that are not good for them (or the same one or two items every day). As a result, over time, mealtimes have evolved into a desperate struggle to get some nutrition into a child who would rather starve than give in. All we really want is to be able to have a pleasant family dinnertime and our children to eat something other than the same thing every day maybe even something that is good for them. While most parents would love for this mythical event to be possible, for many it is simply not a reality.

RECOGNIZING THAT THE ROUTINE IS NOT WORKING

By the time we realize how much we struggle at mealtime, the pattern of unsuccessful and unpleasant mealtimes is often so ingrained (for both the child and the parent) that it is not easy to change. The good news is that, as with all routines (particularly ineffective or non-preferred ones), they can change. However, the way to fix them does not lie in the mealtime routine. A real solution to this problem will require us to create a new mealtime routine. As a behavior analyst, I learned a long time ago, that fixing "bad" or ineffective routines was extremely difficult. However, creating new routines was always much easier. So when I encounter a mealtime routine (or any other routine) that is going badly (for both the parents and the child), my first inclination is to find a way to develop a new routine around eating, rather than try to make the currently ineffective routine work. There is almost always too much bad history and habits to overcome (for both the parents and the child).

To be clear here, I am talking about children who are selective eaters, not about children who refuse to eat and are at risk of serious medical consequences due to malnutrition and other health impacts of food refusal. For those children, specialized medical and behavioral intervention should be sought. But, for those children who prefer a limited set of (often not so nutritious) foods—and will argue, whine, throw a tantrum and, in general, make the lives of parents and caregivers difficult until they finally concede and give them the foods they want (or the child leaves without having eaten the foods their parents have prepared)—change is possible.

ENVISIONING THE CHANGE

As parents and caregivers we want our children's behavior to change, however we often fail to recognize that in order for that to happen we must first change our behavior. It is simply a fact that as long as we continue to do the things that are not working, they will continue to not work. We tend to see our children as obstinate or inflexible, without recognizing that we are both "stuck" in a routine or pattern that is not leading in the direction we would like to go. The first steps down this road are for us to recognize that **we** need to make the change and then for us to decide what that changed routine would be in our ideal version of mealtime. We literally need to "rethink" what mealtime is and can and could be for us as a family.

When I ask parents and caregivers what they would like mealtime to look like in an ideal world, they often find this very difficult, they have followed the pattern for so long, they have a hard time seeing any other way. But in the end most parent will say that they would like the child to "just eat what is given to them and to be able to have a pleasant time without arguments." These two basic points are in my view essential to a change in mealtimes. What is typically true of problem mealtimes is that we do not simply give children food and have pleasant conversations with them during mealtimes. We tend to do other things most of which are not consistent with this goal.

So the next step is to work with families to rethink how we start, conduct and end activities involving food, and it mostly involves us changing our behavior. When we do this there is a much better chance that our child will change their behavior. Sometimes I will go as far as suggesting that we work on food acceptance in settings other than the kitchen or dining room where meals time problems occur, but often we do not need so drastic a change.

FIRST STEPS

1. Decide to make today successful: You know what your child does and does not eat every day. If you think about it you can tell yourself exactly what will and will not happen. Since you know what will be

THE POWER OF SUGGESTION: Children are smart; they can recognize food and can eat. They do not require you to tell them to do so, the presence of food on the table is enough of a prompt.

eaten and what will not, skip the “Not going to be eaten” food (today) and limit the amount of the food they will eat so that you do not have to have a fight *today*. You want to focus on remaking the mealtime experience for both of you. To do so, new habits will have to be established. One of these habits is having appropriate expectations about your child’s eating behavior. Today, your child is not going to suddenly eat food that they have refused every day for the past months or years. Their intake is likely to be similar to what it was the last several mealtimes. Recognize this so you can set reasonable expectations for eating *today*. If you only present food today that will likely be eaten, there is little to no opportunity for argument. Doing this is a first step in making it so that you do not feel compelled to do anything except provide food and have a pleasant conversation with your child. Doing this will enable you to do step 2.

> “New habits need to be established, one of which is having appropriate expectations about your child’s eating behavior. Today, your child is not going to suddenly eat food that they have refused every day for the past months or years.”

2. Skip the Argument: This is easier said than done, but If your child always refuses to eat the foods when you ask them to eat, consider skipping the “ask,” (if the demand always results in refusal, it will today as well). Skipping the part where you ask/tell them to eat, and then they reliably tell you “no” and you then tell them they have to…, is a simple idea with often profound effects. Arguments about food typically require someone to start the argument and, whether we realize it or not, we typically start it. We say things like “you need to…” when in fact the child does not “need to.” We really want them to eat the foods we have prepared, but from their perspective (which matters more them than ours) they do not “need to.” Recognizing this basic fact and the fact the request to eat is almost always followed by refusal to eat, can free you up to simply present food.

3. Be Social, Not Controlling: Children are smart; they can recognize food and can eat. They do not require you to tell them to do so, the presence of food on the table is enough of a prompt. If you also have food and simply begin eating, without telling your child to eat, they may do so. If they begin eating, great, then you should start a wonderful conversation with them about anything other than food. Tell them about your day, ask them about theirs. Make it social and not about eating (or not eating). Be fun, be funny. Have the conversations you always wanted to, the only thing stopping you from talking about what you want to talk about, is you (and a long history of talking about food problems).

> "Making the decision to establish the routine we *want* to have is a good first step."

4. Recognize that skipping a meal occasionally is not a direct threat to your child's health: Assuming your child is within developmental norms for weight and height, if they do not eat one meal (or only a small amount today) they will be OK, and they will be hungrier at the next meal. I find that many parents today are extremely uncomfortable with the idea of their child missing a single meal. So much so that they try extremely hard to get a child who may not be all that hungry to eat. Become comfortable with the idea that developing children are more and less hungry at times and will not unduly suffer if they decide not to eat and as a result miss a meal. This realization can go a long way to changing the dynamic over mealtime eating. Allowing child to be "all done" if they are picking at, but not eating their meal. Parenting is challenging and we sometimes get so caught up in our role as nurturer that we may see failure to feed our children every four to six hours as a cardinal offense and evidence that we are a bad parent. Often, I find that this is one of the big hurdles for parents to overcome as it can be the source of their overwhelming investment in "making" a child eat when they really do not want or need to.

CHANGING THE SUBJECT: Start a wonderful conversation with your child about anything other than food. Tell them about your day, ask them about theirs.

5. Food Presentation Without Eating Requirement: This is one of my favorite ways to introduce new foods. Simply placing food on a plate that adults (parents and caregivers) take items from and eat, but do not prompt or require the child to take or eat. Numerous studies have shown that when foods are presented without an explicit directive to eat, over time (typically five to 10 days) many children will end up "trying" the food item or items. If little attention is paid to not eating and much social interaction (unrelated to eating the item) follows trying new foods over time, this habit tends to strengthen. The hard part is for the adults to make mealtime about the time spent together and not about the meal.

Changing the ongoing struggles with our children around mealtimes requires that we change what we do at and around mealtimes. This time and setting present us as parents and caregivers with choices. We **can** choose not to make mealtimes a fight, we do not **have** to feel compelled to make our children eat. We can simply prepare foods for our children to eat and socialize with them while they are eating. If they are not eating we can talk to the other children or adults at the table.

What we say or do is not actually under the control of our children. We choose to nag, argue and negotiate, we can also choose not to do so. That despite how it feels, our kids do not make us tell them things 20 times, we make us do that and we can decide not to continue a cycle that we know is unproductive but often hard to change while it is happening. Making the conscious decision to establish the routine we want to have rather than continue the one we know to be ineffective and unpleasant is a good first step. The behavior of our children can and will change if we recognize that our behavior must change first for theirs to change. •

ABOUT THE AUTHOR

Behavioral Education Assessment and Consultation Inc. (BEACON Services of Massachusetts and BEACON of Connecticut). Dr. Ross is also President Massachusetts Association for Behavior Analysis. He received his doctorate in educational leadership from Nova Southeastern University and his master's in applied behavior analysis from Northeastern University. He is the co-director of the BCBA certification program at Cambridge College in Cambridge, Massachusetts. In addition to his teaching and research roles at BEACON, he consults with programs and works directly with individuals with autism and Asperger's syndrome as part of his caseload responsibilities at BEACON. Dr. Ross has presented more than 100 applied research poster presentations, workshops, and symposia at ABAI conferences and authored several related articles.

THE ROLE OF NUTRITION & WELLNESS IN HEALTHY SCHOOLS

BY GARIMA JAIN

Nutrition is the science of nourishment which plays an important role in the growth and development of children, with a healthy diet synergistically enhancing physical and mental abilities. Nutrition dictates more than a person's body mass index. The balanced nutrition a child receives during the first few years of life can affect their health for years to come.

Poor nutrition can result from lack of food as well as overeating, since nutrition is about more than simple caloric intake. Proper child development relies on a solid nutritional foundation, which includes the correct amount of each nutrient. Having nutritional knowledge and making informed choices about the foods one eats can help achieve optimum health. Good nutrition is essential in keeping current and future generations healthy across the lifespan.

A study published in *The New England Journal of Medicine* measured children who were hospitalized for malnutrition during their first year of life. The doctors found that these children were consistently smaller than children who had not experienced malnutrition, even three and four years later. At the other end of the spectrum, the Academy of Nutrition and Dietetics suggests that poor nutrition in the form of overfeeding can contribute to weight issues later in a child's life. The Centers for Disease Control and Prevention (CDC) has conducted numerous researches on the importance of nutrition and healthy eating to prevent diseases in children and adults[1].This is particularly crucial since the findings show that fewer than 1 in 10 children and adults eat the recommended daily amount of vegetables and fewer than 1 in 10 children and adults eat the recommended daily amount of fruits. This contributes to nutritional deficiencies and diseases.

> "Children with Special Health Care Needs are more vulnerable to nutritional deficiencies. The Centers for Disease Control and Prevention reports nearly 1 out of 5 children in the United States has a special health care need."

Children with Special Health Care Needs (CSHCN) are more vulnerable to nutritional deficiencies. The Centers for Disease Control and Prevention reports nearly 1 out of every 5 children in the United States has a special healthcare need.[2] Children and youth with special healthcare needs (CYSHCN) require more care for their physical, developmental, behavioral, and emotional needs than their typically developing peers, making the role of nutrition even more crucial. According to Nutrition Guidelines for Children with Disabilities and Chronic Illnesses Journals, as many as 40% of infants and children with special health care needs are at nutritional risk. A survey of children from birth to age three years with developmental delays in early intervention programs found 70-90% had one or more nutrition risk indicators which includes altered growth, increased or decreased energy needs, medication-nutrient interactions, metabolic disorders, impaired ability to utilize nutrients, poor feeding skills, and partial or total dependence on enteral (tube feeding) or parenteral (intravenous feeding) nutrition.[3]

HOW DOES NUTRITION AFFECT SCHOOL PERFORMANCE?

Nutrition has a direct impact on children's academics, according to a 2010 study from *The Journal of Nutrition,* which found that undernourished two-year-olds entered the school later and were 16% more likely to fail at least one grade in school than their well-nourished peers. The scientists behind the study determined that this could decrease the child's lifetime income by about 10%. The United Nations Standing Committee on Nutrition says that even in mild or moderate situations, stunted growth resulting from poor nutrition is correlated with poor academic performance and lowered mental capacity.

Student participation in the United States Department of Agriculture (USDA) School Breakfast Program (SBP) is associated with increased academic grades and standardized test scores, reduced absenteeism, and improved cognitive performance. On the other hand, skipping breakfast is associated with decreased cognitive performance (e.g., alertness, attention, memory, processing of complex visual display, problem solving) among students. There is enough evidence to support that lack of adequate consumption of specific foods, such as fruits, vegetables, or dairy products, is associated with lower grades among students.

Nutrition can also have a direct impact on emotional or psychological development. The Center for Development has studied psychiatric issues where developmental emotional issues related to autism, hyperactivity, depression, bipolar disorder, schizophrenia and anxiety are associated with nutritional imbalances. Some minerals, such as calcium, have proved to be extremely important for emotional development. The deficits of specific nutrients (i.e., vitamins A, B6, B12, C, folate, iron, zinc, and calcium) are associated with lower grades and higher rates of absenteeism and tardiness among students. Poverty can be a significant contributor to nutritional imbalance.

Nutrition has an impact on behavioral development. Dr. David E. Barrett, a Harvard Medical School psychologist, and Dr. Marian Radke-Yarrow, a National Institutes of Health child development psychologist, performed research focused on behavioral issues in six to eight-year-old children. Their research showed that social behaviors were even more susceptible to the negative effects of poor nutrition than learning functions were. The children in the study who had poor nutrition during the critical two-year period after birth appeared withdrawn, less active and were less helpful than their well-nourished counterparts. There is evidence to support that children who are undernourished due to hunger are not able to focus, so they often have a lower attention span and behavioral and discipline issues. This leads to lower grades, higher rates of absenteeism and even grade retention. A well-nourished child has increased alertness and stamina to participate in therapies, educational activities, social interactions and benefits from fewer illnesses and improved coping skills.

Integrating Nutrition Across the WSCC Framework

Schools should provide students and staff with access to healthy foods and beverages, consistent messages about nutrition, and opportunities to learn about and practice healthy eating. Here are some evidence-based strategies and promising practices for using the **Whole School, Whole Community, Whole Child (WSCC)** approach to promote nutrition education and healthy eating behaviors across the school setting.

Nutrition Environment and Services	🟩 Allow students sufficient time to eat their meal. 🟩 Provide options for children with special dietary needs, per federal regulations.
Physical Education and Physical Activity	🟩 Ensure that students have access to free drinking water in the gym and other physical activity areas.
Health Education	🟩 Include nutrition education as part of a comprehensive health education curricula. 🟩 Ensure that health education curricula align with the *Dietary Guidelines for Americans 2015-2020* and address the healthy eating behavior outcomes in CDC's Health Education Curriculum Analysis Tool.
Community Involvement	🟩 Set up joint-use agreements for shared spaces, such as community kitchens and school gardens. 🟩 Link schools wit out-of-school programs that promote healthy eating.
Family Engagement	🟩 Encourage schools to provide materials about school nutrition programs and nutrition education in languages that students and parents speak at home.
Employee Wellness	🟩 Encourage school staff to model healthy eating behaviors. 🟩 Ensure that school staff have access to healthy foods and beverages in faculty vending machines.
Physical Environment	🟩 Give students access to safe drinking water across the school building or campus. 🟩 Give students the opportunity to learn how to grow food—for example, by creating a school garden.
Social and Emotional Climate	🟩 Ensure that food is never used as a reward or punishment. 🟩 Make sure that students who receive free or reduced price meals are not identified.
Counseling, Psychological, and Social Services	🟩 Train school staff to recognize signs of eating disorders and disordered eating. 🟩 Ensure that school staff can confidentially refer students to appropriate staff members for follow-up and referral to primary care providers as needed.
Health Services	🟩 Manage the nutritional needs of students with chronic health conditions, such as food allergies or diabetes.

Visit www.cdc.gov/healthyschools/wscc/strategies.htm for more information and additional examples on how to integrate nutrition strategies using the WSCC framework.

Centers for Disease Control and Prevention
National Center for Chronic Disease Prevention and Health Promotion
Division of Population Health

WHOLE SCHOOL WHOLE COMMUNITY WHOLE CHILD (WSCC) MODEL THE IMPORTANCE OF NUTRITION

The Whole School, Whole Community, Whole Child (WSCC) model recognizes the critical role nutrition plays in the overall growth, development and academic success of children and youth. The WSCC model is student-centered and emphasizes the role of nutrition, the connections between health and academic achievement, and the importance of evidence-based school nutrition policies and practices. Nutrition leads to overall wellness and schools can play a critical positive role.

FOOD FOR THOUGHT : NUTRITION INTEGRATION ACROSS WSCC FRAMEWORK

CDC SCHOOL NUTRITION
www.cdc.gov/healthyschools/nutrition/schoolnutrition.htm

CDC CHILDHOOD NUTRITION FACTS
www.cdc.gov/healthyschools/nutrition/facts.htm

CDC INCREASING ACCESS TO DRINKING WATER IN SCHOOLS
www.cdc.gov/healthyschools/npao/pdf/water_access_in_schools_508.pdf

COMPREHENSIVE FRAMEWORK FOR ADDRESSING THE SCHOOL NUTRITION ENVIRONMENT AND SERVICES
www.cdc.gov/healthyschools/nutrition/pdf/School_Nutrition_Framework_508tagged.pdf

LOCAL SCHOOL WELLNESS POLICY
www.cdc.gov/healthyschools/npao/wellness.htm

NATIONAL SCHOOL LUNCH PROGRAM AFTERSCHOOL SNACK SERVICE
www.fns.usda.gov/school-meals/afterschool-snacks-faqs

OFFICE OF DISEASE PREVENTION AND HEALTH PROMOTION: DIETARY GUIDELINES
health.gov/dietaryguidelines

SCHOOL HEALTH GUIDELINES TO PROMOTE HEALTHY EATING AND PHYSICAL ACTIVITY
www.cdc.gov/healthyschools/npao/pdf/mmwr-school-health-guidelines.pdf

UNITED STATES DEPARTMENT OF AGRICULTURE: CHOOSE MY PLATE
www.choosemyplate.gov

UNITED STATES DEPARTMENT OF AGRICULTURE: LOCAL SCHOOL WELLNESS POLICY
www.fns.usda.gov/tn/local-school-wellness-policy

UNITED STATES DEPARTMENT OF AGRICULTURE: NUTRITION STANDARDS FOR SCHOOL MEALS
www.fns.usda.gov/school-meals/nutrition-standards-school-meals

UNITED STATES DEPARTMENT OF AGRICULTURE: TEAM NUTRITION
www.fns.usda.gov/tn/team-nutrition

WATER AND NUTRITION
www.cdc.gov/healthywater/drinking/nutrition/index.html

School is the place to start to encourage wellness since 95% of children, ages five to 17, spend six to seven hours per day at school. A wellness *culture* begins with school leaders, including parents, administrators, and staff, and the first step is to ensure that the school is guided by a regularly updated wellness policy. A wellness *policy* is a written document meant to guide the school district's efforts to create healthy school nutrition and opportunities for physical activity. These policies, supported by the CDC, help promote healthy school environments so that children can thrive and become healthy adults. School wellness policies often serve as the backbone of a healthy school community.

The WSCC model has provided guidelines to integrate nutrition across the framework in all components to promote success of each child. The model promotes nutrition environment and services by providing opportunities for students to learn about healthy eating habits and ensuring access to healthy and appealing foods and beverages, such as school meals, smart snacks, and water access. Health Education should include nutrition education as part of the curriculum, ensure that the curriculum aligns with the Dietary Guidelines for Americans 2015-2020, and address the healthy eating behavior outcomes in the CDC's Health Education Curriculum Analysis Tool.

Schools' collaboration with parents is crucial as engaged parents ensure better outcomes for children. Schools can provide parents materials about school and home nutrition, provide educational opportunities and encourage families to participate in school programs and activities that promote healthy eating. •

ABOUT THE AUTHOR:

Garima Jain is the Central Region Coordinator for the Parents as Champions for Healthy Schools Project. This is housed at the SPAN Parent Advocacy Network. For more information, see https://spanadvocacy.org/programs/champions

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2. https://www.cdc.gov/childrenindisasters/children-with-special-healthcare-needs.html
3. https://www.doh.wa.gov/Portals/1/Documents/8100/961-158-CSHCN-NI-en-L.pdf
4. https://spanadvocacy.org/programs/champions

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PRACTICAL FEEDING TIPS FOR PARENTS AND CAREGIVERS OF CHILDREN WITH NEUROMUSCULAR DISORDERS

BY RACHEL EZEKIEL-FISHBEIN

HMS’s goal with the Coming to the Table series is to share concepts necessary to develop safe feeding support plans to help families and school personnel address the needs of children with complex feeding needs.

PHOTOS PROVIDED BY RACHEL EZEKIEL-FISHBEIN

Sociologists and psychologists have long touted the benefits of family mealtime for child development. Research released by Oxford University in 2017 suggested that "communal eating increases social bonding and feelings of wellbeing, and enhances one's sense of contentedness and embedding within the community."

Creating family mealtimes can feel daunting for parents in the special needs community, according to Marianne Gellert-Jones, MA, CCC-SLP, a clinical feeding specialist and speech language pathologist at HMS School for Children with Cerebral Palsy in Philadelphia. HMS recently released the first two videos in its "Coming to the Table" series of free online videos and companion print materials to provide practical feeding tips for children with neuromuscular disorders.

"Everyone wants to eat with their children. It's part of family life," says Gellert-Jones. "Children with significant feeding needs can be at risk for aspiration, struggle with feeding efficiency, and become fatigued due to neuromuscular deficits. Many children also have significant underlying gastrointestinal or other medical issues that can impact their oral feeding ability and their enjoyment of feeding experiences. We want to help decrease families' stress and make it safe and enjoyable for children with oral feeding challenges to be included in mealtimes."

The school serves children and young adults with complex disabilities from across the country. Most students have identified oral feeding issues. The school develops individualized feeding support plans for each student and provides training for staff, parents and caregivers.

GOOD COMPANY: *(Opposite page)* HMS student Sabina Heim is thrilled to be able to join her friends during mealtime. She is helped by HMS student feeder Maxine Fussell-Mills.

Eight-year-old Sabina Heim of Glen Mills, PA, enrolled at HMS two years ago. Her feeding issues began in infancy. At six months of age, doctors inserted a gastrostomy tube (g-tube) to ensure Sabina was getting adequate nutrition. Due to Sabina's significant issues with muscle tone, fatigue, and difficulty coordinating the suck/swallow/breathe sequencing necessary for safe oral feeding, her family was apprehensive about oral feeding. They feared she'd aspirate—a typical fear for parents and guardians of children with neuromuscular disabilities.

"Sabina's eating has always been a source of fear and anxiety for us, because even if she chokes on something a little bit, it's a big deal," says Michelle Heim, Sabina's mother. "I come from a huge Italian family that thinks a meatball can cure anything, and here was my daughter who couldn't partake in family meals. It could change the whole dynamic of a family event or holiday."

Last year, after a feeding assessment with Sabina's team and her mother, HMS developed a new feeding support plan focused on improving Sabina's comfort trying new foods, fostering greater independence, and promoting socialization during mealtimes.

TABLE TALK : INDIVIDUALIZED FEEDING SUPPORT PLANS

Individualized feeding support plans for each student focus on many areas that are critical for safe and enjoyable feeding, including:

POSITIONING

Positioning is the most essential area to consider when engaging in oral feeding with children who present with neuromuscular challenges. The hips must be positioned all the way back in the chair. Once a stable base of support is established, the trunk, head and neck will be better aligned to promote safe swallowing.

MANUAL SUPPORT

Most students at the school require hands-on support to achieve lip closure, and jaw support, so they can swallow. (To get a feel for why this is important, try to chew and swallow a piece of food or swallow a sip of water with your mouth open. You'll be surprised at how challenging this can be.)

PROPER UTENSILS

Utensil features (such as size, bowl depth and shape) are matched to meet the needs of each child to best promote successful oral feeding. Utensil selections are made based upon the size of the child's mouth, where the food needs to be placed in the mouth, and the child's specific oral motor challenges.

TEXTURE

The texture of the food must match the oral-motor skills of the child to allow them to manage and swallow food and liquid safely. HMS prepares its daily menu in unmodified/regular, chopped or pureed textures. This allows students with varied needs to enjoy and taste the same foods as their peers and promotes the experience of a shared meal amongst staff and students.

PREFERENCES

It is easy to lose sight of preferences when creating a safe eating plan, but it's important to remember that everyone wants a choice about what they eat and how they eat it (ketchup, mustard or relish on your burger? Soup first or as an entrée?). Part of building independence and making mealtime enjoyable is teaching students to communicate their preferences and ensuring that caregivers respect them.

SOCIALIZATION

All staff training promotes mealtime as a social time. Often, when oral feeding is limited or challenging, all the talk surrounding the meal focuses on food and the volume the child ingests. HMS's staff works to ensure that mealtimes are also opportunities for social engagement with peers and staff. Shared mealtime experiences really do support children in building relationships.

PERSONAL TASTE: HMS student Diana Rich enjoys a meal with feeding specialist Marianne Gellert-Jones. At home in Massachusetts, Diana likes to eat exactly what everyone else around the table is eating in exactly the same way they are eating it; At school, however, she is more comfortable having her food blended or chopped to make it easier to eat.

While Sabina still gets the majority of her nutrition from her g-tube, she is now also enjoying many of the same foods as her peers in the cafeteria, alongside her friends. Previously she had only enjoyed a few tastes of familiar foods provided from home. According to her mother, Sabina now loves mealtime and enjoys sharing stories with her family about what and how much she has eaten.

HMS's goal with the Coming to the Table series is to share concepts necessary to develop safe feeding support plans to help families and school personnel address the needs of children with complex feeding needs outside the HMS community.

Each video encourages caregivers to try experiential activities to drive home key concepts of positioning and manual support. The multi-media combination of written and video instruction in the Coming to the Table series was designed to be accessible to individuals with varied learning styles. All of these materials are accessible for free on HMS's website: https://hmsschool.org/.

"When a child gets their diagnosis, eating together is the single activity most families feel is a 'must' to maintain some sense of normalcy," says Gellert-Jones. "There are so many things their child can't do and giving up on feeding is something about which families truly struggle. Our aim is to aid children with oral feeding and swallowing challenges to safely engage in some oral feeding experiences together with their families. It may not look the same as everyone else's mealtime and it may need to be different depending upon the environment, but mealtime and oral feeding experiences remain incredibly important in most families. We want to help children continue to participate in that activity in a safe and meaningful way."

Research has yet to identify any single therapeutic method to make all kids more successful feeders. However, training caregivers and families to feed children safely has been shown to improve outcomes. Untrained feeders can contribute to mealtime stress and fear for the child, and also unknowingly contribute to significant health issues.

"There are many opportunities for professional development in the area of feeding for speech and occupational therapists," says Gellert-Jones, "but there isn't much geared toward caregivers or paraprofessionals who are providing direct care outside of a therapy session. The Coming to the Table Series isn't designed to replace professional support, but may be referenced by other professionals and accessed by families to reinforce basic concepts for safe feeding across many environments."

Not every oral feeding experience can be transformed into a full meal, but with training, many families and caregivers can provide safe and enjoyable oral feeding experiences. Some children may only enjoy a "therapeutic taste," which means a light gloss of the food on their lips or a spoon dipped in food or liquid and placed in their mouth. Others may be able to enjoy a more significant meal with a modification in the food/liquid texture offered or they may only enjoy part of a meal orally before receiving their tube feeding.

Diana Rich, 21, who has cerebral palsy and fluctuating muscle tone, moved into the residence at HMS when she was 14. Her father, Carry Rich, describes Diana as a "foodie." Her favorite foods are sushi and steak.

"You try to make life as normal as you can with the special conditions you've been given," says Carry Rich. "We've always eaten meals together as a family. Diana's needs are always in the forefront and we have to be conscious of what we're giving her."

Diana comes from a large family that enjoys spending time together. When she's home in Massachusetts, Diana likes to eat exactly what everyone else around the table is eating in exactly the same way they are eating it. That can mean corn on the cob or chicken on the bone. At school, however, Diana is more comfortable having her food blended or chopped to make it easier to eat. Due to her difficulties with managing her muscle tone, Diana cannot independently manipulate a bolus of food in her mouth to move it back to her molars for safe chewing.

"Mealtime is a very social time for us because it takes so long for Diana to have a satisfying meal that goes from her mouth into her stomach. It's tiring and you can't rush it,” explains Rich. “She loves the real food and I will often hold a piece of food on the side of her mouth for a very long time and she will just chomp on it and grind it.”

Diana, who uses an augmentative communication device to speak, often directs her mealtime routine using her device and her eyes. HMS student care supervisor Lauren Dukes, who works with Gellert-Jones to train HMS’s personal care attendants, emphasizes the importance of communicating with students throughout meals.

“I want students to have a choice about what they eat,” says Dukes. “This gives them dignity and teaches them to advocate for themselves.”

CONVERSATION PIECE

A mealtime conversation might sound like this with the student answering using a communication device:

Aide/Parent: You’re having chicken fingers and French fries for lunch today. Does that sound good?

Aide/Parent: Do you want ketchup on your chicken fingers (holding up choices so the student may eye gaze to their choice or use their device to respond)?

Aide/Parent: No? Okay. How about mustard? Would you like mustard on your chicken fingers?

Aide/Parent: Yes. Okay. A little or a lot? (The feeder mixes just a little in a small amount for the student to taste, knowing if they do too much or the student doesn’t like it the meal can be ruined for them.)

Ongoing communication is particularly important for students who are also visually impaired—as many students at HMS are—to help guard against any surprises during the meal. Even when you are not sure if a child can understand what you’re saying, assumed competence is important. Using language throughout meals also reinforces the concept of meals as a social opportunity and can support learning.

The social aspect of mealtime often goes by the wayside for children with oral feeding challenges. In most cultures, we celebrate with food, and the child who is left out because of medical issues, misses out on myriad opportunities to engage and connect with others.

Communication throughout the meal also reinforces students’ agency, encouraging students to advocate for themselves and direct their mealtime experience. While a child may not be able to feed him- or herself, they can choose what they are going to eat, when they are ready for the next bite, and how they would like that food presented.

After 30 years in the field, Gellert-Jones has lost track of how many times she has reassured caregivers and parents that the definition of a successful meal is not an empty plate.

“Think about how you’d want someone to feed you. You’d want them to focus fully on you and provide the care you couldn’t provide to yourself.”

“Forget the old adage about cleaning your plate,” says Gellert-Jones. “The definition of a successful meal is when the child and the person feeding them have had an enjoyable mealtime experience, in whatever form that takes on for that child. There are always opportunities to engage and include children in mealtimes, even those who present with the most significant feeding challenges. The goal of our video series is to train people to provide support that allows each individual to safely participate in mealtime activities across multiple environments.”

“We are sometimes scared and very cautious, but we’re learning to not be afraid to try things,” says Michelle Heim, eight-year-old Sabina’s mom. “We’ve learned how much she’s really capable of and how much she loves to see what she can do and advance to the next level. Like a typical kid, she feels a huge sense of accomplishment that she can follow through and do something new.

Understanding each child’s individual needs will alleviate uncertainty and apprehension.

“The number one thing is understanding how your child manages food, and that is completely individual,” explains Carry Rich. “For my daughter, the most important thing is portion control—how much of a spoonful will go into her mouth. Next is providing the right support. I have to use both of my hands—one under her jaw with my fingers on her cheeks and the other to hold a spoon or whatever she is chewing on. I know that I have to get the food into the right position in her mouth so she can reach it with her molars. And I need to make sure she is positioned correctly—that she is not leaning to the side or forward or bent over, so she is in a good position to swallow.”

The key to creating a strong feeding relationship is to keep your focus fully on the child.

Lauren Dukes advises parents, family members and caregivers who are watching the videos: “Think about how you’d want someone to feed you. You’d want them to focus fully on you and provide the care you couldn’t provide to yourself. Communicate throughout the whole meal, not just at the beginning and listen to the child in whatever way they can communicate. Don’t make assumptions, because their preferences may change from day to day. Remember this is about them, not you.”

Feeding can be challenging when the education and training isn’t provided to make it safe and enjoyable. When only a few close individuals are trained, comfortable, and safe feeding your child, the world in which your child can live is drastically limited.

“We hope to develop an entire series of Coming to the Table videos to provide training about a broad range of oral feeding issues for caregivers and families of children with neuromuscular disabilities,” says Gellert-Jones. “We believe these videos can expand the experiences in which children take part by imparting knowledge and increasing the confidence of parents and caregivers when engaged in feeding children with significant challenges across multiple environments.”•

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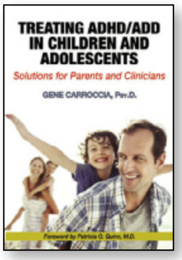

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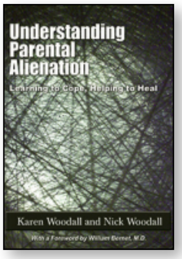

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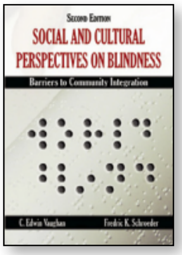

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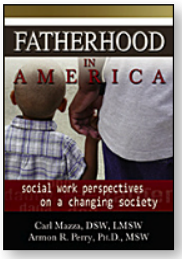

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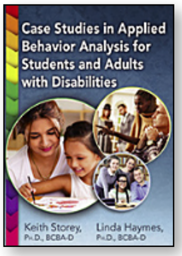

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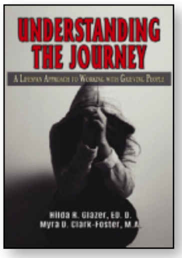

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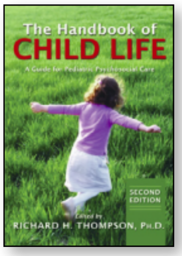

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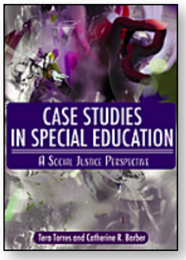

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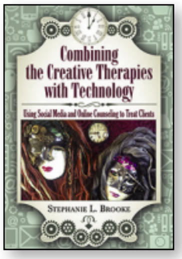

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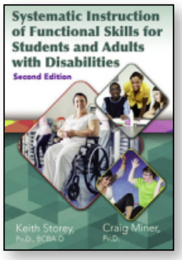

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Parents of children with intellectual/developmental disabilities may not initially realize that their child may also be struggling with mental health issues. It may be difficult to determine the cause of challenging behaviors.

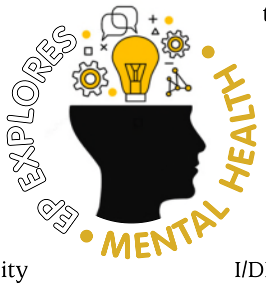
IT'S MORE COMMON THAN YOU THINK: HOW TO GET HELP WHEN YOUR CHILD HAS A DEVELOPMENTAL DISABILITY *AND* MENTAL HEALTH ISSUES

BY LAUREN AGORATUS, M.A.

PREVALENCE

Research shows that 35-50% of children with neuro/developmental disabilities may also be susceptible to mental illness.[1] The difficulty is that many systems are in silos, meaning that systems that deal with developmental disability may not address mental illness and vice versa. According to the NJ Family Crisis Handbook (see Resources), "The problem is the DD community doesn't have the mental health expertise; but the mental health community doesn't know how to deal with challenging behaviors or modifying their approach for someone with a developmental disability. The expertise in both the areas of developmental disabilities and mental health is essential for cost effectiveness and, more importantly, better patient outcomes."

There is also the misperception in some professionals that individuals with developmental disabilities will not benefit from mental health treatment. Families have been told that "impairments in cognitive abilities…make psychotherapy ineffective." Some parents have been told that "children with developmental disabilities are not capable of benefiting from mental health services." This is inaccurate; many mental health therapies can be modified for those with developmental disabilities.



It makes sense that individuals with intellectual/developmental disabilities (I/DD) could also have difficulties related to mental health since I/DD is described as including deficits in adaptive behaviors and social/emotional coping skills.

HOW TO TELL THE DIFFERENCE

Challenging behaviors may be difficult to distinguish, particularly in the moment. Families may also have emotional reactions which may muddy their thinking. One myth is that developmental

disabilities are the only cause of maladaptive behavior. People with I/DD can have mental illness, just as in the general population.

Parents have called the Children's System of Care in their state for help and are often asked if their child has a developmental disability. They may then be referred to a behaviorist when in fact they need mental health help. A child with a developmental disability who is threatening to kill themselves or others is in crisis, and behavior modification is ineffective.

Families can try to get a functional behavioral assessment from the school district (determines if the behavior is a function of the disability). Parents can also get a mental health assessment from a pediatric provider.

HELPING PROFESSIONALS TO HELP YOUR CHILD

Parents need to make sure that they're being clear with providers about what's happening with their child. Is it a typical "meltdown" due to autism or other developmental disability? Is it a mental health crisis outside of what is normal for the child?

Families must be aware that school districts may segregate students in either out-of-district placements or even home instruction. Home instruction was initially used for medical issues and is now being misused for challenging behaviors. School districts can include counseling, positive behavioral supports and interventions (PBIS), and other related services in school. IEPs (Individualized Education Programs) identify supports and services for children with disabilities, including I/DD and mental health disabilities, in schools. Families can contact their Parent Training and Information Center (see Resources) for help in this situation. Community-based services are essential for both children and adults in light of the Olmstead court decision.[2] Those with a dual diagnosis of developmental disability/mental illness (DD/MI) are more likely to be segregated due to the institutional bias that still exists in Medicaid.

One solution is to utilize cross-training across the DD and mental health systems. This must be ongoing due to high turnover of professionals. In addition, stakeholder input must include families of children with DD/MI as well as family-led organizations. Services must be consistent, regardless of geography.

While family caregiver engagement is key, this must be done in compliance with HIPAA (Health Insurance Portability and Accountability Act) to protect privacy. This is particularly essential in states with minor consent to treatment. There should also be procedural safeguards in place when children and parents disagree on treatment. It is difficult for anyone, even an adult, to recognize when they may need help if they are in crisis.

It is essential that underserved families be reached and served. Any family engagement must be representative of the population served. Services must be culturally and linguistically competent and result in the reduction of stigma.

A WORD ABOUT RESTRAINTS AND SECLUSION

Individuals with developmental disabilities, mental illness, or both, are a vulnerable population that is far too often subject to the inappropriate use of restraints, aversive interventions, and seclusion, all of which can result in increased morbidity and mortality. Restraints and seclusion are ineffective as behavioral intervention and are experienced by those subjected to these interventions as trauma, impeding recovery. The American Academy of Pediatrics (AAP), Maternal & Child Health Bureau (MCHB), and the Substance Abuse and Mental Health Services Administration (SAMHSA) among others, have developed guidance to eliminate the use of these techniques. The AAP actually considers these techniques as maltreatment of children with disabilities, akin to abuse (see **https://pediatrics.aappublications.org/content/127/5/e1367**). The key is the use of PBIS, emergency planning, and preventive strategies.

BARRIERS AND PROGRESS

One of the biggest issues is that there are not enough providers who are competent to appropriately serve individuals with DD/MI. Sometimes this is linked to low reimbursement rates so some providers are not willing to take Medicaid. Some states have addressed network inadequacy by integrating mental health into primary care. This is done using a child psychiatrist in a consultative model with a primary care physician.

Many states now have Children's Systems of Care (CSOC; see Resources). These now include services for children with developmental disabilities, mental illness, or both. States may also have families serving on a CSOC stakeholder group providing input on systemic issues.

FINAL THOUGHTS

If possible, de-escalate to avoid involvement with juvenile justice or police. However, if the person is a danger to self or others, call 911.

In summary, progress is being made in that some systemic changes are beginning to address both developmental disability and mental illness. Functional communication will help children from becoming frustrated and acting out. Prevention (being proactive), rather than being reactive, is most likely to help one avoid crisis. Using a comprehensive approach, families of children with developmental as well as mental health challenges will have their concerns better addressed.•

ABOUT THE AUTHOR:

Lauren Agoratus, M.A. is the parent of a young adult with multiple disabilities. She serves as the State Coordinator for Family Voices-NJ and as the central/southern coordinator in her state's Family-to-Family Health Information Center. FVNJ, the NJ F2FHIC, and the FFCMH State Organization, are all housed at the SPAN Parent Advocacy Network (SPAN) at www.spanadvocacy.org

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2. https://www.ada.gov/olmstead/

CRISIS AVOIDANCE : MENTAL HEALTH RESOURCES

HRSA Maternal & Child Health

TITLE V (in your state)

https://mchb.hrsa.gov

nami National Alliance on Mental Illness *Find Help. Find Hope.*

NATIONAL ALLIANCE ON MENTAL ILLNESS

www.nami.org/Find-Support/Family-Members-and-Caregivers

PARENT TRAINING AND INFORMATION CENTERS

(for school issues)

www.parentcenterhub.org/find-your-center

NFFCMH *National Federation of Families for Children's Mental Health*

NATIONAL FEDERATION OF FAMILIES FOR CHILDREN'S MENTAL HEALTH

www.ffcmh.org/our-affiliates

PerformCARE

(NJ) REVISED FAMILY CRISIS HANDBOOK: A MENTAL HEALTH, STABILIZATION, AND WELLNESS TOOLKIT

www.performcarenj.org/pdf/families/revised-family-crisis-handbook.pdf

POLICE

COMORBIDITY OF MENTAL ILLNESS AMONG CHILDREN WITH DISABILITIES

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

WHAT IS IT?

"**Comorbid** - existing simultaneously with and usually independently of another medical condition."[1]

"**Comorbidity** is associated with worse health outcomes, more complex clinical management, and increased health care costs."[2]

The term is used for children and adults with developmental disabilities along with co-occurring mental illness and behavioral difficulties. For example, when a youngster with developmental and behavioral difficulties is examined, it can be difficult to determine the underlying cause of these difficulties. In addition, because of their cognitive and adaptive limitations, individuals with a developmental disability are less likely to have developed appropriate coping skills for a variety of their difficulties.[3] (Note: a secondary condition is a disorder to which a person is more susceptible by virtue of having a primary disabling ailment.)

> *"Over the past decades the prevalence of comorbid mental and physical disease increased dramatically, reaching epidemic proportions in many countries. In persons over the age of sixty the simultaneous presence of two or more diseases has become the rule rather than an exception. Comorbidity is also increasing rapidly at younger ages where the negative consequences of comorbid conditions are as numerous and as troublesome as those that occur at a higher age."*[4]

There is every reason to believe that this increasing trend in the proportion of individuals who have comorbid conditions will continue in the years to come. The epidemic spread of unhealthy lifestyles increases the likelihood of occurrence of several diseases which tend to appear together, such as cardiovascular disease and diabetes. In addition, it is possible that deterioration of the environment will lead to a higher intake of pollutants and abnormalities in the immunological system of humans and thus, facilitate the occurrence of allergic and other diseases.[4]

Comorbidity does not mean the simple addition of two diseases that independently follow their usual courses. The simultaneous presence of two or more diseases will worsen the prognosis of all the diseases that are present, lead to an increasing number (and severity) of complications, and make the treatment of all of them more difficult and, possibly, less effective. A series of reviews published in recent years provides ample confirmation of these findings. [4]

What is worse is that one of the comorbid diseases often is overlooked. This is particularly true for mental illnesses which are frequently comorbid with physical illnesses. Non-psychiatric specialists and general practitioners usually are focused on the illness about which they know a great deal and which they wish to treat, often missing or underestimating the importance of mental disorders that might also be present. Specialists in disciplines other than psychiatry and general practitioners avoid making a diagnosis of mental illness, because:

- **Uncertainty about the diagnosis and treatment of psychiatric disorders.**
- **They would like to avoid the perceived stigmatization of their patients that occurs when they are labeled as mentally ill.[4]**

Psychiatrists are no better than other specialists at identifying comorbid conditions. They often deal with the mental illness they have extensive experience with and miss or undertreat comorbid physical illness and orthopedic problems. One can hope that in the future, all psychiatrists will acquire sufficient knowledge to diagnose and treat (or refer) non-psychiatric diseases and that the discipline of psychiatry will, therefore, become unnecessary. But we are far from this goal. For the time being we can admire psychiatrists who are able to provide care to people who have a physical as well as a mental disorder and regret that many cannot or do not wish to do so. [4]

> There is every reason to believe that this increasing trend in the proportion of individuals who have comorbid conditions will continue in the years to come.

> The epidemic spread of unhealthy lifestyles increases the likelihood of occurrence of several diseases which tend to appear together, such as cardiovascular diseases and diabetes.

The reality is that in cases of comorbidity there is a direct association between the severity of the physical condition and most classes of mental disorders, as well as with functional impairment in youngsters. Specific patterns of comorbidity have important implications for determining the causes and mechanism for prevention and interventions of these conditions. [5]

SPECIFIC EXAMPLES

1. Autism spectrum disorder in comorbidity with developmental, psychiatric and medical conditions

Autism spectrum disorders (ASD) often co-occur with other developmental, psychiatric, neurologic, or medical diagnoses. Findings from a national study of more than 2,500 eight-year-old youngsters with ASD included:

- 20% were classified with ASD by age 3; 36% between 3 and 5 years; and 44% after age 5 years.
- Overall, 83% were diagnosed with a co-occurrence with another developmental diagnosis.
- Specifically, 10% were diagnosed with a psychiatric co-occurrence and 16% were diagnosed with a neurologic comorbidity.
- "Highlighting the need for clinicians to keep in mind the high prevalence of associated diagnoses with an ASD diagnosis, and the possibility that in younger children other symptoms or disorders may be masking or obscuring core symptoms of ASD…" [6]

2. Genetic disorders

"The burden of genetic disorders associated with physical disabilities and psychiatric disorders is connected to increasing healthcare expenses and demands on the patients and their caregivers. Psychiatric comorbidities such as anxiety and mood disorders affect a large number of children and adolescents with genetic disorders, leading to poor quality of life and impaired psychological adjustment. Research on this population is scarce compared with studies on the comorbidity of psychiatric problems with physical illnesses (e.g. endocrine disorders and neurological problems)."[7]

3. Cerebral Palsy

Cerebral palsy results from brain damage or injury; comorbidity frequently with reported conditions which provide further obstacles regarding self-care, independent living and symptom management. Risk factors may be reduced with proper medical attention and practical treatment plans as some conditions result from unattended disorder symptoms. [8]

Some common coexisting conditions:

- Approximately 30 to 50 percent of cerebral palsy patients suffer from intellectual impairment, but individuals with spastic quadriplegia show the highest prevalence of impaired cognitive and mental ability.
- Up to 50 percent of cerebral palsy patients experienced one or more seizures over the course of their lifetime and afflicted individuals suffering from epilepsy concurrently experience significantly increased risk of intellectual disability.
- Spinal deformities, commonly occur in patients with cerebral palsy, causing chronic pain and inhibiting the pursuit of normal physical movements, such as standing, walking, and sitting.
- Cerebral palsy patients commonly experience vision and hearing impairment and speech and language disorders.

- Adults living with cerebral palsy have an increased risk of developing lung and heart diseases, typically due to inhalation of food particles into the lungs which can lead to aspiration pneumonia.
- Though inactivity and obesity show a high prevalence in children without mental and physical disabilities, those with cerebral palsy have a significantly increased risk for both given their limitations in participating in physical activities in addition to the tremendous amount of energy involved in self-care. [8]

OVERVIEW

The listing of comorbidity conditions of children with disabilities is an essential step in preparing parents, family members and other care providers (as well as health care personnel) to provide for youngsters with a wide complexity of health and social needs.

The lesson to be learned is that no extended group of children with disabilities should be defined by a single umbrella categorization (as with all children and adults). We can only improve our efforts to care for our children with an increased awareness of their individuality. •

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Steven P. Perlman, DDS, MScD, DHL (Hon) is the Global Clinical Director and founder, Special Olympics, Special Smiles and Clinical Professor of Pediatric Dentistry, The Boston University Goldman School of Dental Medicine.

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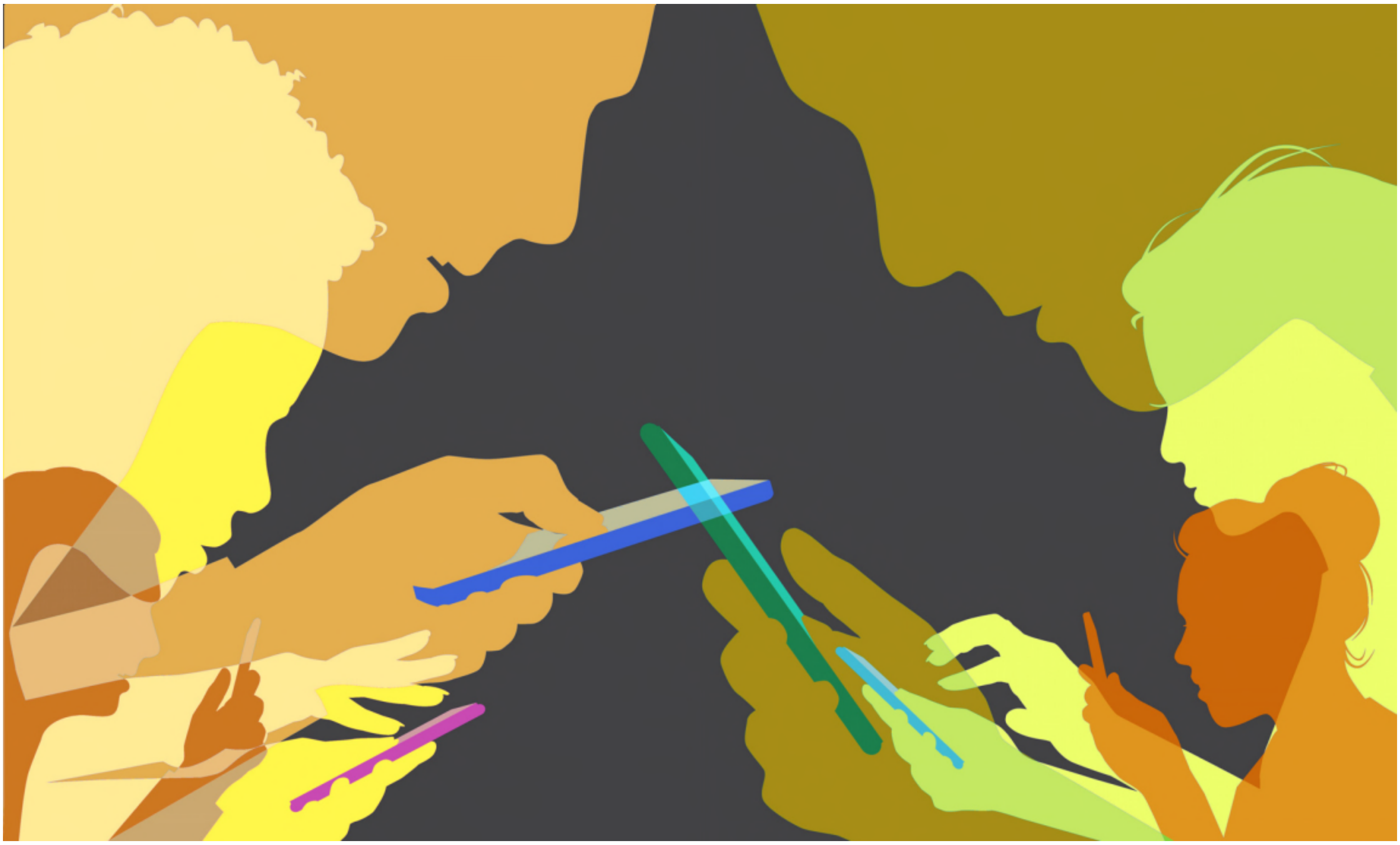
AMERICAN ACADEMY OF DEVELOPMENTAL MEDICINE AND DENTISTRY

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.

SOCIAL MEDIA, THE INTERNET, & MENTAL HEALTH



BY ERIK BEAN, ED.D.

Never before has information, both useful and destructive, been more available than at this very moment. The useful information and accompanying graphical components do not need an explanation. We can simply say we are grateful for the technology, the immediacy, and the accuracy of the information we choose to absorb, to lead a productive and happy life. After all, it is through apps and social media we can instantaneously communicate with family, friends, and work, to more effectively enjoy the day and plan for tomorrow. But this access can have a negative impact on our youth. For years we have seen the popularity of social media grow and we have all heard stories of tragedies associate with it. Children and teens suddenly find themselves caught in a self-esteemed pickle, judging their sense of worth by the number of likes or lack of likes their post may yield.

EP EXPLORES MENTAL HEALTH

And for young people interacting over the Internet, the temptation for abuse and to wander to areas dubbed the "dark web" can lead any "well-adjusted" individual into addiction or worse, isolation and loneliness, let alone those with compromised mental health issues. Even if they do not become victim to the dark web, there is a preponderance of "fake news" and even "fake ads." This phenomena is documented in my own paper, "Industrial age advertising identify solutions for a 21st century social network driven world" at the Internet, Politics, Policy 2018: Long Live Democracy conference at Oxford.

The most fascinating walk away from the conference was that so-called normal or well-adjusted individuals may, from time to time, reshare information about a political candidate they want to see elected even if they have not properly vetted that information for accuracy and its source. We are all responsible to read between the internet lines and use information wisely. The implications for our youth can be even more consequential than in adults.

Youth who exhibit any number of traits along the "atypical" categories are among those most at risk when it comes to properly understanding information, interacting with social media, and the internet. For example, kids struggling with anxiety, depression, or a plethora of other mental health issues.

On top of the strains from social media, these children face other battles as well. Some face difficulties socializing or deal with a mental illness, but it is not properly treated because age becomes a barrier. My son, Ethan, took his own life. He was autistic and struggled socially. He also was an example of a child who could never get an accurate diagnosis because of his age. He had a mood disorder and found himself in the juvenile justice system. Despite his struggles, we never believed he would take his own life. Honestly, I don't believe any parent expects it or sees it coming. However, suicide rates continue to climb. For each child the reasons vary, and it could come from multiple feelings. An 11-24-19 report (**www.cbsnews.com/news/functional-magnetic-resonance-imaging-computer-analysis-read-thoughts-60-minutes-2019-11-24/**) on the CBS television show 60 minutes showcased a team from Carnegie Mellon University who believe for many people who take their lives, their brains are wired differently. These feeling of taking their life may not be necessarily tied to a current situation or atypical diagnosis. So it might not be about medication to deal with the feelings as much as that scien-

SCREENING PROCESS : RESOURCES FOR MENTAL HEALTH AND THE INTERNET

Here are good resources on exploring the Internet and its societal affects, to simply let you know who they are so you can follow them how you see a fit knowing yourself, your children, and your family.

EDUCATIONAL

OXFORD INTERNET INSTITUTE
Oxford University, ENG
www.oii.ox.ac.uk

INFORMING SCIENCE INSTITUTE
Santa Cruz, CA, USA
www.informingscience.org/About

THE CENTER FOR INTERNET RESEARCH
Haifa, Israel
http://internetcenter.haifa.ac.il/index.php/en/home-english/48-about

JMIR MENTAL HEALTH
One of the many journals on the topic
https://mental.jmir.org/2018/2/e44/

MENTAL HEALTH AMERICA
www.mhanational.org/risky-business-internet-addiction

GOOGLE SCHOLAR
Related articles
https://scholar.google.com/scholar?q=internet+research+and+mental+health+organizations

WORLDOMETER
Startling real-time health statistics
www.worldometers.info

GOVERNMENTAL

NATIONAL INSTITUTE OF MENTAL HEALTH
www.nimh.nih.gov

WORLD HEALTH ORGANIZATION
www.who.int/mental_health/en

CENTER FOR DISEASE CONTROL AND PREVENTION
www.cdc.gov/childrensmentalhealth/research.html

tists might be able to rewire brains so the feelings of ideation can be curtailed.

As a result of my son becoming a foot soldier of the mental health crisis ending in his life, I intend to raise awareness in schools and beyond. I have met with a state senator and plan to testify before a Michigan legislative committee about the juvenile justice system's handling of children with mental illness. The system is flawed and needs adjusting for children like my son. It's too late for him, but by joining forces and through education I believe we might be able to slow it down.

My book, *Ethan's Healthy Mind Express*, co-authored with Emily Waszak, went on sale on November 23, International Survivors of Suicide l Day. The book we believe is the first children's mental health primer and we include 5 lessons – including a warning to avoid the dark web, areas of the internet that can lead to isolation or mistrust. My wife, Stacey, and I hope to use the proceeds from the book to go into schools with the Ethan's Healthy Mind Express story. My wife and I also started the Ethan Bean Mental Wellness Foundation (EBMWF, https://ethanbean.org) with a mission to help distribute the latest research and information to assist in leading an international conversation about mental wellness and let each individual family decide how to best mitigate the potential risks.

It takes the whole community. As we say in the book, "It's not just the train, it's really the track!" meaning it's not just the kids who need to understand how to get along, the community must consider new ways to help inclusion and new ways to combat feelings of suicide for those with suicide ideation. I never want Ethan to be forgotten. He felt like he was. Only we, as a community, can create the change necessary to ease the suicide epidemic. It is up to us to protect our youth.

Youth who exhibit any number of traits along the "atypical" categories are among those most at risk when it comes to properly understanding information, interacting with social media, and the internet. For example, kids struggling with anxiety, depression, or a plethora of other mental health issues.

For additional information on the Internet and mental health, see this study published on Aug. 13, 2019 in The Lancet, "Roles of cyberbullying, sleep, and physical activity in mediating the effects of social media use on mental health and wellbeing among young people in England: a secondary analysis of longitudinal data" (https://www.thelancet.com/journals/lanchi/article/PIIS2352-4642(19)30186-5/fulltext).

The research community is waking up to the risks and hope you stay tuned to the EBMWF so we can take this information and aid those we reach. We are just establishing ourselves and open to collaborating with other like-minded people and organizations for the sake of better mental health for all.•

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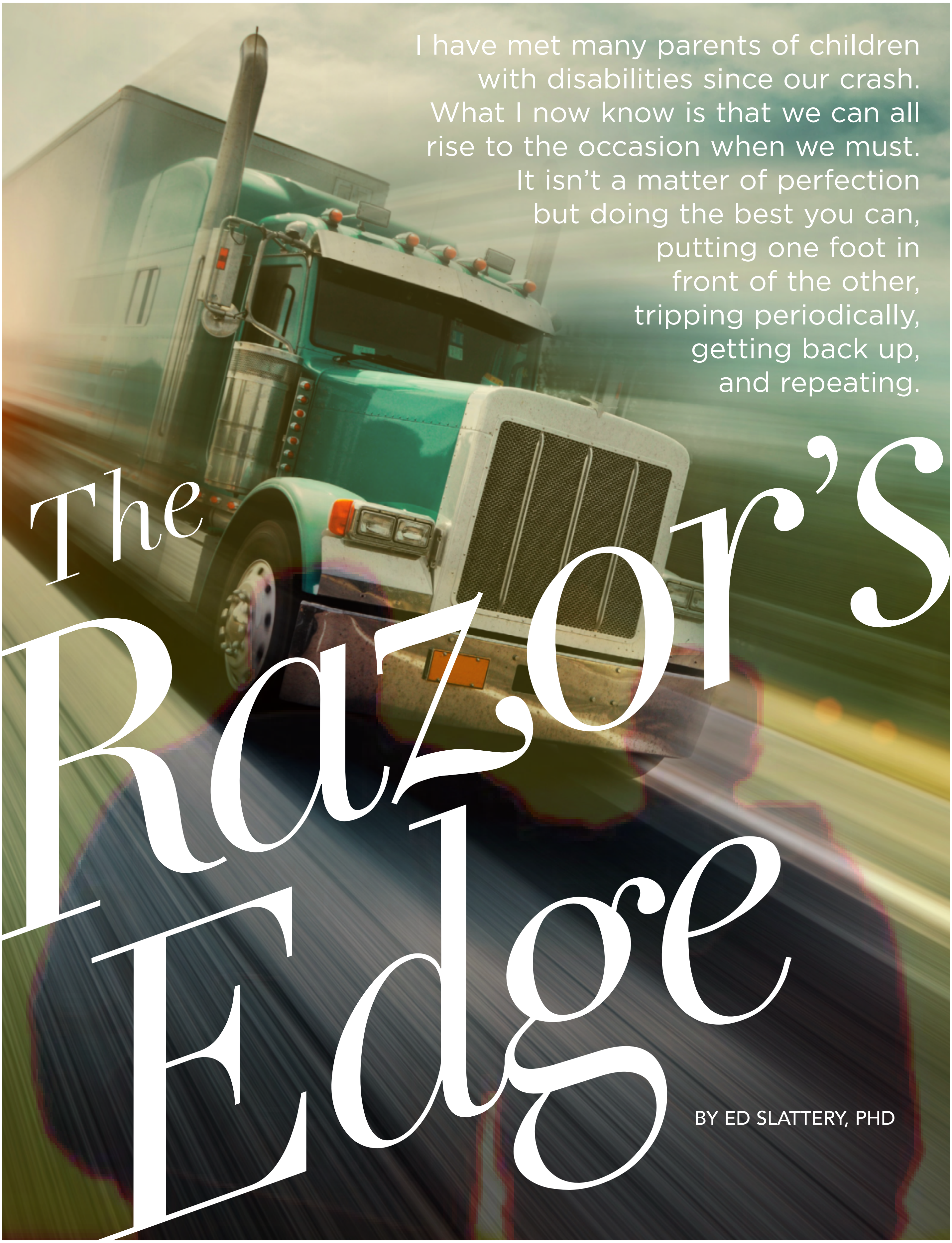
Erik Bean, Ed.D. is Associate Research Chair at University of Phoenix.



I have met many parents of children with disabilities since our crash. What I now know is that we can all rise to the occasion when we must. It isn't a matter of perfection but doing the best you can, putting one foot in front of the other, tripping periodically, getting back up, and repeating.

The Razor's Edge

BY ED SLATTERY, PHD

I always thought I was a good dad. I was involved in my sons' lives and, together with my wife, we strove to raise good human beings; strong men of both body and mind to contribute to society and lead happy and responsible lives. So, I thought I was a good parent, until a tired trucker crashed into my family's car, killing my wife and severely disabling my youngest son. Then I quickly learned I was out of my depth.

My wife Susan Slattery was killed almost instantly when a trucker fell asleep at the wheel of a triple tractor-trailer on the Ohio Turnpike as traffic slowed for construction. She was one of 3,686 people who were killed in large truck crashes on American roadways in 2010. My two boys, Matthew and Peter, 12 and 16 at the time, were two of the 80,000 people the Federal Motor Carrier Safety Administration (FMCSA) says were injured in crashes that same year; numbers that have surged thirty percent since my family's crash nine years ago.

Susan was not just my wife, not just mom to our two amazing boys, not just a popular mathematics professor at a university outside of Baltimore. She was our rock, the center of our family; the tutor, the den mother, the field trip volunteer, the activity organizer, the fundraiser. She was the love of my life and there isn't a second of a day that we don't miss her and feel her loss.

I am now a widower, a single father caring for my youngest son Matthew who suffered a crippling traumatic brain injury from the crash. I quit work to be his full-time caregiver; he is wheelchair-bound and will need care for the rest of his life. While we are fortunate enough to have been able to build a state-of-the-art, universally-designed home to free the house of any traditional hurdles to a disability like Matthew's, I am still reminded every day of just what my family lost at mile marker 190 on the Ohio Turnpike.

Susan's death was easy, in a way. It was final. It's Matthew I grieve for every day. He's my constant reminder, a reminder that, in the end, our tragedy was pure happenstance. That driver made the decisions he made, the trucking company ran the routes it did the way it did, and Matthew is the living result. Our fortunate settlement cannot, and will not ever really square that in a way that makes sense of our loss.

I call it the razor's edge.

Every day it is like I am walking on this really thin edge. On the left is this wonderful world with this kid, this guy who makes me laugh, who loves me, whom I adore, and whose accomplishments I revel in. But on the other side, is the same kid with all the things he should be doing, but he isn't doing. Matthew should have gone to prom, be getting drunk, finding love and heartbreak, and getting his driver's license. He will never do those things, at least not in a normal way. That is my razor's edge, fall to the left and everything is rosy, fall to the right and everything is scary.

This is a line I know I will precariously straddle the rest of my life. I tried at first to make it easier by trying to find purpose in our tragedy through other people. I wanted to join forces with the trucker, whose own life suffered in many ways as well. He went to prison and now, to this day, he can no longer drive a truck. I wanted us to tell our story together, to a nation, a cautionary tale to help create change; how the drive to lower the cost of transporting good(s) across this country can be paid in injury, death and loss of freedom. It was, for a while, how I planned to avenge my wife's death and my son's disability; it was how I would make sure it wasn't all in vain.

But, for reasons I hope you will read in the book, *The Long Blink,* that didn't happen.

So, in order to avoid falling off to the wrong side of that razor's edge, I needed to find a way to balance myself. Following the incredible example set by my wife, we give back. We give back until it hurts. I've started several nonprofits aimed at helping the children with disabilities as severe as Matthew's. I also created a fund at the Kennedy Krieger Institute in Baltimore to bridge the gap between what an insurance company is willing to pay, and what families can afford. I credit all the doctors and staff there for Matthew's recovery and I never want to see another family go without the resources we received.

I also advocate on Capitol Hill for truck and highway safety with the Truck Safety Coalition. I have told every lawmaker who will listen, of my family's story, and will continue to do so, in an effort to increase safety regulations. I also help counsel families who have experienced tragedy like we have, in the hopes that I can offer them comfort and insights from my experience.

> "That is my *razor's edge,* fall to the left and everything is rosy, fall to the right and everything is scary."

Mostly though, I focus on Matthew. His accomplishments are almost always small steps, but they deserve the same kind of fanfare of a prideful father in his child athlete. Matthew's athletic prowess may be limited, but his determination and sheer will are the opposite. He would rather use his disabled right hand to push his glasses up from the tip of his nose with his reluctant pointer finger than use his now dominant left hand. I've learned to just let him figure it out on his own.

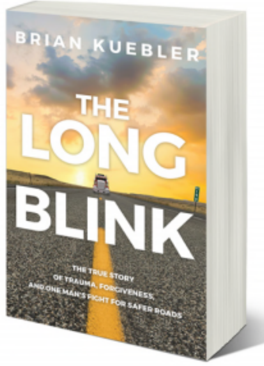
Recently, he began equine therapy and I cannot begin to describe what it is like to see my son not only ride a horse with assistance, but bond with the animal in such a way that it provides such pure joy for my boy.

Most important, Matthew is happy. He laughs, makes jokes, and possesses a wit that, if you're too patronizing with your conversation, he will gladly expose.

Still though, he remains severely handicapped and needs intense assistance to accomplish all of it. Often, I wonder, what is he really thinking? What is it that he is not able to express to me because of his aphasia? These questions haunt me.

My other son healed fully from all his injuries and setbacks from the crash, He not only went on to graduate high school on time, but also achieved Eagle Scout, the highest rank in Boy Scouts. He worked hard and never missed a beat despite the severity of his injuries. Peter graduated from Rhode Island School of Design and is making a career as a senior designer on the West Coast. I am prouder than hell of him but always worry about how he integrated all of his own losses into his psyche.

The strides of both my boys though, are a great source of joy for me, but I have come to the realization that it cannot make me whole. My sons' successes and accomplishments and, in Matthew's case, his continued incremental improvement are gifts, but when it comes to my youngest, they can also be a curse.



Title: **The Long Blink: The True Story of Trauma, Forgiveness, and One Man's Fight for Safer Roads**

Author: **Brian Kuebler**

Publisher: **Behler Publications**
Publication Date**: September 24, 2019**
Paperback: **224 pages**
ISBN-13: **978-1941887042**
Available at Amazon, Barnes and Noble or www.brian-kuebler.com

It is the only lasting regret I have in my life. I obviously regret losing Susan and the injuries to my boys. I regret the whole thing, but what continues to face me every single day is Matthew, and I will never, never get over it. Every day of my life I have to see this child not accomplish what he could accomplish. And that is a pain so few can ever understand.

I say this not as a burden, but a duty. The way I see it, I have maybe another good 20 years left on this planet and it is my purpose to honor my sons and my late wife. I owe it to them to tell our story so that maybe, just maybe, other families may never have to experience our fate.

I have met many parents of children with disabilities since our crash. What I now know is that we can all rise to the occasion when we must. It isn't a matter of perfection but doing the best you can, putting one foot in front of the other, tripping periodically, getting back up, and repeating.

Once people know my story, or read the emotional narrative in The Long Blink, they often say they couldn't do what I am doing; they aren't strong enough. I always respond, "Of course you could. You might even do it better." •

ABOUT THE AUTHOR:

Ed Slattery lives with his son Matthew outside of Baltimore, Maryland. The family's story is the subject of a new book by award-winning investigative journalist Brian Kuebler titled, *The Long Blink: The True Story of Trauma, Forgiveness and One Man's Fight for Safer Roads.* The release, by Behler Publications, is available wherever books are sold.

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NEVER STOP TRYING

PHOTO PROVIDED BY KIMBERLEE RUTAN MCCAFFERTY

BY KIMBERLEE RUTAN MCCAFFERTY

A few weeks ago, I was scrolling through Facebook and happened upon one of my old posts, which was being reposted on the Autism Speaks blog and Facebook page. It was a piece entitled “Dear Future Caregiver of My Son with Autism,” and was a letter to future care givers about my boy and my hopes for his life. For the most part, it went over well, although truth be told, I don’t often read the comments on my pieces. I rarely learn from the negativity, and often the commentators are “trolls” who upset other readers who come to my defense, and generally I’m just not into the futility of it all. I began writing this blog over nine years ago after my second son was diagnosed, and I’ve learned over time how to deal with criticism. I write for me, and for any reader who can take comfort in my words and realize he or she is not alone.

The piece received about a hundred comments; I skimmed through them and all seemed well until I hit the last one. The writer said: “She didn’t try. She tried to change her son when there was not anything wrong with him to begin with,” which I believe was in response to the paragraph I wrote below:

> *I want you to know we tried. We finally got him to crave sleep (that one took a few years, yes you can thank me now), to eat things that weren’t carbs including two veggies (that one’s going on my tombstone, I am still so proud), to learn how to dial back some of the innate aggression that occurred when he didn’t get his way. We taught him to use a fork (okay, sometimes) and to understand that leaving the house is often fun, and should last more than 37 minutes. I encouraged him to go on errands with me and not try to purchase everything he saw (just a heads-up, that will not work at Walmart or Toys R’ Us, be warned).*

It also may have been in response to my commentary regarding how difficult it could be to keep him from carb overload, that when his DVDs are defunct, he can be intractable in his desire to keep trying to play them.

I’ll never know for sure which was this specific reader’s complaint; perhaps it was all of it.

As I’ve mentioned, I generally do not respond to commentary left on Autism Speaks or on my blog, as I feel strongly my time can best be spent elsewhere, but I felt I had to respond to this. I’m doing so in complete honesty, not because I’m upset. We’ve been an autism household for over 16 years now, there are many other things far more upsetting to deal with than this. I’m responding because my take on this commentary is that I should be shamed for trying to make his life better.

And I will not remain silent about that.

To this reader I will proudly say I have tried to change some of his behaviors since he was diagnosed, all in the cause of turning a child who was suffering from sleep deprivation, gut issues, transportation fears, a desire to only eat carbs, and sometimes aggression, into one who revels in his life and is happy. I will say to this reader you're dead wrong—I did try, and will continue to try to give him the best life possible, and not just for him, but for the rest of his family too.

There is nothing wrong with my severely autistic son; I love him for who he is. When you're a parent however, and you see your child suffering, I believe you have a moral imperative to try to ameliorate that suffering. So, reader, you're right about this. I tried to change my son into someone who sleeps, because that's best for his health and for the health of the rest of his family. I've tried to teach my son limits regarding snack foods and introduced vegetables, because that's what's best for him. I tried desperately to eliminate his aggression so he could thrive, and in this, I am proud to say we are mostly successful. And yes, I've worked very hard to change his tolerance to the outside world, not just for him and our family in the present, but for the future and those taking care of him for 40 years when I'm dead.

We are not rich. Justin will not have "Rain Man" accommodations someday. He will not have family to care for him, and will be in a group home, and will have to go out some days. I know this because I worked in one for several months, and sometimes, the entire group just has to go. I worked hard on building his tolerance to the outside world because folks, I am a planner, and while I see the boy in front of me I also see the man to come, the man who will be living with people barely paid to take care of him, who most likely won't love him.

> *"I tried not to change the fundamental core of who he is, but instead to give him his best life possible. I will continue to try to give him a life he loves, to keep him safe, to push his limits so he doesn't miss out on anything that could bring him pleasure."*

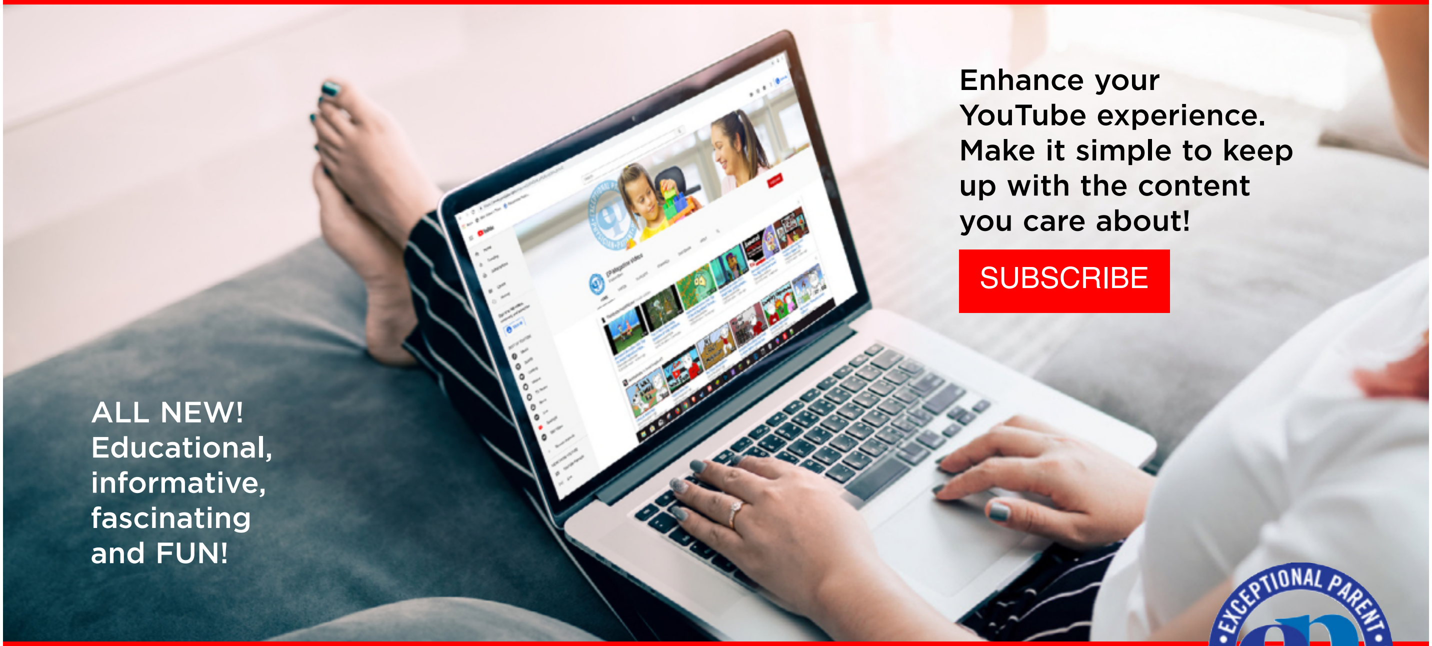
I have worked desperately hard to help him become a joyful child who will be as easy as possible for his future caregivers so they can meet his needs when I'm in the grave. I did try. I tried not to change the fundamental core of who he is, but instead to give him his best life possible. I will continue to try to give him a life he loves, to keep him safe, to push his limits so he doesn't miss out on anything that could bring him pleasure.

He and his brother are my life. I will always try to create an oasis of happiness and peace for them both.

And in that endeavor, I will never stop trying.•

ABOUT THE AUTHOR:

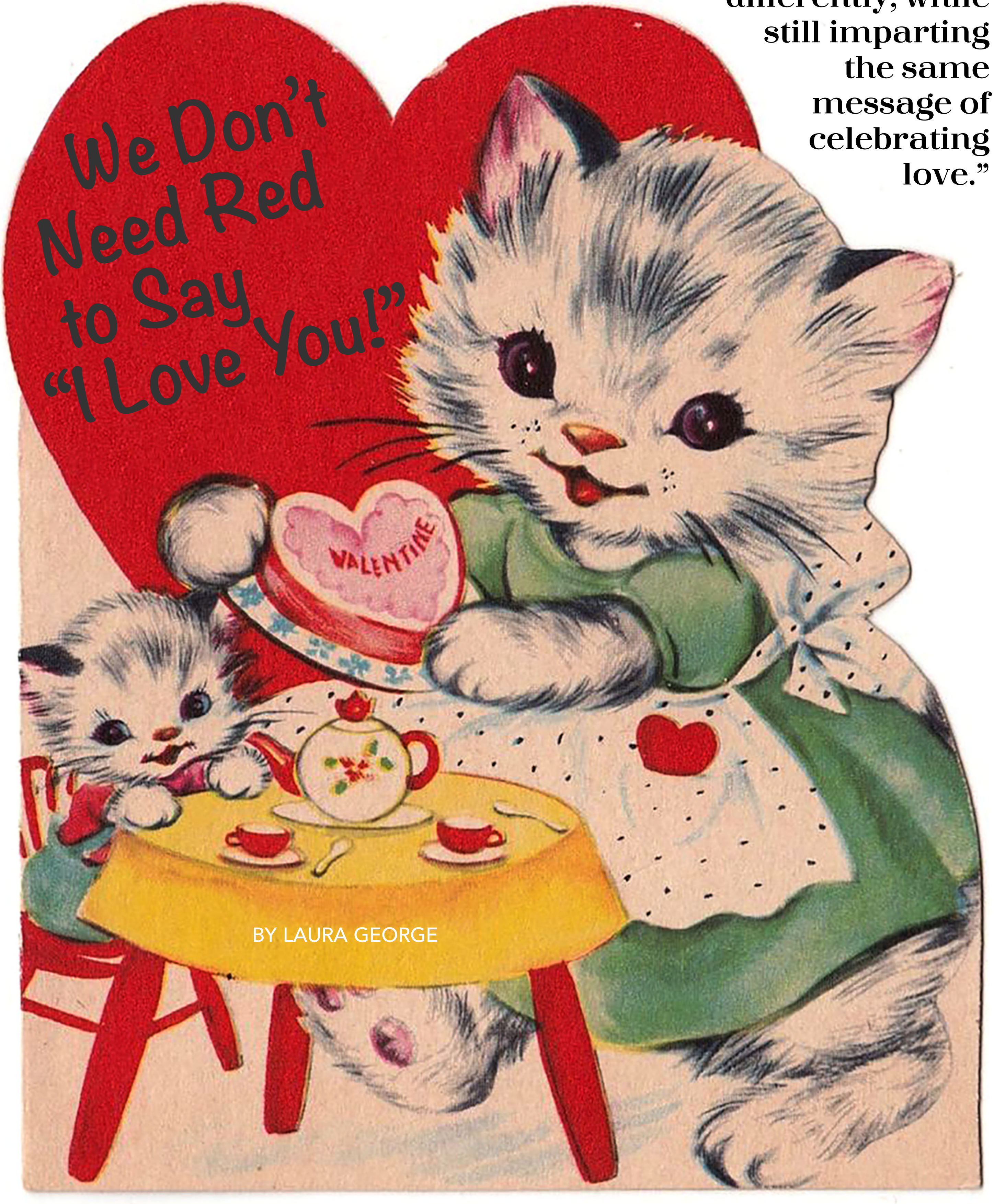
Kimberlee Rutan McCafferty, mother to two sons on the autism spectrum and an Autism Family Partner at the Children's Hospital of Philadelphia (CHOP). Kim is also the author of a blog at autismmommytherapist.wordpress.com. Kim's book *Raising Autism: Surviving the Early Years* is on sale on Amazon here.



“For many parents of exceptional children such as myself, it has become important to learn how to observe Valentine’s day differently, while still imparting the same message of celebrating love.”

We Don’t Need Red to Say “I Love You!”

BY LAURA GEORGE



Seasonal thoughts of love are in the air for Valentine's day. Candy hearts, assorted hard candies, chocolates, flowers, and perfumes are some of the traditional items to give that help us demonstrate our love for one another.

Holiday participation is especially important for parents like myself when we teach and enjoy sharing that moment with our children. According to History.com, the giving of food and perfumes on Valentine's day came around the 18th century where "small tokens of affection were exchanged." According to HistoryExtra.com, when Hallmark produced their first Valentine card, the commercialization of the holiday occurred. It then became common to exchange symbols of love and affection with one another. Today, it is the holiday that is not just observed between lovers, but also between siblings, even at elementary school, and is considered a popular holiday in America.

These days, there's also more of an acceptance and understanding that not all children will be able to observe Valentine's as others do, with store-bought cards and candies. In fact, for many parents of exceptional children such as myself, it has become important to learn how to observe Valentine's day differently, while still imparting the same message of celebrating love. It must be remembered that some children cannot eat the color red, have milk, eat corn, or even be near nuts due to allergies and the possibility of anaphylaxis. Other children might be chemical sensitive to perfumes and flowers, which can cause respiratory concerns or other challenging issues. There are also children who do not have the ability to see, hear, touch, or comprehend the item being given. They may let you know that Valentine's is holiday they cannot easily participate in or enjoy in the way others do.

Have you ever seen or had those little pastel colored candy hearts? Though the candies may be pretty, children with color dye issues cannot have them. So it might be considered ironic that those little candy hearts that are synonymous with the holiday have their history in the medical community. The same pharmaceutical profession that is relied upon to create medications to help our children heal and recover. According to HuffPost.com, the traditional candy hearts that come with a wide variety of compassionate and caring phrases first arrived in 1847. A machine that produced sugar paste medicinal lozenges was created by a pharmacist to address the long process that historically had been used to make them. Eventually, he tired of making the lozenges and converted the process to make candy instead. Later on, the pharmacist's brother started a process using food coloring to put words on them. A section in the latter part of the article suggests that during the Civil War, soldiers would use them to send romantic letters to their lovers who were civilians.

Yes, the irony of those sweet tokens of love is that they cannot be seen by some children who are blind, tasted by those with allergies or swallowing disorders, felt by those who don't have tactile sensation, and perhaps smelled by those who have chemical sensitivities. Children who cannot hear sadly cannot listen to the words of others describing their enjoyment of the sweets. Last but not least are the children with developmental disabilities, some of whom may have limited understanding of the events occurring around them.

For any parent who loves their exceptional child deeply, it is important that they feel comfortable and enthused about celebrating this holiday of love. For me, it is not important to give my daughter red-colored food to let her know of the love I have for her and who she is. What does matter is that I create an opportunity for my child to smile.

So where do you begin? First, you need to consider what your child is capable of doing and design the holiday around their best personal traits. Speak with fellow support groups, family, school, research the Internet and, most important of all – ask your child how they would like to observe and participate in this loving season.

With my daughter, her teachers have made it clear they appreciate my regular, educational notes about my child's serious immune issues. The teachers send me notes asking for creative ideas and solutions to maintain equal inclusion of my child in class activities. If you know in advance that your child's class is having a party, do not wait for the teacher to reach out to you. Offer to be there on the day of the party to assist with all the activities; be present behind the scenes. The teachers will greatly appreciate your proactive interest.

Most school parties will have an exchange of cards. Consider creating pieces of Valentine shapes that children can put together, or give instructions for how these can be created. This will give them a sense of accomplishment and pride in handing out their creations to the other children. Offer to write the names and tiny messages on the Valentine cards to eliminate writing frustrations for those who may face some challenges.

BE MINE : VALENTINE CARDS

Here are some helpful links for ideas to create cards with your exceptional child:

21 FREE PRINTABLE VALENTINE'S DAY CARDS FOR KIDS & ADULTS

https://blog.thepapermillstore.com/21-free-printable-valentines-day-cards-kids-adults

Tangible Valentine Cards

TANGIBLE VALENTINE CARDS

www.pathstoliteracy.org/strategies/tangible-valentine-cards

PLAY TIME: VALENTINE FUN AND GAMES

After the card exchange, the children will probably want to eat and play games. Here are some fun activity ideas:

PATHS TO LITERACY

Valentine's Day Fun for Children Who Are Blind and their Siblings for Kids & Adults

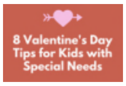
www.pathstoliteracy.org/strategies/valentines-day-fun-children-who-are-blind-and-their-siblings

SIGN LANGUAGE GAMES CRAFTS AND ACTIVITIES

www.pinterest.com/iCANsign/sign-language-games-crafts-and-activities

TACTILE VALENTINE'S CRAFTS & IDEAS FOR BLIND KIDS

www.pinterest.com/wonderbabyorg/tactile-valentines-crafts-ideas-for-blind-kids



TIPS FOR HELPING CHILDREN WITH SPECIAL NEEDS ENJOY VALENTINE'S DAY

www.abclawcenters.com/blog/2017/02/13/special-needs-valentines-day-tips

VALENTINE'S DAY FOR CHILDREN WITH VISUAL IMPAIRMENTS OR MULTIPLE DISABILITIES

www.pinterest.com/pathstoliteracy/valentines-day-ideas-for-children-with-visual-impa

SO GOOD: VALENTINE SWEET TREATS

Then there are all the candies and chocolates to be enjoyed:

CHOCOLATE COVERED FUN FOR ALL AGES AND ABILITIES

By Mary E. Ulrich Feb 14, 2019 Climbing Every Mountain

https://climbingeverymountain.com/chocolate-covered-fun-for-all-ages-and-abilities

GODAIRYFREE

Dairy-Free Valentine Day Recipes by the Dozen

www.godairyfree.org/news/dairy-free-valentines-day-recipes

NATURAL CANDY STORE

www.naturalcandystore.com/category/valentines-day-candy

TOO COOL: VALENTINE WISHES

If the child has a serious medical condition that has them in the hospital, consider participating in one of these projects:

CARDS FOR KIDS WITH CANCER FOR VALENTINE'S DAY

https://k1047.com/2018/02/07/cards-kids-cancer-valentines-day

THE VALENTINE PROJECT

https://thevalentineproject.org

HOW TO MAKE A FRIENDSHIP BRACELET

www.instructables.com/id/how-to-make-a-friendship-bracelet-1

BEADS OF COURAGE

www.luriechildrens.org/en/blog/beads-of-courage--representing-a-childhood-cancer-journey

HOW TO MAKE ORIGAMI FLOWERS

For the teens who want to be especially creative

www.origamiway.com/origami-flowers.shtml

For parents whose children may not be able to participate in Valentine festivities, try to create the day for them anyway. You can sit down with a crayon, paper and glue to make a Valentine. Or take them to their favorite place to partake in their favorite entertainment activity with them. Let their dog sit on their lap. Trust me, they experience extra special love by the way you communicate with them and touch their hearts.

As for my own daughter, who has a seriously long list of allergies and is not allowed to consume the color red, I will be making her:

LOVE YOU: VALENTINE SPECIALTIES

ALMOST OH-REE-OH'S RECIPE

www.savoryspiceshop.com/recipes/almost-oh-ree-ohs

SIMPLY OLD-FASHIONED MARSHMALLOWS (Corn Syrup-Free)

https://jerryjamesstone.com/recipe/old-fashioned-marshmallows

While all these ideas may sound amazing, remember not to lose sight of the importance of Valentine's Day. It is not about the colors, the chocolates, the handwriting, the gifts, or any other item that can be seen, felt, touched, tasted or even heard. It is not about how much was bought for the other person, or even how much labor was put into creating something for them. This day is about inclusion and not differences. This is a day to actively make others understand they are loved. What the child with special needs receives will be amazing because you have taken time to weave them and their unique needs seamlessly into the day – so they are truly able to participate and enjoy Valentine's Day.

Now I am off to the kitchen to make cookies with my child, giving her a hug and kiss first. Happy Valentine's Day! •

ABOUT THE AUTHOR:

Laura George is an Emergency Management Disability Liaison and sits on the National Center for Independent Living Emergency Preparedness Committee [www.NCIL.org] as well as other national, state, and local committees. This past year she has assisted with flood, hurricane and tornado disasters spanning from Colorado to Texas to North Carolina and the Bahamas. She has spent the last 13 years volunteering her time, consulting, presenting and writing on the idea that emergency design needs to include everyone. She is the author of *Emergency Preparedness Plan: A Workbook for Caregivers, People with Disabilities, the Elderly and Others.* In her spare time, she shares smiles with her daughter who has PANS & Immune Issues and dog (assistant), Turkey.

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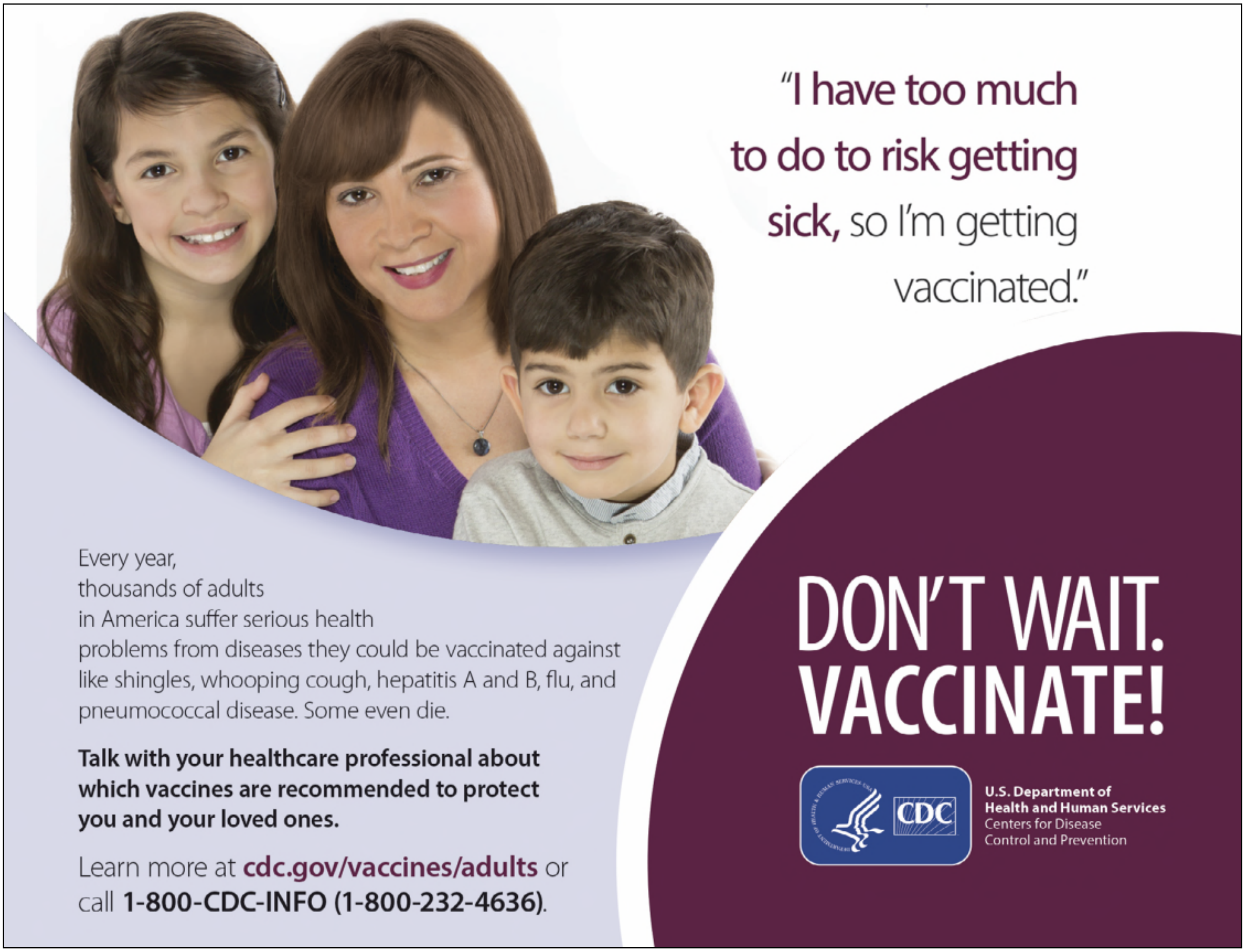

Livable Design was borne out of real-life experiences – both my own and those of friends and family members. In particular, I learned firsthand in my youth that the way our homes are typically built compounds the frustration and indignity of living with mobility issues.

LIVING WITH RESPECT, FREEDOM & DIGNITY

BY JEFFREY DEMURE, AIA

Those of us fortunate enough to currently live without mobility issues may not realize that, at some point in our lives, each of us is likely to experience a physical challenge – and not only when we get older. People of all ages and from all walks of life can experience a temporary or permanent loss of mobility. An estimated 24.1 million Americans live with a severe disability that interferes with their ability to perform one or more activities of daily living and/or requires the long-term use of assistive devices such as wheelchairs, crutches, canes, and walkers. Seven million of these Americans are children under 15 years old.

This is a staggering statistic, and the solution is something my company and I have been working on for over a decade called Livable Design.™ Livable Design was borne out of real-life experiences – both my own and those of friends and family members. In particular, I learned firsthand in my youth that the way our homes are typically built compounds the frustration and indignity of living with mobility issues.

I've been an architect for more than thirty-five years. I'm licensed in 15 states, and I've put my architectural stamp on over one hundred thousand homes throughout the country. I'm passionate about designing buildings that can work.

When I was a 22-year-old architecture student at the University of Arizona, a motorcycle accident left me with fifteen broken bones. For months afterwards, I was unable to walk unless I used bulky, specialized crutches. When I was finally discharged from the hospital, my parents' home in upstate New York was the only place available for me to convalesce – so home I went. But I quickly

PHOTOS PROVIDED BY APRIL ROBERTS/WWW.LIVABLEDESIGN.COM

A WELCOME HOME: The last thing anyone wants in a living space is for it to feel clinical or institutional. Rather, we want it to be warm, inviting, and comforting, honoring and respectful to every person who crosses our threshold, making each guest feel loved and cared for.

learned that the home I grew up in, like most homes, wasn't built for someone with limited mobility.

For months, I was unable to bathe myself, access the bathroom, or perform other basic daily tasks without help. As a young adult, having my family members help me with those basic activities was mortifying, to say the least. While trying to navigate around indoor spaces that had never before seemed tight or constrained, I constantly banged my elbow, fingers, and my remaining good knee on door frames, walls, and counters. And getting up and down the stairs in that house on those crutches wasn't just challenging—it was downright dangerous.

These unexpected challenges added more stress, pain, and frustration to an already difficult physical and emotional recovery. After months of physical therapy, I healed. However, I never forgot how the loss of my mobility, independence, and dignity made me feel during this challenging time. In my office, we call solutions that are not well conceived "duct-taped." That's how well today's homes function when you have a mobility issue. Plant-on ramps, institutional retrofit grab bars, and aftermarket toilet contraptions are not seamless, beautiful, or dignified. We can do better!

Livable Design is based on a simple approach to using inclusive features when designing and building homes. To be clear, it is not a substitute for the Americans with Disabilities Act (ADA) or other regulatory programs, and it shouldn't be construed as related. When we first started working on Livable Design, we began with a list of 137 design elements and honed in on the most fundamental essentials. We landed on these five cornerstone components that define the essence of Livable Design:

A Zero-Threshold Covered Entry with a Stepless Approach and Ample Clearance

The first component of Livable Design is a stepless entry for at least one of the home's access points (front door, garage door, entry door). This simple change is revolutionary in changing the way residential space flows, and not just for those with mobility issues. Livable Design means removing the steps. Key components of the entry include a minimum forty-eight-inch-wide stepless walkway with a maximum 1:12 slope leading to a door protected by at least forty-eight inches of structural cover. There must be a five-by-five foot clearance space on both sides of the door, which has a zero threshold.

A Bedroom on the Ground Floor

The next component of Livable Design is having at least one bedroom on the ground floor in close proximity to the downstairs bathroom. This is key, because if you or someone else in your family have mobility issues, a bedroom on the ground floor can literally mean the difference between staying in that home or being evicted into a different living environment.

A Full Bathroom on the Ground Floor with Reinforced Walls

The third component of Livable Design is an adaptable bathroom on the ground floor. A Livable Design bathroom, the key to which is adding eighteen inches to a typical hall bath, with the extra space located beside the strike side of the door. This simple change ripples throughout the bathroom, making it possible to navigate using a mobility-assistive device. The shower is a minimum five-by-three-foot curbless shower (or has a removable curb); or the tub is a transfer tub, featuring a wide ledge to sit on while swinging your legs into the tub. Reinforcing the walls costs very little while building, but a few extra half-sheets of four-by-eight-foot, three-quarter-inch plywood on the wall in a bathroom allows you to install fall-rated towel bars that don't pull out of the drywall or to add a support bar in the shower, if needed. Blocking in the walls is a cost-effective and highly efficient means of ensuring the long-term adaptability of a home. When planned for, this solution is simple, but as an afterthought it's mind-numbingly elaborate, difficult, invasive, and expensive to incorporate.

A Kitchen with Ample Clearance Space and Multiple-Height Work Surfaces

Most kitchens are not designed with adequate space to navigate with a mobility-assistive device. Livable Design provides a five-foot-diameter clearance in U-shaped kitchen configurations and forty-two inches minimum in other configurations. If an island is constraining the space, the floor must be finished under the island, and the island must be removable. You also need thirty-by-forty-eight inches of clear space in front of appliances. These simple dimensions make the difference between a kitchen that functions and a kitchen that forces you out of your home. The other key component here is having at least one surface (preferably more) that is no higher than thirty-four inches above the floor. An excellent solution for this is a multilevel island with a drop-down area. The lower level allows someone in a seated position to prepare food, and it's also ideal for a young child who wants to help. (A simple, old-school, slide-out cutting board also satisfies this provision.)

Large Doorways and Adequate Circulation and Clearance Space

Livable Design makes any hallways a minimum of forty-two inches wide, with a preferred width of forty-eight inches. The level of richness this simple change can bring also has incredible significance to those with mobility issues. Canes, walkers, wheelchairs, and strollers can easily move through such a space without banging up people's fingers or elbows, smacking into walls, or, in the case of a stroller, waking up a sleeping infant. Accommodating clearance space also means wider doorways. In a Livable Design home, all doorways are standardized to a width of three feet, with eighteen inches of space on the strike side of the door. This not only adds a unified, consistent aesthetic from one space to another, but also keeps purchasing simple for the builder by maintaining a uniform size for all doors and door frames.

BATHING BEAUTY: A Livable Design bathroom features an additional eighteen inches of space in a typical hall bath, making it possible to navigate using a mobility-assistive device. The shower is a minimum five-by-three-foot curbless shower or a transfer tub, featuring a wide ledge to sit on while swinging your legs into position. Reinforced walls allow instalation of fall-rated towel bars or support bars in the shower.

These five core elements are the foundation upon which Livable Design is built. Since we want to design and build homes that offer inclusivity without sacrificing elegance and joy, our firm's concept of beauty focuses on taking the "hospital" out of "hospitality." The last thing anyone wants in a living space is for it to feel clinical or institutional. Rather, we want it to be warm, inviting, and comforting, honoring and respectful to every person who crosses our threshold, making each guest feel loved and cared for. The incorporation of beauty is a key element. As an architect, I like to say, "A thing of beauty is a joy forever, but ugly just hurts every day." To embrace Livable Design is to honor and respect the need for human dignity and to acknowledge the reality that most of us, at one time or another, will experience mobility issues.•

*[Excerpt from **Livable Design** by Jeffrey DeMure, AIA]*

ABOUT THE AUTHOR:

Jeffrey DeMure, AIA is the founder of Jeffrey DeMure + Associates Architects Planners. Together with his team, DeMure has spent the last ten years developing Livable Design™, a revolutionary collection of simple, cost-effective elements that can be incorporated into the design of any living space to make it more fully inclusive for residents and guests of all ages and mobility profiles. You can learn more about JD+A at www.jdaarch.com

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EP's Innovative New Digital Strategy

Exceptional Parent Magazine is proud to announce the launch of 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 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.

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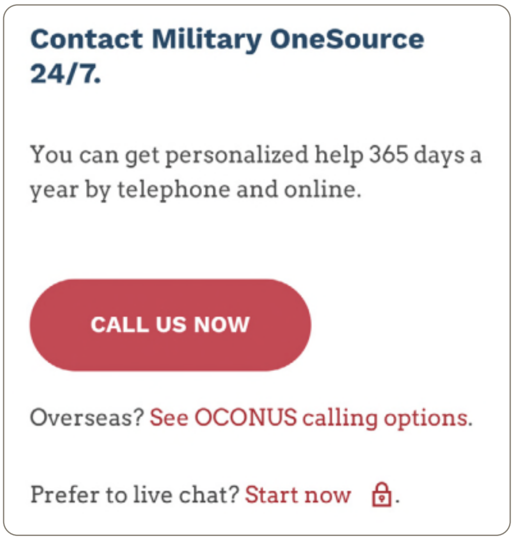
1. *Clarify your focus (identify your beliefs, values and vision, and goals)*
2. *Set you up for success (create an action plan to achieve your goals)*
3. *Prepare you for the unexpected (eliminate roadblocks or barriers that stand in the way)*
4. *Keep you on course (hold you accountable for your goals)*
5. *Celebrate your achievements (acknowledge your hard work when you reach your goal)*



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- *Health condition management*
- *Stress management*
- *Life transitions*

HOW CAN A COACH HELP WITH LIFE TRANSITIONS?

Having a plan can sometimes make major adjustments and life changes easier. A Military OneSource health and wellness coach can help you make a plan before or during those life transitions when you're adapting to changes such as deployment, moving, becoming a new parent or retirement.

WHO'S ELIGIBLE FOR HEALTH AND WELLNESS COACHING?

The Military OneSource Health and Wellness Coaching Program (www.militaryonesourceconnect.org/achievesolutions/en/militaryonesource/Content.do?contentId=27178) is a free resource for eligible service members (regardless of activation status) and certain others including:

- Active duty.
- National Guard.
- Reserve members
- Immediate family members and survivors of active-duty, National Guard and reserve members

HOW DO I GET STARTED WITH A HEALTH COACH?

Call 800-342-9647 to sign up for health and wellness coaching sessions. You can choose from three Health and Wellness Coaching Program session options:

- Phone
- Secure, real-time online chat
- Secure, real-time video session

ARE THERE SELF-DIRECTED WELLNESS PROGRAMS AVAILABLE?

If you prefer to work without a coach, visit the United States Department of Agriculture MyPlate Plan (www.choosemyplate.gov/MyPlatePlan) to try a self-directed online program that tracks things like nutrition and exercise.

You're one call away from starting to live a healthier life. Call today for the information, support, encouragement and accountability a Military OneSource health and wellness coach can give you.

– Military One Source

THE TRANSFORMATIVE POWER OF ADAPTIVE SPORTS PROGRAMS

For many years, individuals with disabilities have been using sports as a therapeutic tool to overcome serious injury or illness and as a means of recovery. They fight their personal battles on the track, in the pool and on the court to send a very powerful message to themselves, to their families and to the public that serious injury or illness does not have to interrupt the pursuit of a meaningful and productive life.

Recognizing this, the Department of Defense, in coordination with the United States Olympic Committee, created the Warrior Games (https://dodwarriorgames.com), an inter-service adaptive sports competition to showcase the resilient spirit of today's wounded, ill and injured service members. Athletes from all branches of the military compete against each other in a range of adaptive sporting events. Having overcome debilitating injuries and medical conditions, the service members embody the warrior spirit and serve as role models for other survivors worldwide.

PHOTO COURTESY DOD/ROGER L. WOLLENBERG

The United Kingdom's Prince Harry founded the Invictus Games (https://invictusgamesfoundation.org) after attending the 2013 Warrior Games in Colorado. He saw the impact that sports played in the recovery of service members and was inspired to launch a similar event designed for wounded, ill and injured military members and veterans from around the world that uses sports to promote healing and support rehabilitation.

WARRIOR GAMES, INVICTUS GAMES: SPORTS AS MEDICINE

Many athletes say that participating in adaptive sports boosts their self-esteem, improves their mental and physical health, and makes them stronger and more resilient, generally. But not until recently have scientists begun to specifically and purposefully measure the effects of adaptive sports programs to determine their role in rehabilitation. See these resilient competitors in action! Check out featured videos, stories, photo essays and more at the following DoD Special Reports Pages:

- 2018 DoD Warrior Games: www.defense.gov/News/Special-Reports/0618_warriorgames
- 2017 Invictus Games Toronto www.defense.gov/News/Special-Reports/0917_invictus-games

A HOLISTIC APPROACH TO RECOVERY, REHABILITATION AND COMMUNITY REINTEGRATION

Adaptive sports and other reconditioning activities help service members come to terms with traumatic injuries or illness by inspiring them to realize what is still achievable by focusing on ability. Adaptive sports promotes holistic growth and achievement by addressing several factors, including:

- *Being part of a team promotes a* ***sense of belonging and peer support,*** *of knowing you're not alone in your struggle.*
- *The* ***opportunity to renew the power of service to country*** *and strong desire to pursue a higher purpose that have always inspired service members in combat and life.*
- *Competition* ***rekindles the sense of passion and determination of the warrior spirit*** *that is part of a service member's DNA, the courage to move forward despite barriers and obstacles.*
- *The chance* ***to be celebrated and recognized,*** *supported by family, friends and people from around the world, boosts self-worth and self-efficacy.*

Adaptive sports engages service members and veterans mentally, emotionally, spiritually, physically and socially – finding hope and strength through their common experiences.According to the Department of Defense's Office of Warrior Care (warriorcare.dodlive.mil/carecoordination/masp), the benefits of physical activity for ill and injured service members also include reduced stress, increased quality of life, lower blood pressure, weight management and enhancement of the rehabilitative process.

FINDING AN ADAPTIVE SPORTS PROGRAM

The Office of Warrior Care oversees the Military Adaptive Sports Program, which provides reconditioning activities and competitive athletic opportunities to all wounded, ill and injured service members. The program empowers wounded, ill and injured service members through physical and mental activities that engage, stimulate and inspire recovery. Learn more about the military services' wounded, ill and inured programs:

- U.S. Army Warrior Care and Transition Program: www.facebook.com/ArmyWCT
- U.S. Marine Corps Wounded Warrior Regiment: www.woundedwarriorregiment.org
- U.S. Navy Wounded Warrior – Safe Harbor: www.navywoundedwarrior.com
- U.S. Air Force Wounded Warrior Program: www.woundedwarrior.af.mil
- U.S. Special Operations Command Warrior Care Program: www.socom.mil/care-coalition/Pages/Warrior-Care-Program-Mission.aspx

In addition, the Department of Veterans Affairs Office of National Veterans Sports Programs & Special Events co-sponsors adaptive sports clinics and competitive events for disabled veterans of all ages and abilities. This includes the Grants for Adaptive Sports Programs, which provides grant funding to organizations to increase and expand the quantity and quality of community-based adaptive sports activities for veterans with disabilities and members of the armed forces. To find out more, visit www.va.gov/adaptivesports •

– Military One Source

PUZZLES & CAMO SHELLY HUHTANEN

Wake Up Call

I saw cracked molars and places on my teeth that looked like they had been hacked with a drill. I finally responded, "These teeth look like they belong to an old and tired Army wife with a child with autism. That's what these teeth look like."

Dental work is a subject that makes parents raising children with sensory issues cringe. I feel like this theme is discussed in my columns every year. After the last column about dental work with Broden, I told myself that I would never write another column about a trip to the dentist again. I felt I had explored that topic to its fullest extent and it was time to put it to rest, but there was a development this week and I could not ignore the fact that it happened.

As one might have guessed, Broden did have his first dental appointment since we moved to our new installation. I have to remind myself that years ago, I would cry in the car after his dental appointments because they were so emotionally exhausting. The dental offices were ill-equipped to work with us and they didn't know how to work with children on the spectrum. I dreaded visits to the dental office with my son to the point that Mark would take off work so he could help me. I think he was just as worried about my emotional state as he was Broden's. Last week, I told Mark I could handle his appointment alone because I knew we would be fine even though it was a new dental office. I had already visited the dental office and interviewed the dental hygienist and was explicit in what he needed.

Broden knocked it out of the park. There were three staff members with us to ensure the visit was a success. They listened to me, and I'm proud to say Broden did a great job. He did such a fantastic job, there were staff members in the hallway sticking their head in the office, amazed at how well he was doing.

One staff member said, "He doesn't seem to act like he has severe autism. I'm in awe."

I quickly piped back, "He does have severe autism and we didn't get this far without a lot of hard work."

JAW DROPPING: "The dental hygienist seemed to understand what was going on with me more than I did. She flashed the pictures on the screen. I looked up at the screen and at first, I couldn't believe what I was seeing."

As we left the appointment, I kept telling Broden how proud I was of him. He had handled the appointment so well, it seemed that the staff was actually looking forward to seeing him again. It felt surreal. Years ago, I would have never seen this as our reality. But I soon learned that all of this hard work has come with a price.

A few days ago, it was my turn to get my teeth cleaned. I really thought I would be in and out in about 45 minutes and would have to listen to a quick lecture about how I don't floss regularly. The appointment turned sour once the dental hygienist looked into my mouth, asking "Have you felt a lot of stress and anxiety lately? Do you clinch your teeth at night? Do you have a night guard?"

Perplexed by all of these questions, I lifted my head from the dental chair and gave her a quick synopsis of my story. Looking back, I was sort of snippy, "I don't know. You tell me. I'm an Army wife with two boys, one with severe autism. Do you think I'm stressed? Do I need to give you a run down on my husband's deployments, or give you the number of hours I have spent in IEP meetings?"

She paused, stepped back and then said, "My goddaughter has severe autism so you don't need to say anymore, but I'm going to take a few pictures of your teeth and the dentist is going to take a look." I questioned what all the fuss was about. I'm just getting my teeth cleaned and I didn't have time to be finicky about some worn down teeth. Frankly, I didn't want to take the time.

After some pictures were taken and the dentist came in and told the dental hygienist some acronyms and dental terms that I didn't understand, the dentist turned around and said that I needed to come back into the office to have some work done on my teeth, "I want to take a look at your mouth guard and we need to find a way for you to be kinder on your teeth. We'll get you taken care of." As he left the room I thought, "At this rate, I'm dreading my eye appointment. Getting old sucks."

The dental hygienist seemed to understand what was going on with me more than I did. I was so used to being the caretaker, I had not realized what it was doing to me. She asked me to stay seated and said, "I want you to see your teeth. I want you to really look at them." She flashed the pictures on the screen, "What do you see?" I looked up at the screen and at first, I couldn't believe what I was seeing. I saw cracked molars and places on my teeth that looked like they had been hacked with a drill. I finally responded, "These teeth look like they belong to an old and tired Army wife with a child with autism. That's what these teeth look like." I wanted to cry. I wanted to cry for me.

> "The stress and anxiety have weighed on me. I need to start making some changes and start focusing more on self-care. Self-care does not mean I'm selfish. It means that I love my family enough to ensure that a healthy me is still around to love them."

After a few minutes of silence in the room, she reminded me to be kind to my teeth and also that I needed to care for myself. I see this appointment as a reminder. If I don't take care of myself, then I won't be able to take care of my family. All these years, I've focused on making strides with Broden and ensuring that Hayden is getting what he needs, but now I see that my body has taken a toll. The stress and anxiety that I have felt over the years and the worrying have weighed on me. I know I need to start making some changes and start focusing more on self-care. Self-care does not mean I'm selfish. Self-care means that I love my family enough to ensure that a healthy me is still around to love them. •

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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