PLUS: UNITED STATES MILITARY SECTION

EXCEPTIONAL PARENT
MAGAZINE
MARCH 2019
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IN THIS ISSUE:

THE DIGNITY *of* RISK: GOING *to* COLLEGE

PLUS: ANXIETY AND INACTION

GETTING YOUR CHILD UN-STUCK

ALSO INSIDE:

LIFE SKILLS *from a* MOBILE COFFEE CART

AN EP EXCLUSIVE:

THWACK! BE GONE PANDAS

AND EP EXPLORES:

DEVELOPMENTAL DISABILITIES

SCHOOLS *and* CAMPS

EP's ANNUAL ISSUE

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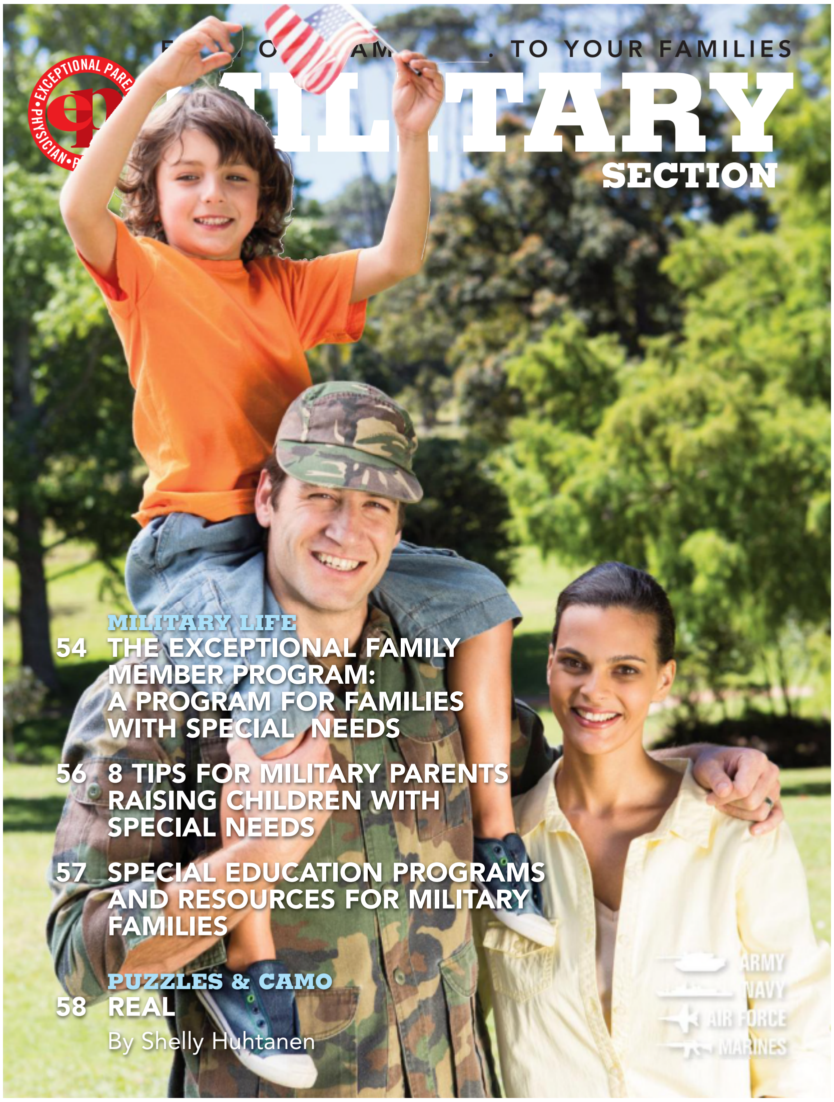

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Information and Support for the Special Needs Community

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— Rick Rader, MD

EP magazine neither endorses nor guarantees any of the products or services advertised in the magazine. We strongly recommend that readers thoroughly investigate the companies and products being considered for purchase, and, where appropriate, we encourage them to consult a physician or other credentialed health professional before use and purchase.

I Prefer Mine Rare Thank You

For decades, *Exceptional Parent* magazine has served as a bastion of information, resources, advocacy and support for the rare disease community. We have long nodded in agreement with the old medical school axiom: "When you hear hoof beats, think of horses, but don't overlook the possibility that they may be coming from zebras."

It was lunchtime at a national medical conference,

I found myself at an open table with seven other docs who welcomed the opportunity for some respite after four straight hours of death by Power Point. After the lame formalities of everyone introducing themselves and where they were from, the majority of the docs turned to their cell phones to catch up with messages from their offices, clinics, colleagues and families.

The doc sitting next to me took out a pad and scribbled notes as he repeated what was being communicated to him on the phone. They were numbers, big numbers. Very big numbers.

When he got off the phone, I couldn't help but engage him. "I sure hope those weren't lab values for a patient of yours."

"Not even close," he said. "I'm bidding on stamps coming up for auction, I collect stamps."

"Oh, a philatelist," I said, trying to score points and show off.

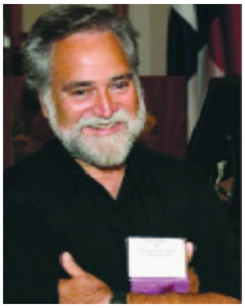
He added, "My entire life, it's been my passion since I was six. After 50 years, I'm starting to play with the big boys."

While I didn't ask, he was quick to add, "The first postage stamps were made available on May 1, 1840, in England, and with it began the hobby of stamp collecting."

From the numbers he jotted down, Bob, the epileptologist from Omaha was placing bids on some obviously very valuable and rare stamps.

I threw in the only thing I knew about stamps, "Are you bidding on the Inverted Jenny?"

One of my uncles was a stamp collector, and whenever the family got together for holidays, he would share his latest acquisitions. He told me about the Inverted Jenny. The Inverted Jenny is a United States postage stamp first issued on May 10, 1918 in which the image of the Curtiss JN-4 airplane (being used in the early days of "air mail") is printed upside-down. It is arguably the most famous error in American stamp printing. Only one sheet of 100 of the inverted stamps was ever found, making this error one of the most prized in all philately. The Curtis JN4 was also known as "Jenny," and the stamp went on sale the day before the launch of the U.S. airmail services.



"Not that there is one coming up for sale, but that stamp is out of my league. The last one sold at auction for over a million-and-a-half dollars."

"Wow," I replied, "guess that makes it one of the rarest stamps ever made." Bob was quick to point out that stamp collectors don't actually consider the Inverted Jennys to be particularly rare – 100 stamps is a sizeable amount within the world of philatelists. The British Guiana, one cent magenta is considered the most valuable and rarest stamp in the world. Only one of its type exists now, which is used and cut in the shape of an octagon. It sold at auction for nine-and-a-half-million dollars."

I wished Bob good luck with the upcoming auction and headed off towards the afternoon break-out sessions.

I began thinking about the concept of "rare" and how it has captured the imagination of people worldwide. How "rare" does something have to be in order for it to be considered "rare"?

It's not just stamps, coins, sinkholes, flowers and insects, that by their sheer numbers can be considered rare. Human traits can be rare.

S. Grant writes in "10 Amazing Powers from Rare Genetic Mutations": "Compared to many other species, all humans have incredibly similar genomes.

OVERLOOKED BEFORE: A disease or disorder is defined as rare when it affects fewer than 200,000 Americans at any given time.

However, even slight variations in our genes or environments can cause us to develop traits that make us unique. These differences can manifest in ordinary ways, such as through hair color, height, or facial structures, but occasionally, a person or population develops a characteristic that distinctly sets them apart from the rest of the human race.”

There are a multitude of “rare” characteristics that are found in our species. For instance, there is a genetic mutation where the PCSK9 gene is missing and it results in the individual being able to eat anything without getting high cholesterol. Some people have a genetic mutation that disables their copy of the CCR5 protein, which turns out, protects them from the HIV virus. People with the sickle-cell trait have a high resistance to malaria. There are “cold dwellers” who have adapted to extreme cold temperatures; they can maintain their body temperatures better without shivering and have relatively fewer sweat gland on the body and more on the face. Sherpas and other high-altitude dwellers produce fewer red blood cells and can survive in high altitudes and are less susceptible to altitude sickness. We find a tribe in Papua New Guinea, the Fore People, are immune to developing Kuru – a degenerative and fatal brain disease spread by eating other humans. There are also people with a very rare blood type known as “Rh-null”—only 40 in the world that do not have a single Rh antigen making their blood so rare that researchers refer to them as “Golden blood.” Unfortunately, only nine donors of this blood exist in the world. Their blood can be life-saving to those with rare and almost unobtainable rare blood types.

> “The only commodity in the rare disease community is the truth; truth of its recognition, existence and acceptance. But it is only the starting point.”

Other humans such as a small group called the Moken, have crystal-clear underwater vision. There are members of the Afrikaner population (South Africans with Dutch origins) with a mutation in the SOST gene (which controls a protein, sclerostin that regulates bone growth). They have super dense bones and are immune from osteoporosis and avoid bone fractures, broken hips and hunched spines. And there are people with a rare genetic mutation of the gene DEC2 which causes them to physiologically need less sleep than the average person. They show no negative effects from sleep deprivation.

So, there are rare mutations that provide rare people with rare protective mechanisms that provide rare benefits for their lives.

But the medical world I live in is not demarcated by mutations that protect people or provide people with life-enriching conditions. My field is engaged, impacted and challenged by rare genes, rare mutations, rare deletions and rare duplications that form the basis for rare diseases. I live on the outskirts of the rare disease community. I say on the outskirts because the majority of the issues I deal with daily are not rare. Autism, cerebral palsy, Down syndrome, Fragile X and intellectual disabilities are not considered “rare” by definition. They are, however, according to the legions of parents, patients, professionals, providers and pedagogues that are impacted by them daily; they are life- changing, challenging, often unchartered and lifelong.

A disease or disorder is defined as rare in the United States when it affects fewer than 200,000 Americans at any given time. In Europe they define a rare disease when it affects less than 1 in 2000.

And while the word “rare” conjures up images of a handful in Europe alone, as many as 30 million people may be affected by one of over 6000 existing rare diseases. Eighty percent of rare diseases have identified genetic origins while others are the result of infections (bacterial or viral), allergies, and environmental causes, or are degenerative and proliferative. Fifty percent of rare diseases affect children.

Clinicians may spend a lifetime without ever encountering a rare disease, or better put, “a patient with a rare disease.” Dealing with a rare disease improves the clinical acumen of the provider by challenging their comfort level, causing them to think outside of the proverbial “cook book” clinical thought process. A rare disease provides the physician with the opportunity to become a sleuth and to emulate the character created by the physician author Sir Arthur Conan Doyle, the legendary detective Sherlock Holmes. Holmes provides the foundation for working with the rare disease universe, “Once you eliminate the impossible, whatever remains, no matter how improbable, must be truth.”

The only commodity in the rare disease community is the truth; truth of its recognition, existence and acceptance. But it is only the starting point.

Rare Disease Day takes place on the last day of February each year. The main objective of Rare Disease Day is to raise awareness among the general public and decision-makers about rare diseases and their impact on patients’ lives.

Some of the concerns related to rare diseases is the lack of scientific knowledge and quality information on the disease which often results in a delay in diagnosis and access to appropriate treatment and care. Unfortunately, we are also all too familiar with those aspects of the rare disease and disabilities community which are not rare; inequality, indifference, ignorance and injustice.

For decades, *Exceptional Parent* magazine *(EP)* has served as a bastion of information, resources, advocacy and support for the rare disease community. We have long nodded in agreement with the old medical school axiom: “When you hear hoof beats, think of horses, but don’t overlook the possibility that they may be coming from zebras.” •

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

WHAT'S HAPPENING

DISABILITY COMMUNITY CELEBRATES THE REINTRODUCTION OF THE DISABILITY INTEGRATION ACT

Members of Congress from both side of the aisle came together recently to celebrate the re-introduction of the Disability Integration Act (DIA) at the Senate Capitol Visitors Center.

The Disability Integration Act is a bill that would affirm the rights of people with disabilities and seniors to have the real choice to live in the community by requiring insurance companies that would offer institutional services to also offer those same services in the community.

"At its core, the Disability Integration Act is about one simple thing: that people with disabilities must be treated as equally as those without." said Senate Minority Leader Schumer "People with disabilities are too often denied the choice to receive at-home care and support services. This bill ensures that would never happen again."

VOTE FOR FREEDOM: The Disability Integration Act was reintroduced by Senator Schumer and Representative James Sensenbrenner.

The bill, which received bipartisan support in both the Senate and the House in the last Congress, was reintroduced by Senator Schumer and Representative James Sensenbrenner.

"I am proud to re-introduce this bill, because all Americans should share in the American Dream, and that begins in the community in someone's own home," said Representative Sensenbrenner.

It is not a coincidence that the celebrations and the reintroduction took place on January 15th, Dr. Martin Luther King Jr.'s birthday. The Disability Rights Movement has deep ties to the Civil Rights leader and has long marked this day as Freedom Day, with celebrations of the progress that has been made and direct action aimed at furthering the cause. To many in the Disability Community the DIA was made for Freedom Day, and the day the legislation finally passes will forever be known as Disability Freedom Day!

DIA has widespread support in the Disability Community. "This bill builds on the idea that the independent living movement was founded on. DIA will mean that disabled and elderly Americans no longer have to move into institutions to get the services we need to live our lives," said Anita Cameron, the Mistress of Ceremony at the event. The bill ends what disabled activists have long called "the institutional bias" by requiring that any insurer offering long term supports and services must make them available in the community setting rather than only in institutions and nursing facilities.

Much of the excitement over the reintroduction comes from the feeling that DIA's time has come. "The midterm elections changed everything. With Democrats taking over the house, there is a real opportunity to pass the bill on the House side this year" said Kelly Buckland, Executive Director of the National Council for Independent Living. "As someone who uses attendant services and has spent time in a nursing facility, I can't begin to express how exciting it is that this is finally going to happen." To this end, ADAPT and the broader Disability Community have called upon the House of Representatives to pass DIA before July 26th of this year.

ADAPT's history, the issues we are fighting for and our activities can be followed on our web site at **www.adapt.org**, our ADAPT Facebook page and on Twitter – look for #ADAPTandRESIST

– Adapt.org website

VA To Accelerate Claims For Purple Heart Recipients

At a congressional hearing in late February, VA Secretary Robert Wilkie announced that effective in April, it will provide priority disability benefits claims processing for the initial claims from discharged combat Veterans who have been awarded the Purple Heart Medal.

Secretary Wilkie announced his decision at a hearing before the House Appropriations Subcommittee on Military Construction, Veterans Affairs, and Related Agencies.

"Those who hold the Purple Heart, the recognition of wounds taken in battle, will now receive priority consideration when it comes to claims before the Department of Veterans Affairs," said Secretary Wilkie.

The Veterans Benefits Administration will amend its priority processing categories to include initial claims received from Purple Heart recipients on or after April 1, 2019.

Purple Heart recipients are already treated on a priority basis at VA hospitals and are exempt from co-payments for their medical care.

The Purple Heart award is the oldest U.S. military decoration and is awarded to U.S. service members for wounds suffered at the hands of the enemy. General George Washington awarded the first purple-colored heart-shaped badges to soldiers who fought in the Continental Army during the American Revolution. In 1932, it was revived to commemorate Washington's 200th birthday.

PHOTO COURTESY ADAPT.ORG

WHAT'S HAPPENING

CIVIL RIGHTS GROUPS CHALLENGE UNCONSTITUTIONAL USE OF SOLITARY CONFINEMENT, DENIAL OF MENTAL HEALTH CARE IN SACRAMENTO COUNTY JAILS

On February 12, 2019, the Prison Law Office, Disability Rights California, and Cooley LLP filed a motion in federal court to halt the unconstitutional use of solitary confinement for people with serious mental illness and the denial of adequate mental health care to people in the Sacramento County Jails.

A copy of the complaint and the motion are available at **www.disabilityrightsca.org/cases/mays-v-county-of-sacramento.** The motion was filed as part of a certified class action lawsuit that was filed in July 2018 on behalf of all people incarcerated in the Sacramento County Jails. The motion challenges the county of Sacramento's practice of confining hundreds of people alone in small, locked cells for 23.5 hours or more per day under a designation called "Total Separation." People in "Total Separation" spend weeks, months, and even years without social contact. More than 75% of them require mental health care. Some have such serious mental illness that they require psychiatric hospitalization.

Experts hired by Sacramento County have described the county's solitary confinement practices as "dramatically out of step with emerging national standards and practices." At least three people have died by suicide in "Total Separation" solitary confinement since the experts made this finding.

"We are calling on Sacramento County to discontinue its use of profound and prolonged solitary confinement. The conditions in Sacramento County's solitary confinement units are harmful, dangerous, and unnecessary. The county must act quickly to end the use of solitary confinement for people with serious mental illness and greatly expand the amount of time people are allowed to spend outside of their cells," said Margot Mendelson, staff attorney at the Prison Law Office.

Goldyn Cooper has been housed on Total Separation (or "T-Sep") status for roughly two and a half months. Describing his experience, he said, "I feel hopeless and am unable to cope with the extreme isolation in T-Sep. I do not have a cellmate and am confined to my cell for most of the day. Sometimes I am only offered time out of my cell late at night. I feel trapped, like an animal."

FIGHT FOR FAIRNESS: The motion filed in federal court calls on Sacramento County discontinue its use of profound and prolonged solitary confinement and challenges its failure to provide access to adequate mental health treatment.

The Plaintiffs' motion also challenges the county's failure to provide access to adequate mental health treatment. As the need for mental health care among the jail population has increased, the county has not allocated sufficient resources to meet those needs. As a result, people in psychiatric crisis are routinely placed on long waitlists to receive care, and are housed in tiny concrete cells where a grate in the floor serves as a toilet. Other people who are awaiting psychiatric hospitalization spend days semi-naked in "multipurpose rooms" that were never intended for human habitation.

"These serious problems are longstanding, and are the result of the dangerous overrepresentation of people with mental health needs who are incarcerated at the jail and the county's failure to provide the resources to deliver clinically necessary treatment to them," said Tifanei Ressl-Moyer, an attorney at Disability Rights California. "An adequate remedy will be neither simple nor cheap, but it is urgently needed."

Added Cooley Partner Jessica Valenzuela Santamaria, "With this motion, we hope to vindicate the rights of a particularly vulnerable population that is at a heightened risk of decompensating in the county of Sacramento's custody. Freedom from prolonged and oppressive solitary confinement and adequate access to mental health care are critical components of the jail's ability to pass constitutional muster."

The class action complaint also asserts that Sacramento County violates the Constitution by failing to provide adequate medical care and failing to take sufficient measures to prevent suicide. The complaint further alleges system wide violations of federal and state disability law.

Disability Rights California is a non-profit organization that protects the rights of people with disabilities. **Visit disabilityrightsca.org**

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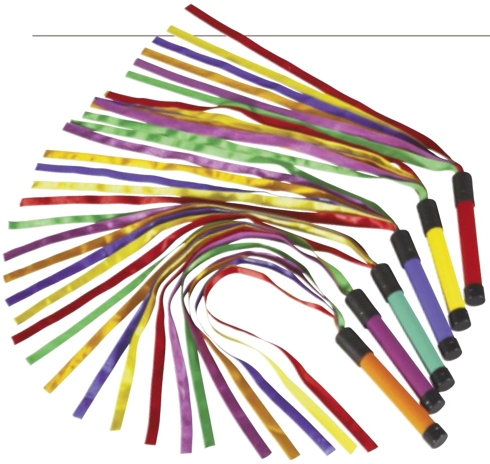

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Exceptional Parent Magazine is proud to announce the launch of www.ep-magazine.com – our all new website which coincides with our expanding role as a leader in the field of special needs publishing and communications.

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.

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

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

Our Child Has An Intellectual Disability – Should We Be Concerned About Having A Second Child?

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

HISTORY

Three Generations of Imbeciles Are Enough

"So wrote Justice Oliver Wendell Holmes, Jr. in ***Buck v. Bell****, a 1927 (U.S.) Supreme court case upholding a Virginia law that authorized the state to surgically sterilize certain 'mental defectives' without their consent."* [1]

Carrie Buck was a patient in the Virginia State Colony for Epileptics and Feeble-minded. Upon a finding that she was "…the probable potential parent of socially inadequate offspring, likewise afflicted, that she may be sexually sterilized without detriment to her general health, and that her welfare and that of society will be promoted by her sterilization, the Court upheld her involuntary tubal ligation. The Court infamously justified its decision… It is better for all the world if, instead of waiting to execute degenerate offsprings for crime or to let them starve for their imbecility, society can prevent those who are manifestly unfit from continuing their kind. Buck herself did not learn of her sterilization until decades later — she was told at the time that the operation was an appendectomy… more than 65,000 people were sterilized under such laws, which were enacted in more than 30 states… (State laws permitted) sterilization of individuals deemed unfit to reproduce — most commonly institutionalized persons with mental illness, or even conditions such as epilepsy …" [1]

The doctors who sterilized Carrie Buck claimed she was a "feeble-minded" woman whose future offspring posed a threat to society. Her life paints a very different picture. As a youngster, Carrie was fostered by the Dobbs family. As a teenager she gave birth to a child out of wedlock, fathered by a nephew of the Dobbs. After learning of Carrie's pregnancy, the Dobbs petitioned to have her institutionalized, claiming that she was "feeble-minded." [2]

MORE RECENTLY

Eugenics is the science of improving a human population by controlled breeding to increase the occurrence of desirable heritable characteristics. Developed largely by Francis Galton as a method of improving the human race, it fell into disfavor only after the perversion of its doctrines by the Nazis. [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.

THE DEEP END: The older the age of the pregnant women, the greater the risk of having a child with Down syndrome; At age 25, her risk of having a baby with Down syndrome is 1 in 1,340. By the time she is 45, that risk climbs to 1 in 35.

> *"Most cases of severe intellectual disability* (formerly called mental retardation) ***are not inherited, but are instead the result of random genetic mutations… The finding should offer reassurances to parents of those with intellectual disability, (who are considering having more children) that the likelihood of passing on the condition is low…"*** [4]

Mutations in a group of genes associated with brain activity frequently cause an intellectual disability.[5] While some genes have been identified as causing an intellectual disability (ID), it's unclear what leads to the condition in most people. [4]

YES, THERE ARE INHERITED GENETIC CAUSES OF ID

Two of the most common are:

Down syndrome, the most common genetic origin of ID, occurs in 1 out of every 700 births. Down syndrome derives in name from John Langdon Down, who first pinpointed the disorder. The condition is caused by an extra chromosome. An error in cell division during prenatal growth results in an extra third chromosome 21. The extra chromosome is called Trisomy 21.

Down syndrome has a unique pattern of symptoms which doctors recognize at birth. The child's eyes usually have an upward slant. There also are white spots on the iris. The child's ears have an unusual shape. The neck is shorter than usual. The shape of the face is full. The profile of the face tends to be flat. The palm of the hand may have a profound crease running cross ways. A person with Down syndrome may not have all of these physical features. Then definitive diagnosis of Down syndrome requires a blood test to reveal abnormal Trisomy 21.[6]

The older the age of the pregnant women, the greater the risk of having a child with Down syndrome. If the woman becomes pregnant:

- *At age 25, her risk of having a baby with Down syndrome is 1 in 1,340.*
- *At age 30, her risk is 1 in 353.*
- *At age 40, her risk is 1 in 85.*
- *At age 45, her risk is 1 in 35.* [7]

The child with Down syndrome may have problems such as heart defects, respiratory problems and eye defects, and may variously exhibit the following characteristics: auditory and visual impairment, delayed fine- and gross-motor skills, difficulties with thinking and reasoning and applying knowledge in new situations.[7]

Adults with Down syndrome experience "accelerated aging," meaning that in their 40s and 50s they experience certain conditions that are more commonly seen in elderly adults in the general population; such as dementia.[8]

Fragile X syndrome is one of the most common forms of inherited ID affecting 1 in 5,000 male births. Usually males are more severely affected by this disorder than females. Most affected males have mild to moderate intellectual disability, while about one-third of affected females are intellectually disabled. They may have attention deficit disorder. About one-third of individuals with fragile X syndrome have features of autism spectrum disorder. Most males and about half of females have characteristic physical features that become more apparent with age; including a long and narrow face, large ears, a prominent jaw and forehead.

NO GUARANTEES: In most cases, intellectual disabilities are the result of random mutations of genes, which could just as well produce marvels of memory or general intelligence.

The impact on particular genes prevents necessary protein material which leads to defects in synaptic transmissions. The syndrome gets its name from the fact that when cellular chromosomes from individuals with the syndrome split during reproduction, they appear to contain a gap or constriction at the end of the long arm of the single X chromosome. [9]

But again, ***"Most cases of severe intellectual disability*** *(formerly called mental retardation)* ***are not inherited, and are instead the result of random genetic mutations.*** Consultation with a geneticist and your pediatrician may be advisable.

WHAT ABOUT ANOTHER CHILD?

Do you remember the joy when you both learned that you were pregnant? As the months went by, the excitement only increased as the all-important anticipated date of meeting your first child neared. Upon arrival she (or he) was so tiny and beautiful. You lost sleep, took turns caring for those few pounds of joy; trying to figure out how such a tiny squirming little person could require so much care and attention - especially since this little package came without instructions or a *use by date*, guarantee or warranty and could not be returned to the manufacturer. There was the first bath, somehow trying to figuring out how to clip those tiny finger and toe nails that scratched everything, the unbelievable numbers of laundries and the usual up-chucking of milk.

Yes, they were difficult but happy times. Later there were the challenging periods when you learned of your first child's limitations. But there was so much that the new little person could do that expanded the life and joy of your family. Come to think of it, your marriage also did not come with any warrantees and guarantees.

As to a second (or even a third) child, repeated studies indicate in most cases, **intellectual disabilities are not inherited,** but the result of random mutations of genes that are associated with the brain – **which could just as well be mutations which produce marvels of memory or general intelligence.**

OVERVIEW

It has been almost a century since U.S. Supreme Court Justice Oliver Wendell Holmes, Jr. in Buck v. Bell, in 1927 wrote that "Three Generations of Imbeciles Are Enough." At the time of his writing, the germ theory of medicine (by Louis Pasteur) and Charles Darwin's book *On the Origin of Species* were only fifty-plus years old. The first antibiotic (penicillin) was discovered because Alexander Fleming forgot to clean an uncovered petri dish in 1928. In the past, individuals with intellectual and other disabilities were out of sight in large institutions or back rooms of homes. In 1967, there were more than a quarter of a million individuals with ID (then referred to as mental retardation) and other developmental disabilities (DD) in state institutions. It was not until the end of the twentieth century that the number of residents with ID/DD decreased by 75%. [10]

Today, individuals with intellectual and developmental disabilities are truly members of our society. They live and work in our communities and partake of the many activities that are available to all of us. It's time to forget Justice Oliver Wendell Holmes and his archaic world and plan our family's future; especially when modern research and knowledge provides **realistic expectations of the safe and productive setting that we can offer our children.**

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HEARTSIGHT CHRISTINA LLANES MABALOT

EP WELCOMES A New Column! NEW CONTRIBUTOR

Where It All Began

The noblest outcome of my physical blindness is that I've learned to perceive life and the world with my heart. While the heart is usually associated with love and warm fuzzy feelings, the deeper meaning of having heart is connecting one's physical state with something greater beyond ourselves, something that makes our heart beat.

I am the fourth of five children, four of whom have aniridia (underdeveloped iris) and have been legally blind since birth. Often kept in the house by our mindful parents, I didn't really realize that I was “different” and the ironic thing is that my only sighted sibling felt he was the quirky one.

One of the hardest decisions that my parents had to make revolved around our education. My overprotective father demanded that we go to a residential school for the blind. Anxious about what people would think about us, he said, “I don't want my kids to be mocked and ridiculed when they hold a book or paper next to their eyes when they read.” In rebuttal, my mother said, “I don't want my kids to be any more different from most people than they already are.”

In the 1960's, when mainstreaming was unheard of, my mother fought for us to be admitted in a private school for girls. Mainstreaming almost cost my parents' marriage.

My mother literally begged the nuns at the school to accept my oldest sister into kindergarten. Little did they know then that there would be three more visually-impaired children to follow. Thus, began the evolution of a visually-impaired student, blending into a sighted world.

> “I grew up in the Philippines, where educational services for children with disabilities at that time simply didn't exist. Since I couldn't see the blackboard, I entreated seatmates to make carbon paper copies of Math and Science notes which my mom would later read to me at home. To make my seatmates feel good about the job, I'd call them my ‘executive assistants.’”

It felt so different from home with the family wherein visually-impaired kids were the majority. Initially, I felt that family was my refuge and school would be my Waterloo. I grew up in a developing country, the Philippines, where educational services for children with disabilities at that time simply didn't exist. It was sink or swim for me which, it turned out, was good, because it taught me survival skills which saved me in numerous impossible situations. My touch typing skills were self-taught. Since I couldn't see the blackboard, I entreated seatmates to make carbon paper copies of Math and Science notes which my mom would later read to me at home. To make my seatmates feel good about the job, I'd call them my “executive assistants.”

Understanding my lessons took extra steps, and the tape recorder was my best friend. There were no short cuts. I once tried cheating in a Science quiz by asking my seatmate the answer, but our teacher caught me and was asked to stand at the back of the classroom facing the wall. So, I was determined never to cheat again. Eventually I learned Braille through the Hadley Correspondence Course and I availed myself of the services of the National Library of Congress' Talking Books Services. At the end of the day, however painful academic struggles were, I felt that hanging out with school friends was the best part of coming to school. I was convinced that the sighted world wasn't that bad after all.

I learned that to keep good friends, I had to be one. Early on, I yielded to the truth that attitude is everything – especially because there were those who acted blind-o-phobic, and the only way I could blend into the community was by being pro-active. Being a chatterbox with an incredible ability to laugh at the faintest sneeze made things easier for me. A stream of faux pas became a part of daily living and led to skill-sharpening. From those experiences I have collected a throve of the funniest stories ever told. If I learned how to keep a poker face while telling the funny stories, I'd be a wealthy stand-up comedian.

Laughter and optimism come in handy when facing barriers in the world out there, the biggest of which are cultural and social. Seemingly, the greatest advantage of being blind is to not “see” barriers. After all, “what is essential is invisible to the eye.” All my life, most people would tell me, “You can't…” I couldn't “play with other kids because I might hurt myself… I couldn't attend a regular school because I wouldn't be able to cope…I couldn't get employed because I couldn't work… and, I wouldn't be able to get married because I couldn't be a wife

PHOTOS PROVIDED BY CHRISTINA LLANES MABALOT

LOOKING UP: The Mabalot family *(from left to right):* Paulo, Jem, Christina and Silver. "The most valuable lesson I've learned through my condition is to live my life the way I want to – full of laughter, joy and endless jokes, which my family is absolutely fond of. Anyway, the world does not shut itself off from the blind, does it?"

and a mother…" Good thing I knew better than to be confrontational but still be able to demand for my rights. I had to feel my way through one obstacle at a time and prove that "he who overcomes is he who perseveres and believes he can."

In my obstacle-riddled life story, I have fallen and failed, I've been victorious and joyful, I've gained and lost relationships. All those times, I've learned how to bounce back because I believe that one's greatest obstacle might just be one's greatest miracle. One of my greatest miracles was raising my sighted son, Paulo, and our exploits together are part of a story best told for another day. I am proud to say that he is now is a Navy corpsman pursuing a career in Dentistry. My second great miracle is how the most wonderful sighted man stuck with me through almost 25 years of the oddest marriage.

The third miracle in my life involves my younger child, Jem, who is also visually impaired. Truth be told, the hardest thing in my life was, still is, and will always be having to endure the thought of Jem having aniridia. It is a million times harder for a mother who has suffered all the pains to know what her child has yet to discover. I fell into depression for some time when I learned of my daughter's special need. But, yet again, I bounced back and set out to conquer another course in my journey – what I call Life Application 101 – helping blend a visually-impaired child into the community. This has included making sure the sighted child (my son) is given as much attention as the child with disability – a painful lesson I learned growing up and witnessing my sighted brother turn bitter from the lack of my parents' attention.

Yet another miracle in my life: this year, my visually-impaired daughter is graduating college with an International Studies degree. Despite her disability, she has always been a diligent A-student. As a mother who understands deeply how my daughter goes through life, I want her to be free and independent. She lived in Japan for a year as an exchange student and, following college, is aiming to work there as a coordinator for International Relations.

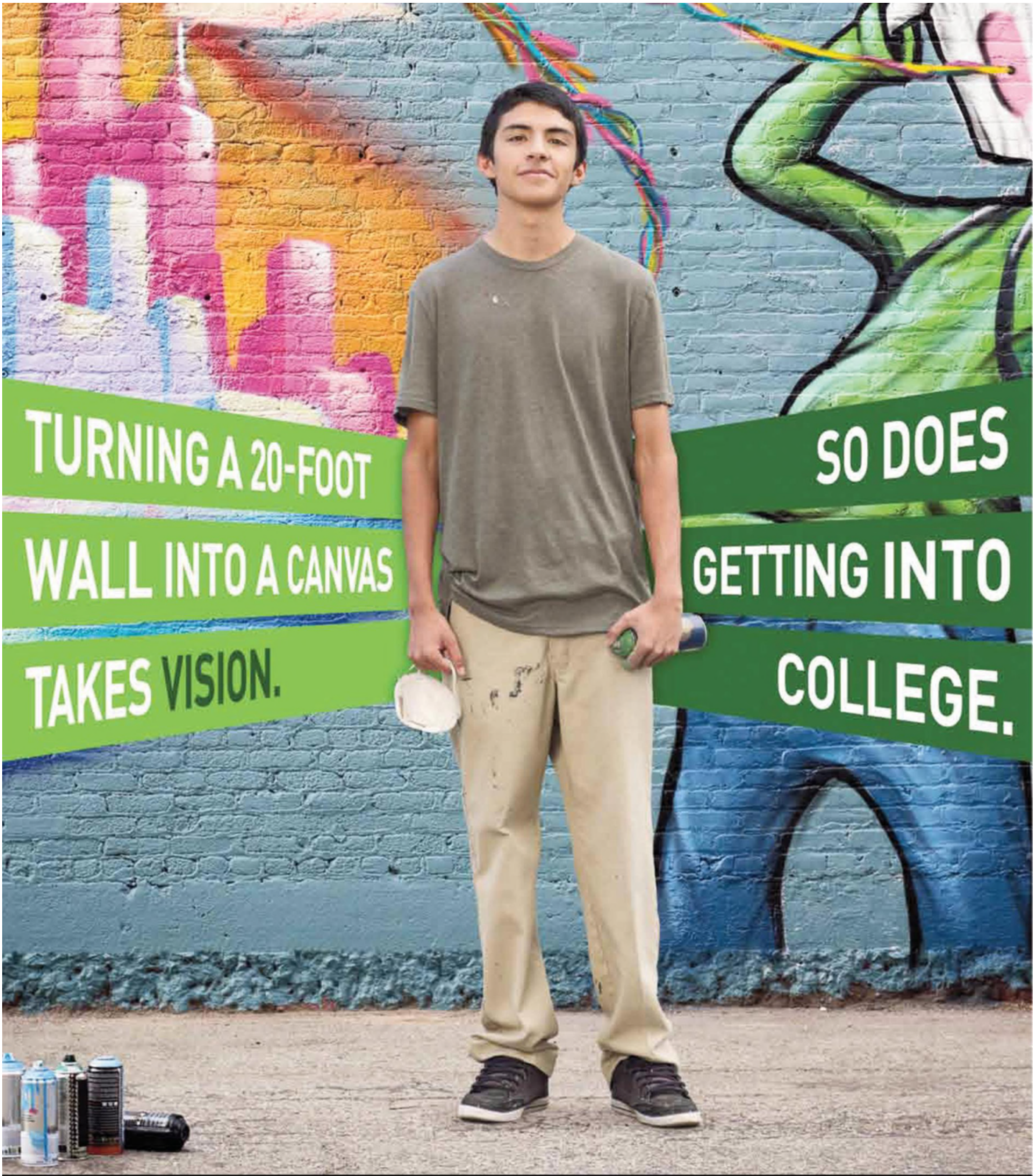
TRUE BLUE: The author with her sighted son, Paulo, now a Navy corpsman pursuing a career in Dentistry.

The most valuable lesson I've learned through my condition is to live my life the way I want to – full of laughter, joy and endless jokes, which my family is absolutely fond of. Anyway, the world does not shut itself off from the blind, does it?

The noblest outcome of my physical blindness is that I've learned to perceive life, and the world, with my heart. While the heart is usually associated with love and warm, fuzzy feelings, the deeper meaning of having heart is connecting one's physical state with something greater beyond ourselves, something that makes our heart beat. Once upon a time, my heart was blind too, because I was focused on my physical blindness! It was bad enough to be physically blind but, alas, it would've been more unfortunate to also be blind in one's heart. Why? All the issues of life spring from the heart. Oh, how my heart desperately needed to be re-created to see right! As I labored through life's challenges, I birthed a transformed heart. "Heartsight" is what I call seeing with my heart. •

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, with aniridia.


TURNING A 20-FOOT
WALL INTO A CANVAS
TAKES VISION.
SO DOES
GETTING INTO
COLLEGE.

THE DIGNITY OF RISK

GOING TO COLLEGE

BY JACKIE SCHWABE

Many parents are not educated on the concept of dignity of risk when we are told our child has an intellectual or developmental disability. Our lack of education and training around dignity of risk can unwittily make us complicit in impeding our child's ability to become a contributing, valued, and respected member of society. Learning how to support prudent risk taking could be the determining factor on whether our children go to college or live in our basement for the rest of our lives.

HELICOPTER PARENT

FEAR OF FALLING

It was a beautiful day. I should have brought my sunglasses, but my "baby-brain" was in full force; the little guy was expected in about four weeks. I held my two-year-old daughter on top of the baby bump as we left the applied behavior therapy clinic where I was told she was "at least" moderately autistic. After dropping my daughter off with the babysitter, I went back to the office and I mourned.

I mourned the loss of seeing her get married, watching her go to college, or helping her move into her own home. My only desire now was to protect her from the cruel world that was taking away her future. This was my entry into helicopter parenting.

I already had three children and I was expecting the fourth.

The day before diagnosis day I would have been described as a laid-back parent. Yet, only 24 hours later, I was swooping in at any sign my daughter might be experiencing a challenge or discomfort. I was scared she was going to fall when she toe-walked. I was afraid, somehow, that anything she tried to do was going to hurt her irrevocably.

PRACTICAL PARENTING

TO BUSY TO HOVER

All at the same time, the new baby was born in September, 40 hours a week of in-home applied behavior therapy (ABA) started and the older children started school. While at the time I was cursing the universe for giving me so much to handle at one time, it was probably the beginning of the practical parenting lessons that I needed to learn by being thrown into real life.

While I was nursing the new baby, I couldn't run after my daughter everywhere she went. Sometimes she would trip and fall right on her face. She would cry and then she would get up. I couldn't help her put on her socks the exact moment she wanted them put on, so she figured out how to do it herself. Too busy to hover, my helicopter crashed, and I was just trying to stay alive somedays.

ENTER LIMITING BELIEF

MINE, NOT HERS

While I mourned what my daughter couldn't do and tried to protect her from failure, it seemed she didn't share my limiting beliefs. Day after day she did what I thought she could not, until one day I had to sit back and realize that perhaps with my well-intentioned desire to protect my daughter, I was holding her back from not only failure, but also from the possibility of success.

Thankfully my daughter didn't mourn the things she would not do, because no one told her she couldn't. Luckily, I kept my fears to myself and my mouth shut as it related to this particular topic. It was now my job to figure out how to get over my own limiting beliefs about what she could or could not do.

GETTING EDUCATED

DIGNITY OF RISK

In the quest to support my daughter, as well as my other three children, I began a quest to find all the resources, tools, and support I could unearth. While I am embarrassed to admit it, it took about five years for me to stumble on to the idea of self-determination and dignity of risk.

Dignity of Risk was first articulated in 1972 in an article written by Robert Perske called "The Dignity of Risk and the Mentally Retarded." While I am not a big fan of the "R" word, I appreciated Perske's point of view. Perske advised that while we think we are being kind by protecting our children, we are really being evil. We are stripping our children of their dignity and keeping them from being all they can become.

Like Perske, Julian Wolpert wrote an article in 1980 called "The Dignity of Risk", considered by some to be seminal research on this topic. Wolpert said our paternalistic approach to disabled people that prioritizes safe guarding them over their rights as individuals to be independent decision makers is a limitation we place on their personal freedom.

RIGHT TO CHOOSE

WHAT DO INDIVIDUALS WITH A DISABILITY WANT?

There was a lot of research and education about all the things that I needed to stop doing, but I wanted to know what I could do to help her be her best self. After all, the result of disallowing my daughter the freedom to fail created a high probability of developing low self-esteem and underachievement, according to Wolpert. What could I do different to make an impact?

Whenever I am at a loss for what to do or how to approach something, I tell myself to K.I.S.S – keep it simple sweetie. I needed to reframe the problem so I could find a new way to look at the solution. What was the problem? What do individuals with an intellectual or developmental disability want from life? Ah, and there it was.

The United Nations Convention on the Rights of Persons with Disabilities' first of eight guiding principles states that persons with disabilities have the right to "respect for inherent dignity, individual autonomy including the freedom to make one's own choices and independence …" They want what everyone wants, the freedom to choose.

FALLING OFF YOUR BIKE

WHAT IS DIGNITY OF RISK?

If everyone wants the freedom to choose, how do I support allowing my daughter to make her own choices? All the same old limiting beliefs came back into my thoughts. Could she make her own choices? How could she make her own choices? What if she falls? What if she fails? What if she gets hurt?

Then I remembered the first time I rode a bike. I was already in second grade. All of my friends already had a bike. My parents told me that I should wear shoes when learning how to ride my bike, but I didn't listen. I skinned the top part of my big toe off shortly after their warning. They tried to tell me, but I got hurt anyway. I learned by natural consequences.

Natural consequences made me think of natural supports. In our community we are always talking about how we can provide our children natural supports. One of those natural supports is to let our children skin their knees even if we know better. Essentially that is dignity of risk. Many of the best achievements were achieve the hard way and they involved taking risks, falling flat on our faces sometimes, and even some suffering. Yet, we all got back up and tried again.

OUR JOB IS TO PROTECT THEM

WHAT PRUDENT RISK?

This idea of allowing my daughter to fail was really hard for me to consider. I've tried to protect all my children from so many things. I made them hold my hand when we walked across a parking lot. I told them to blow on their food so they wouldn't burn their tongue. How far do we take this natural consequence thing?

Penske gave us the answer in his 1972 article: prudent risk. He even went to far as to say that healthy development requires risk taking and that there could be crippling indignity in safety. He hypothesized that prudent risk was a new skill that everyone needed to acquire for the sake of our children and our society.

What is prudent risk? I know you all want me to give you a step by step guide on how to determine what things you should allow and what you should not allow. Unfortunately, I can't do that. But I can tell you how I define prudent risk. Prudent risk is showing care and thought for the future when taking a chance.

So not, we don't throw caution to the wind. If your child is water-seeking, for heaven's sake don't just leave them to wander alone in a water park in hopes that the natural consequence of nearly drowning will teach them. You have to consider for yourself what chances are acceptable and what are not. They won't die if they skinned their toe, so perhaps if they don't heed your warning about riding their bike without shoes, you let that one be a learning experience. They may get seriously injured running into the street, so perhaps don't provide a warning in this case and hold their hand even if they don't want you do.

WHAT IF THEY DO?

GOING TO COLLEGE

I have no idea what the future might bring for any of my children. There is some joy and happiness in the not knowing. My limiting beliefs will sneak in once in a while and I'll have to slow down and reconsider. Now, more often than not, I think how we will support my daughter if she wants to get married, go to college, or move into her own home. Even reading it reworded like that brings a smile to my face.

We can be the new generation of parents. Not the helicopter, or tiger, or whatever all the styles are now. We can be part of the Possibility Parent movement. We can realize that all people want the same thing, the right to choose. Learning how to support prudent risk taking will get our children to college and out of the basement. •

ABOUT THE AUTHOR:

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

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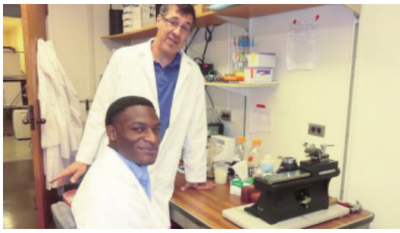

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Adults with disabilities, who are able to, should get at least 150 minutes a week of moderate-intensity, or 75 minutes a week of vigorous-intensity aerobic activity, or an equivalent combination of moderate- and vigorous-intensity aerobic activity.

AHEAD IN THE COUNT: Annandale Village is committed to promoting an active, healthy lifestyle and regular exercise is a key component of daily programming.

KEEPING ADULTS WITH SPECIAL NEEDS *ACTIVE* WITHIN A RESIDENTIAL SETTING

BY JULIE FERGUSON

According to the CDC (Centers for Disease Control and Prevention), people with disabilities are less likely to engage in regular moderate physical activity than people without disabilities, yet they have similar needs to promote their health and prevent unnecessary disease. In fact, health issues like high blood pressure, diabetes, chronic disease and obesity are much more prevalent for individuals with disabilities.

PHOTOS PROVIDED BY ANNANDALE VILLAGE

This makes physical activity even more important, as it can help prevent or lessen the impact of such health issues. Physical activity plays an important role in maintaining health, well-being, and quality of life, particularly for individuals with disabilities.

While health and wellness have always been a priority at Annandale Village, serving approximately 190 adults with special needs, the addition of a state-of-the-art fitness facility provides new opportunities for residents at all ability levels to improve their health. “The strength and stamina that is developed by participating in physical activity can help those we serve maintain a higher level of independence – which directly aligns to Annandale’s mission of maximizing the abilities and independence of individuals with developmental disabilities,” states Adam Pomeranz, Annandale Village CEO & President.

The new fitness facility was the dream of Hope and Scott Blackstock, the benefactors and visionaries who made the dream a reality. When asked what motivated them to help build the fitness facility, Hope said, "Scott and I are big believers in the power of movement to bring joy into the lives of those with special needs. A helpful side effect is that it also greatly improves their physical health, and consequently their mental and spiritual health. Our vision was to have a fitness facility that was truly inclusive to all levels of ability. The Annandale fitness center was designed especially with the residents of the D.Scott Hudgens Skilled Nursing facility in mind. If it can be utilized - under supervision - by our least-abled on campus, then it will be a success. Many states, especially on the west coast, are embracing the idea that nursing home residents should enjoy gentle exercise as part of their daily program. Everyone takes pride in their physical accomplishments...especially our Villagers for whom the gains are very hard won.”

COMMIT TO BE FIT : PHYSICAL ACTIVITY GUIDELINES

The following is a list of Physical Activity Guidelines for Adults with Disabilities from the U.S. Department of Health and Human Services:

☐ **Adults with disabilities, who are able to, should get at least 150 minutes a week of moderate-intensity,** or 75 minutes a week of vigorous-intensity aerobic activity, or an equivalent combination of moderate- and vigorous-intensity aerobic activity. Aerobic activity should be performed in episodes of at least 10 minutes, and preferably, it should be spread throughout the week.

☐ **Adults with disabilities, who are able to, should also do muscle-strengthening activities** of moderate or high intensity that involve all major muscle groups on two or more days a week, as these activities provide additional health benefits.

☐ **When adults with disabilities are not able to meet the Guidelines,** they should engage in regular physical activity according to their abilities, and should avoid inactivity.

Classes in the new fitness facility are held a few times a week under Certified Therapeutic Recreation Specialist, Jeffrey Peters. “With the grand opening of The Justis Blackstock Fitness Center a few months ago, many of the Villagers, what we affectionately call our residents, have already made great strides… We have people of all different backgrounds, capabilities and goals coming together showing each other great respect and encouragement. As the recreation and community inclusion coordinator at Annandale, I am extremely proud of everyone who has been participating in the fitness center and can’t wait to see what achievements lie ahead.”

WORK IT ON OUT: While health and wellness have always been a priority at Annandale, the addition of their new fitness facility provides new opportunities for their Villagers at all ability levels to improve their health. The new fitness facility was the dream of Hope and Scott Blackstock, the benefactors and visionaries who made the dream a reality.

Since 1969, Annandale Village, a non-profit organization in Suwanee, Georgia, has been dedicated to providing residential and non-residential programs and services to adults 18 years and older with developmental disabilities and acquired brain injuries. Their mission is to provide progressive life assistance so the individuals they serve can maximize their abilities and maintain their independence in the least restrictive environment. People with developmental disabilities and their families come first in everything they do.•

ABOUT THE AUTHOR:

Julie Ferguson, is the Community Outreach & Development Manager, Annandale Village at Suwanee, Inc.

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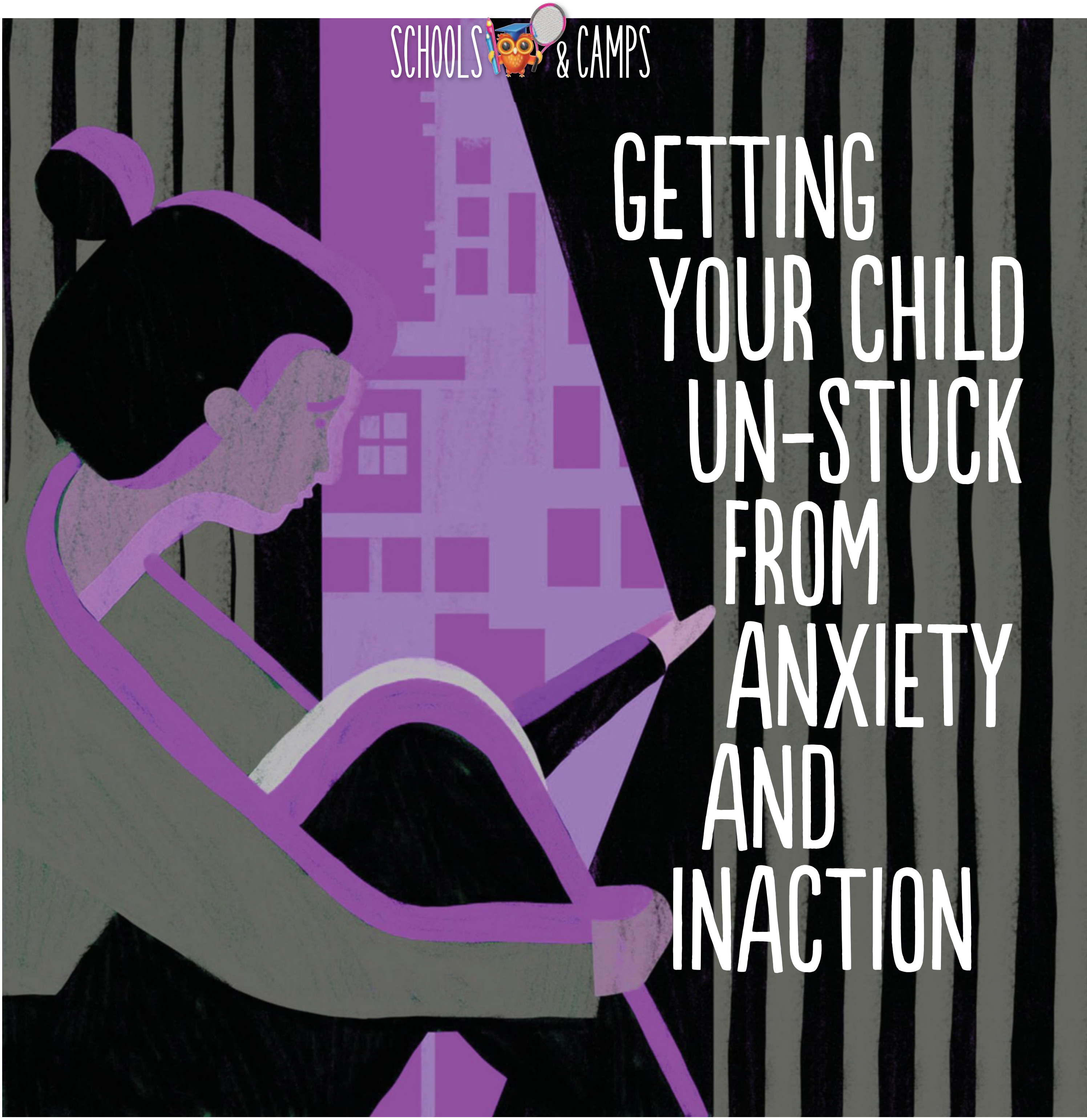


GETTING YOUR CHILD UN-STUCK FROM ANXIETY AND INACTION

BY RENEE DORMOIS SULLINS

As I reflect back on my journey as a parent, especially during my daughter's preteen and teen years, I remember having no idea why my very bright child was not using her potential, and was fighting against me when she needed to get things done. I initially thought it was typical adolescent "laziness." Seeing her struggle and constantly battling with her was frustrating, heart-breaking, irritating and exhausting; as we tried to do everything we could to move her forward, trying to find something to motivate her to stay on task, to finish her work, and to think about the consequences of her INACTION.

> "SADLY, MY DAUGHTER WASN'T PROPERLY DIAGNOSED UNTIL SHE HAD A BREAKDOWN HER FIRST YEAR OF COLLEGE AND WE HAD TO WITHDRAW HER FROM SCHOOL. THEN, IT ALL MADE SENSE WHY SHE BEHAVED AS SHE DID AND WHY SHE'D STRUGGLED SO MUCH. I WANT PARENTS TO FEEL EMPOWERED ABOUT NATURAL, PRACTICAL STEPS TO HELP THEIR TEENS THRIVE."

START ME UP: A holistic approach is imperative in determining the real reason your teen is stuck. Once these elements are addressed, even long-term problems often resolve themselves, moving your teen from just sitting in their potential, to walking fearlessly into their success.

We were at a loss. We tried counseling, nutritional changes in her diet (this was before accurate health information was so readily available about what is truly healthy and what is not), had her take learning differences testing—you name it. We spent lots of time and money to no avail. Like they say, if I only knew then what I know now. What I know now would have saved all of us a lot of stress, as well as time that we could have been enjoying being together as a family. That's why I am passionate about helping teens and parents of teens, especially those students with ADD, ADHD and/or clinical anxiety; I've been in that parent's shoes. Sadly, my daughter wasn't properly diagnosed until she had a breakdown her first year of college and we had to withdraw her from school. Then, it all made sense why she behaved as she did and why she'd struggled so much. I want parents to feel empowered about natural, practical steps to help their teens thrive.

Parents come to me all the time telling me the same things: "worn-out,", " done everything I think I can do," "I have begged and pleaded" with their teen to do their homework and study; and most important… I hear, "I just want him/her to be happy."

Our stress over our kids' procrastination and failure to function effectively/efficiently, causes them stress as well. This typically leads to arguments, emotional distancing, anxiety, depression and a very unhappy child.

When you have a child you KNOW is intelligent and capable of success, but you see them in a pattern of doing "everything last minute" aka the "P-word" Procrastination – it's tempting not to push them, give them ultimatums, and instruct them in the ways that work for *you* to get *your* "to-do" list done.

As a Life Coach, and as one who has mentored hundreds of students for the past 12 years through my own nonprofit organization, I've realized that a teen doing what works best for them, and obeying their parents' rules, do not have to be mutually exclusive. As adults, we all have ways of doing things that seem to "click" for us, patterns we've developed that seems quite effortless and second nature. Some of us are productive in the morning, while others have their creative energy kick in later at night. Some of us learn best by doing, others by hearing, and others by seeing, and some even like myself, are a hybrid of learning modalities.

However, as parents, we often don't realize that our teens are the same way! They are wired to work their best under certain circumstances, just like we are. One of my favorite examples is of a ninth-grade client of mine. She was always "very distracted" while studying and couldn't complete her work in a timely manner. This upset her and caused her stress, frustration, a nervous stomach – all this, even to the point of tears when she was "so behind". She longed for the self-discipline to do everything she knew she could; yet, she was stuck in a cycle of procrastination, which perpetuated her stress response.

So, one of the initial things we looked at was where she was studying – at the dining room table. Sound familiar? I asked where she *really* wanted to study and it was, of course, her room. What teen's room isn't their sanctuary? First, I encouraged her to ask her mother's permission to make the switch from the dining room to the bedroom – something most parents of distracted teens may not been too keen on. But, her mom was willing to give it a try.

Next, we focused on what needed to be done in order to make this work. What might need to be physically moved, or removed, in her room to make it conducive to a great study environment? Once the young lady saw that she could make a change to her environment to make it work for her, not against her, she thrived! Mom was very pleased with the results and one of her daughter's instructors even sent home a note shortly after this shift, and acknowledged the positive and successful changes in her coursework.

Time management is very personal to the individual. Just because, say the planner, with refillable pages works for the parent, this doesn't mean it will work for your teen. Some prefer wall calendars, some like girly floral planners, some use Google calendar, some use large desk calendars – it has to be what works for them.

As a parent, I know giving up the "control" in certain areas can be tough. But when we look at areas where we have suggested, or even imposed, our way of doing it, on or teen… those are capacities that may need to be approached with an open mind for change.

Another reason for your teen being "stuck" may be related to their health. Our minds and bodies cannot be viewed as operating independently of one another. When we try to separate the two, there is an imbalance that can manifest in ways that present obstacles to learning and to overall mental health and happiness. Many teens suffer from poor eating habits, poor gut health, poor sleep habits, too much exposure to electronics, vitamin and mineral deficiencies, lack of exercise and not getting enough the fresh air and sunshine. All of these factors can contribute to poor brain health, leading to poor concentration, low motivation, low energy, and a distracted mind. And for those who already struggle with ADD and ADHD, dietary changes can be very effective. Thus, a holistic approach is imperative in determining the real reason your teen is stuck. Once these elements are addressed, even long-term problems often resolve themselves, moving your teen from just sitting in their potential, to walking fearlessly into their success.

> "IT'S SAID THAT 'WATER FOLLOWS THE PATH OF LEAST RESISTANCE.' THIS SENTIMENT IS OFTEN TRUE OF OUR ACTIONS, ESPECIALLY WITH A TEEN THAT IS STRUGGLING TO EXPERIENCE FORWARD MOVEMENT."

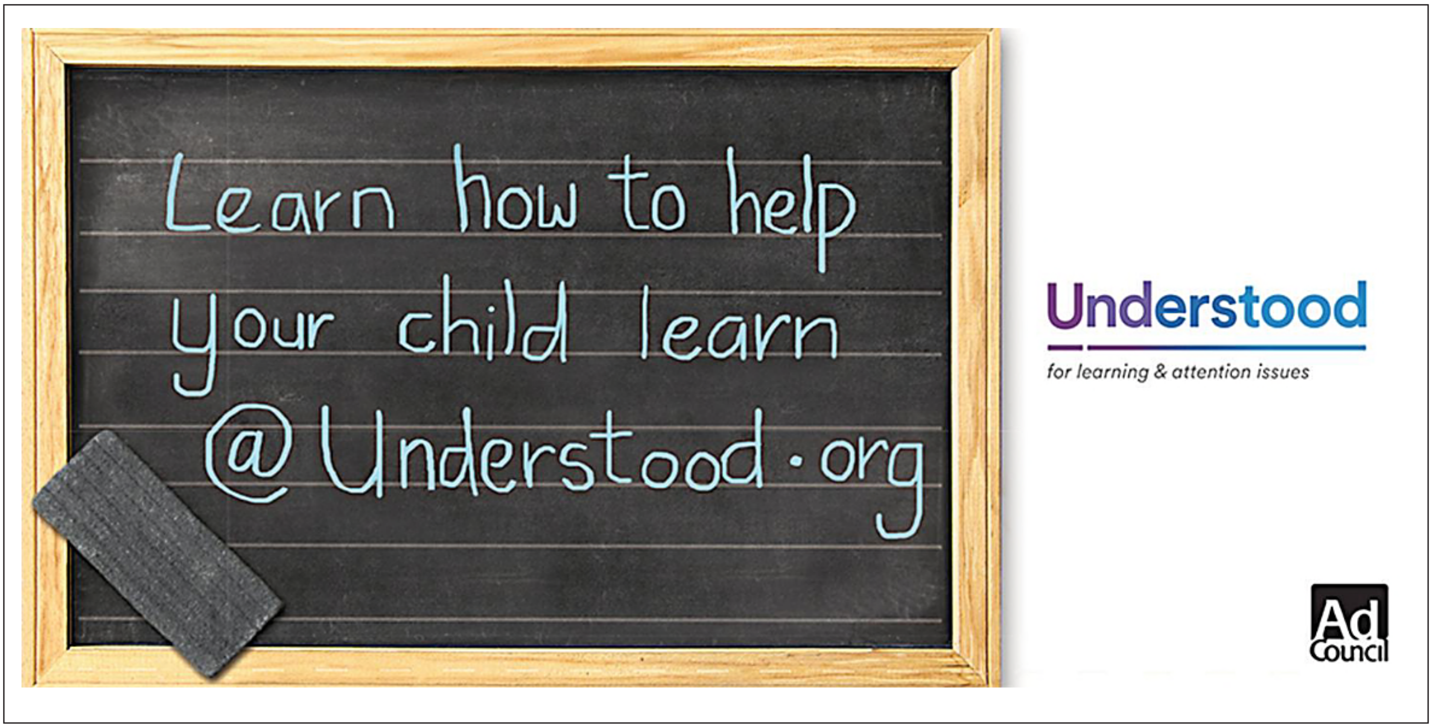
It's said that "water follows the path of least resistance." This sentiment is often true of our actions, especially with a teen that is struggling to experience forward movement. To quote Roy T. Bennett from *The Light in the Heart,* "The comfort zone is a psychological state in which one feels familiar, safe, at ease, and secure. If you always do what is easy and choose the path of least resistance, you never step outside your comfort zone. Great things don't come from comfort zones." We are all successful at taking the path of least resistance, especially when we lack the motivation, or confidence, or know-how to do something. Chances are, your son or daughter knows what they can achieve, and they truly want to, they just don't know how. Here's where mindset-shifting work can be most beneficial. This is like rewiring the brain to form sustainable habits based on the "why" behind the behavior and the desire.

This is why it's imperative to dig deep and find out just what is slowing your child down and getting in the way of achieving all they can with the gifts they have been given. Without the "why," you can't move forward with the "how."

In order to finish what you start, you have to start. That can be the hardest part. But, with the right tools and accountability, your teen will feel empowered and have the confidence and ability to START. And once they do, great things can happen! •

ABOUT THE AUTHOR:

Renee Dormois Sullins, is the founder of Head2ToCoaching, and is a Holistic Health & Wellness & Life Coach for high school students, as well as college students. She's also the founder of Tapestry of Hope, and has mentored over 400 disadvantaged teens since 2006 as a volunteer. She has a passion to give hope to parents who struggle with bright children who suffer with learning differences. Learn more at www.Head2toecoaching.com



Oftentimes, as adults with special needs age out of the school system, they lose much of the independence they experienced while in school. Employment and volunteerism can help to restore some of that sense of independence.

LIFE SKILLS FROM A MOBILE COFFEE CART

BY JAKE SAPP

Nearly three years ago, a small nonprofit in Northeast Georgia recognized a startling lack of meaningful and sustainable employment opportunities for adults with special needs.

Extra Special People (ESP)'s Java Joy is a mobile coffee cart designed to teach responsibility and life skills by employing adults with disabilities to serve coffee and treats to local businesses through a catering model. The mobile coffee cart also serves another purpose: creating a diverse culture experience for local businesses. ESP's corporate partnership program exists to positively impact business culture by providing the opportunity for employees to engage with people of all abilities.

ESP has been creating opportunities for individuals with disabilities and their families to engage, connect and thrive since 1986. The organization runs weekend and after-school programs, family support programs, and events in addition to summer camp. In June 2016, ESP opened the doors on a 14,000 sq. ft. facility in Watkinsville. ESP strives to provide a safe place that individuals with disabilities can call their own.

Java Joy was launched in the fall of 2016 and, since then, has employed 12 adults with special needs who have collectively served more than 200 businesses. While the Java Joy concept is unique in its employment of adults with special needs, what truly sets it apart is the unparalleled customer service by "Joyristas" who are excited for the chance to apply their skills, interact with customers and serve a bigger purpose. With every cup of coffee comes with a warm hug and a trademark phrase, "(In)joy!"

Finding established partners in the community who encourage Java Joy's employees and offer them additional support and training can drive the success of the business and the team. One of Java Joy's partnerships is with Jittery Joe's Coffee, founded and headquartered in Athens, Georgia. Since its inception, Java Joy has been committed to serving a high-quality coffee experience, and the partnership with Jittery Joe's helps to deliver on the commitment. Jittery Joe's has created a unique blend made specially for Java Joy and even invites Joyristas on monthly visits to the roaster to serve customers and learn more about how coffee is made. Their partnership has encouraged our business model and shown Joyristas the bigger role they play within the coffee industry.

A CUPPA JOY: Joyristas have developed a sense of community and have become a goofy, fun-loving family. Weekly sleepovers, lunch dates and carpooling are never out of the question.

After two years in business, this small startup has experienced healthy growth and it has served as a catalyst for personal growth among its staff of Joyristas. Java Joy's mission is to foster a culture of empowerment and autonomy where adults with disabilities can thrive. There, paychecks are not the primary motivation for the Joyristas; rather, the value is found in the intangibles – community, experiences and purpose. Other businesses can learn a thing or two from Java Joy on creating a workplace where satisfaction transcends things like compensation, vacation time and perks, with a turnover rate of zero.

For adults with special needs, the value of getting involved with consistent work or volunteer opportunities cannot be overstated. While Java Joy is a great option for many, it is not the only option available to adults with disabilities. With research and creative thinking, an appropriate fit can be found for all adults with developmental disabilities. Think back to your first job and how that experience shaped your work ethic, self-esteem and world view. Clearly, we all benefit when we rally behind a shared mission to make those same benefits available to adults of all abilities.

INDEPENDENCE

Oftentimes, as adults with special needs age out of the school system, they lose much of the independence they experienced while in school. Relying on parents for all transportation and social interactions can become frustrating. Employment and volunteerism can help to restore some of that sense of independence. Once dropped off, Joyristas are led as employees, with true responsibilities and challenges that make the experience fulfilling. Successes are celebrated and address opportunities for improvement. For these adults, the difference is that their reviews and rejoices are not directed toward their parents—they are communicated directly to the working adults, as they deserve to be faced with as much "real" work experience as they can healthily handle.

I remember seeing this independence exemplified when the Joyristas were asked to work an event that took place during ESP summer camp – a week that many Joyristas look forward to all year long. Instead of complaining about having to leave camp, the Joyristas took it upon themselves to set an alarm, wake up, get ready and meet at the car to head to the event. To sacrifice their time during one of their most anticipated weeks of the year spoke volumes about the impact of this employment experience.

ACCOUNTABILITY

Reminding your adult with disabilities of each everyday task can feel like an uphill battle. Over time, reminders about things like timeliness, hygiene and personal appearance can become frustrating coming from the parents. What we have seen with Java Joy, however, is the power of the "Boss Voice." Hearing those same reminders turned into work requirements can offer your adult a fresh perspective on why each action is important. For many young men with special needs, shaving can be a particularly unpleasant chore; however, to work at a Java Joy event, we require that our male Joyristas have a fresh shave. Employment infuses purpose into personal hygiene and other everyday tasks that might otherwise become burdensome for both parents and young adults.

CONTINUED EDUCATION

One of the biggest fears for parents of adults with special needs is regression. While in school, young people with special needs have access to high support but can experience a drop off when

PHOTOS PROVIDED BY SUZANNE RUTLEDGE

moving to the next chapter of their lives. With all the day-to-day responsibilities of parents, it can be difficult to provide the important mental stimulation your adult child requires to thrive at their highest capacity. Parents may be forced to turn to television and other forms of media to help cover the need for mental stimulation. At Java Joy, Joyristas are challenged with simple math and problem-solving situations that help them develop skills while maintaining sharp mental capacity. For example, one of the more challenging concepts for Joyristas is having them remember how many creams and sugars a customer requested, so learning to write orders down and then seeing that skill translate to a positive customer experience is rewarding and helps to fuel an ongoing desire to learn.

SERVICE WITH A SMILE: Java Joy meets people from all walks of life exactly where they are. The joy transferred to the customers is contagious when Java Joy goes into a new business.

COMMUNITY

For many adults with special needs, loneliness can be the most devastating disability of all. Adults with disabilities often struggle with isolation due to their differences, having no place or community to call their own. It is easy to take workplace relationships for granted, but we must recognize that our work community is often our most consistent outlet for friendship and socialization. At Java Joy, Joyristas have developed more than a sense of community; they have truly become a goofy, fun-loving family. Weekly sleepovers, lunch dates and carpooling opportunities are never out of the question. Recently, one of the Joyristas lost her father, and the way her co-workers rallied behind her was nothing short of inspiring. It was a touching example of the power of community.

PRIDE

A cornerstone of small talk is, “What do you do for a living?” For better or worse, a large part of our identity is defined by what we do and how we contribute to society. The stigma of unemployment can weigh heavily on anyone’s self-worth, regardless of ability. Joyristas are proud of the work that they do and the value they add to the communities around them, and they speak openly about their love for their work. At Java Joy, having a source of purpose and pride is a basic human right that everyone should enjoy.

The managers constantly evaluate and re-evaluate the Joyristas in order to set them up for success as much as possible. Some Joyristas thrive in pouring a precise cup of coffee, while others find their niche in their ability to give a big, warm hug. No matter what skills a Joyrista has, Java Joy does its best to highlight them. Recently one of Joyrista with a knack for the baking portion of our business began her own side business called “Meg’s Mess.” Using the skills she practices at Java Joy, she is able to continue pursuing her passion.

BENEFITS FOR PARENTS & CARETAKERS

In addition to the clear benefits of consistent employment or volunteer opportunities for adults with special needs, participation is equally beneficial to parents and caretakers. The respite from their responsibilities can have a positive impact on mental health. The ability to drop your adult off and have a few hours of “me” time is essential to maintaining emotional wellbeing and can help ease everyday familial stress. Organizations like Java Joy also provide community to parents with similar situations and shared experiences Lastly, the workplace can help to reinforce positive habits from home like healthy eating, good hygiene and appropriate conversation. Having a second place to practice these behaviors is ideal to support what is being taught at home.

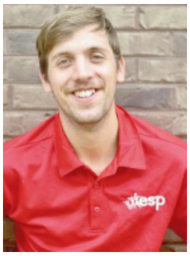
The challenges associated with finding a place that fits the special needs of your adult can be discouraging, with many parents left thinking that the easiest solution is to stick with routine—but the easiest solutions are rarely the best. It may take time and patience to find a good fit, but when you witness your adult child come home after a challenging day of working or volunteering, it becomes clear just how essential being productive in society is for mental and emotional wellbeing. Don’t be surprised even to find that your adult becomes more confident in some of the skills that make him or her unique.

COMMUNITY BENEFITS

One of the most rewarding aspects of Java Joy is the fact that it benefits the community at large, not just the Joyristas. When Java Joy goes into a new business, the joy transferred to the customers is contagious. Many special needs coffee businesses around the country have storefronts where a customer has to make an active choice to engage. Java Joy, however, meets people from all walks of life exactly where they are. Our Joyristas interact with typical adults or children who don’t have a lot of experience with the special needs population. Java Joy strives to to break down stigmas and barriers through a delicious cup of coffee and a warm hug.

While Java Joy has been a wonderful resource for the Joyristas in Northeast Georgia, there are many opportunities in which you can help your adult get involved. Animal Shelters, grocery stores, senior care facilities and beauty salons are all great places to check for paid or unpaid work. No matter what the place, employment and volunteerism can help meet the basic human need of wanting to be needed and dramatically improve quality of life. •

ABOUT THE AUTHOR:



Jake Sapp is the Coordinator of Program Operations at Extra Special People, based in Watkinsville, GA. Jake began as a volunteer for ESP while in school at the University of Georgia and serves as Summer Camp Director in addition to leading Java Joy’s mobile coffee cart business. Jake is married to Annie Kate and loves spending time kayaking, camping, hiking and working with his dog, Goose.

> *"As a mom, when you know better, you do better."*
>
> -Holly Robinson Peete

keep momming.

Being a Mom means being the one person my daughter Ryan can count on. It's just what I do.

But when I noticed she was daydreaming often, having a hard time focusing on her homework, and struggling to focus during conversations with her friends, I was at a loss.

So we went to Ryan's doctor, and he diagnosed her with Attention-Deficit/Hyperactivity Disorder (ADHD). Turns out there are 3 types of ADHD (Inattentive, Hyperactive/Impulsive, and Combined) and Ryan has Inattentive ADHD. Since inattentive symptoms like hers may be less noticeable than hyperactive and impulsive symptoms, it's important that moms like me know what to look for. I'm so glad we found out what was going on.

Sound familiar? Get the ADHD Symptom Checklist, then talk with your daughter's doctor.

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S02635 06/14

The typical school system tends to overlook the obvious needs of the hard of hearing child because the child can speak intelligibly and wears hearing aids, which are assumed will promote normal hearing.

PARENTS AND THE HARD OF HEARING CHILD

BY J. FREEMAN KING, ED.D.

Author's Note

The following is the follow-up article to "Successful Deaf Children: The Parents' Role in Communication and Language Development," which appeared in the September 2018 edition of *Exceptional Parent* magazine.

Children who are hard of hearing often do not fit comfortably into either the Deaf world or the world of those who can hear. These children live between the two extremes, deaf and hearing, and resultantly, hard of hearing children tend to be forgotten and overlooked in the school system in comparison to their peers with severe or profound hearing losses. The hard of hearing population is far from small, and children with mild or moderate hearing losses far surpass the number of those with severe or profound hearing loss. Research has shown that a lack of early identification of hard of hearing children plays a major role in the inattention that is often afforded them. In fact, statistics indicate that the smaller the loss, the greater the number of people who are affected.

Research has also shown that parents of hard of the hard of hearing child often state that their child's hearing loss was discovered at approximately 30 months of age, while the loss of profoundly deaf children was discovered by age 15 months. For the child whose loss is minimal, or whose loss is progressive, and does not appear significant during initial hearing screenings, their remaining hearing and their own adaptive abilities often became their worst enemies. The fact that hard of hearing children typically communicate very well in face-to-face interactions, tends to mask the extent of their hearing loss, often lulling parents and teachers into believing that the child understands more than they actually do. For these children, what they hear feels normal. Therefore, the biggest problem facing the child is not what they do not hear, but what they think they hear.

Doctors and parents often assume that once the child is fitted with hearing aids, he/she will function like a child without a hearing loss. Without a doubt, technological assistance has greatly improved and done much to help the hard of hearing child hear better; however, technological assistance has not solved other prob-

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SOMETHING TO TALK ABOUT: The use of sign language will not delay or prevent the development of spoken language. In fact, it has been shown that the use of sign language can enhance the development of speech and language.

lems, especially behavioral, that might be associated with hearing loss. Studies focusing on social and behavioral issues of these children have reported severe problems. The information presented in various studies concerning behavior problems of hard of hearing children indicate that they do significantly worse on behavior rating scales, even when compared to children with severe losses.

Accepting the fact that a lack of adequate language skills, due to a hearing loss, can be a cause of behavioral issues, do inadequate language skills also have a negative impact on academic performance? The answer is resoundingly, YES. Research reports that even for students with a mild hearing loss (15-25 dB), the average delay in vocabulary and other language skills is over one year compared to hearing peers; the hard of hearing child performs two to three years behind hearing students on standardized academic tests; and, are commonly held back from grade promotion by an average of one and half grades.

Certainly, parents of hard of hearing children are dedicated, hopeful, and desire only what is most appropriate for their child. The parents are struggling to do their best for children who are only partially able to access spoken language, yet who have the capability to learn a visual language and a spoken language, but are often denied opportunities to do so. A major problem is that the parents are often not given adequate information that would assist them in meeting their child's needs. Research indicates that these parents are less likely than parents of profoundly deaf children to receive information about behavioral development, school choices, opportunities to participate in parent groups, legal rights, or sign language instruction/possibilities.

The typical school system tends to overlook the obvious needs of the hard of hearing child because the child can speak intelligibly and wears hearing aids, which are assumed will promote normal hearing. As a result of these assumptions, the child might be disruptive in class due to frustration at not being able to hear in a noisy environment; feel that what they are able to hear is normal; are not aware of or misinterpret what words are spoken; and, are singled out as being slower than their peers because of lack of access to a full and meaningful language.

The terms language and speech are often used interchangeably, both by professionals and parents. However, it is important that the parent of a hard of hearing child understands these terms are not synonymous. Language is a linguistic system of symbols that can be expressed several different ways, including speech or sign language. Speech is not the same thing as language; it is a tool for expressing language. Many hard of hearing children have a complete language foundation, but might not have the capability of speaking intelligibly. It is important that parents understand that the ability to speak is not related to the child's intelligence. Also, the ability to speak does not interfere with the learning of sign language, and the ability to sign does not interfere with the learning of speech.

Parents of the hard of hearing child are looking for answers and support. They want their child to be able to express and understand language and to be able to communicate what is essential in their lives, as well as be accepted socially and develop meaningful friendships. Some families choose to use sign language with their child as well as spoken communication; others opt for spoken language only. Regardless of the communication option chosen, the child should have as much access to language as possible. It is recommended that the parents follow the lead of the child. Is the child primarily a visual language learner or primarily a spoken language learner? If the child is primarily a visual language learner, then sign language should be incorporated into the communication mode.

What is crucial is that the parent communicates with the child to the best of their ability in a deep and meaningful way. The parent does not have to become an expert in either speech teaching techniques or sign language. The key is consistent and meaningful communication.•

TIPS FOR PARENTS OF THE HARD OF HEARING CHILD

- If at all possible, the child should be enrolled in an early intervention program as soon as a hearing loss is identified. This can be facilitated by either the local school district or a school for deaf and hard of hearing children in the area. Such a program should assist the parents with ideas and techniques that will enhance the child's language development as well as support the child's self esteem and identity.
- Most hard of hearing children can benefit from hearing aids or other assistive devices, so attempt to have the child fitted with hearing aids. An audiologist should be selected who has experience in working with hard of hearing children and can assist in finding the most appropriate hearing aid.
- Meet other parents of hard of hearing children. They will provide support and information that only another parent can provide. The early intervention specialist should be able to connect you with parent support groups or other parents in your community.
- Elicit the support and experience of hard of hearing adults. You will find that they will be happy to answer your questions about raising a child with a hearing loss and will be able to give practical suggestions for communication, language, and social development.
- Consider using sign language with your child. The use of sign will not delay or prevent the development of spoken language. In fact, it has been shown that the use of sign language can enhance the development of speech and language.
- Continue with approaches that work and modify those that do not. Follow your child's lead; the hard of hearing child will make it evident whether he/she is primarily a visual or an auditory learner. Once this is ascertained, play to your child's strength (vision), not his/her weakness (hearing).

ABOUT THE AUTHOR:

J. Freeman King, Ed.D. is Professor of Deaf Education, Utah State University in Logan, Utah.

EARLY IDENTIFICATION OF DEVELOPMENTAL CONCERNS IN YOUNG CHILDREN

BY DEEPA SRINIVASAVARADAN

Developmental Health Promotion takes into consideration the current developmental reality of the child, as well as the developmental expectations for the next months and the developmental potential for growth over time.

Developmental disabilities are a group of conditions due to an impairment in physical, learning, language, or behavior areas. About one in six children in the U.S. have one or more developmental disabilities or other developmental delays. Also, 1 in 59 of eight-year-old children were identified with autism spectrum disorders (ASD) in 2014, compared to 1 in 68 children in 2012. The autism rate in New Jersey continues to skyrocket, and once again leads the nation with the highest percentage of children with ASD. In New Jersey, it is 1 in 34 in 2014, compared to 1 in 41 children in 2012, according to a new report by the Centers for Disease Control and Prevention's (CDC's) Autism and Developmental Disabilities Monitoring (ADDM) Network. That represents a 19-percent increase from two years ago when the report was last released. Access the snapshot of key findings of the ADDM Network at **www.cdc.gov/ncbddd/autism/addm-community-report/documents/key-findings-addm-community-report-2018-h.pdf.**

EP EXPLORES • DEVELOPMENTAL DISABILITIES

Of great concern is that many children with developmental delays or disabilities are not identified until after they enter school, by which time they may have already experienced significant delays socially and/or academically and missed key opportunities for early intervention and supports. This is particularly true for children of color, immigrant children, and children in families with limited English proficiency, who are underrepresented in preschool special education but overrepresented in school-age special education. This is in part because, by not being identified early, they miss out on early intervention and preschool services that could reduce or eliminate the need for special education as children and youth. Early childhood is a critical period that can set the stage for one's health trajectory and positive future outcomes. Research and science have also demonstrated that what happens to children, both positive and negative, in their early years can have lasting effects. Therefore, it is important to ensure that young children have good physical, cognitive, social, and emotional development through developmental health promotion activities.

WHAT IS DEVELOPMENTAL HEALTH PROMOTION?

Developmental Health Promotion takes into consideration the current developmental reality of the child, as well as the developmental expectations for the next months and the developmental potential for growth over time. It consists of activities to promote awareness of the importance of and need for tracking and celebrating developmental milestones in young children and following up immediately when concerns are noted. Developmental Health Promotion helps children and families achieve better outcomes by supporting parents to address delays promptly and connecting them to the resources they need. Developmental Surveillance or Monitoring and Developmental Screening of children are integral components of Developmental Health Promotion.

DEVELOPMENTAL MONITORING

Developmental Monitoring means paying attention to how your child plays, learns, speaks, acts, and moves, all of which denote a child's physical, cognitive, communicative, social, and emotional well-being. It is an on-going process that begins at birth and can be done by parents, teachers, and health and early childhood professionals. Comprehensive child development surveillance or monitoring may include:

- *Eliciting and attending to the parents' concerns*
- *Maintaining a developmental history of the child*
- *Making accurate and informed observations of the child*
- *Identifying the presence of risk and protective factors*
- *Periodically using screening tools*
- *Documenting the process and findings*
- *Connecting parents to necessary supports and services*

CDC'S "LEARN THE SIGNS. ACT EARLY." PROGRAM

The Centers for Disease Control & Prevention's "Learn the Signs. Act Early." (CDC's LTSAE) program (www.cdc.gov/actearly) aims to improve early identification of children with autism and other developmental disabilities, so children and families can get the services and support they need as early as possible. LTSAE materials educate families about developmental milestones, including what to expect and when to be concerned about their child's development. These materials are not a replacement for developmental screening, but they help parents to be better informed partners in monitoring early development. With these resources, parents can base their observations on objective, research-based, age-appropriate developmental milestones. They are easy to use and help parents have more realistic expectations about their child's development. Here are some LTSAE resources that parents can use to track their child's development:

At each well-child visit, the parent(s) and the child's doctor should discuss the child's development and any concerns either of them may have. Any concerns noticed during developmental monitoring should immediately be followed-up with a developmental screening.

DEVELOPMENTAL SCREENING

Developmental Screening can help to tell if a child is developing and reaching his or her milestones when he or she should, or if there are delays. Developmental Screening is a process that is completed by doctors and other professionals with training to use validated screening tools, at doctors' offices, in schools, or in community settings. As part of the screen, the doctor or another professional might ask parents some questions about their child or talk and play with the child to see how he or she responds in comparison to other children the same age. Commonly used developmental screening tools include the Ages and Stages Questionnaires (ASQ) and the Survey of Well-being of Young Children (SWYC).

The American Academy of Pediatrics and the Bright Futures Guidelines recommend that all children be screened for developmental delays and disabilities during regular well-child doctor visits at:

- 9 months
- 18 months
- 24 or 30 months

The American Academy of Pediatrics also recommends that all children be screened for autism at:

- 18 month and 24 months

Additional screening may be needed if a child's parent or doctor has concerns or if the child is at high risk for developmental problems due to preterm birth, low birth weight, or other reasons.

DEVELOPMENTAL MILESTONES : RESOURCES FOR PARENTS

Milestones Checklists, Milestone Moments Booklets, Milestones Tracker App, and other resources can be found at www.cdc.gov/actearly


Your Baby at 9 Months

What Most Babies Do at this Age:

Social/Emotional

Language/Communication

Cognitive (learning, thinking, problem-solving)

Movement/Physical Development

Act Early by Talking to Your Child's Doctor if Your Child:

www.cdc.gov/actearly | 1-800-CDC-INFO

Learn the Signs. Act Early.

MILESTONES CHECKLIST
Explains the four domains of development and tracks the developmental milestones for children 2 months through 5 years of age.

www.cdc.gov/ncbddd/actearly/milestones/index.html

NJ'S CHILD DEVELOPMENTAL PASSPORT
A tool for parents to track their child's growth and development. This booklet is intended to be used with the Milestone Moments booklet. Parents can bring this Passport with them to every well-child visit and to update it regularly.


Help Me Grow NJ

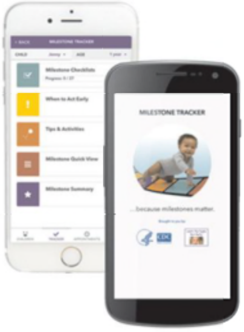
Child Developmental Passport

(A parent tool for tracking your child's health and wellness)

Learn the Signs. Act Early.

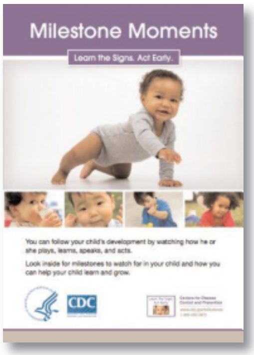
www.spanadvocacy.org/sites/default/files/files/Child%20Development%20%26%20Health%20Passport-English.pdf

MILESTONES TRACKER MOBILE APP
The app features parent-friendly, interactive milestone checklists for ages 2 months through 5 years; photos and videos that illustrate milestones; personalized milestone summaries that can be easily shared with the child's healthcare provider and others; tips and activities for supporting early development, including what to do if there's a concern, and reminders for appointments and recommended developmental screening.



www.cdc.gov/MilestoneTracker

MILESTONE MOMENTS BOOKLET Explains what babies do from 2 months to 5 years of age. It also provides tips that parents can use to help their child's development.


Milestone Moments

Learn the Signs. Act Early.

You can follow your child's development by watching how he or she plays, learns, speaks, and acts.

Look inside for milestones to watch for in your child and how you can help your child learn and grow.

www.cdc.gov/ncbddd/actearly/

TIPS FOR DOCTORS AND PROFESSIONALS

Doctors and other professionals can help perform developmental surveillance or monitoring at each health supervision visit and encourage parents to monitor milestones between visits. They can also:

- ❑ Provide Milestone checklists and the Milestone Moments booklet to families; have parents complete the checklist that is appropriate for the age of their child.
- ❑ Print and post a free flyer encouraging families to use CDC's Milestone Tracker app to track and quickly share developmental progress at visits.
- ❑ FREE materials are available from CDC: print or order (in limited quantities) in English and Spanish. You can also provide customized parent-friendly resources to families by adding your practice's logo and contact information. Email ActEarly@cdc.gov for more information.

Doctors and other professionals can conduct developmental screenings and autism-specific screenings as recommended by the American Academy of Pediatrics using a validated screening tool

- ❑ Visit American Academy of Pediatrics' Screening Technical Assistance and Resource (STAR) Center for information on screening tools, practice resources, and technical assistance: www.aap.org/en-us/advocacy-and-policy/aap-health-initiatives/Screening/Pages/Screening-Tools.aspx
- ❑ View the Birth to 5: Watch Me Thrive! healthcare provider guide that addresses how to talk with parents and where to go for help
  - Refer children with concerning screening results for further evaluation AND to your state's early intervention services. Find your state's early intervention contact information at: www.cdc.gov/ncbddd/actearly/parents/states.html
  - DON'T WAIT! Pay attention to parental concerns and ACT EARLY to make a difference!!

TIPS FOR PARENTS

• **ACT EARLY:** As a parent, you know your child best. If your child is not meeting the milestones for his or her age, or if you think there could be a problem with the way your child plays, learns, speaks, acts, and moves, talk to your child's doctor and share your concerns. Don't wait! Acting Early can make a real difference for your child and you!!

• **Visit www.cdc.gov/Milestones to find the milestone checklist for your child's age.** Use it to track your child's development. When it's time to talk with the doctor, write down the questions you have and show the doctor the milestones your child has reached and the ones that concern you.

You DON'T need a doctor's referral...

If your baby is not meeting developmental milestones

To get Early Intervention Services, call 888-653-4463

Schedule free evaluation for services

❖

Meet case manager

❖

Develop family plan

#ACTEARLY

nj.gov/health/fhs/eis

• **If your child's doctor does not do the recommended screening and/or if you have concerns about your child's development**, you can ask for a screening to be done.

• **Developmental Screening** results are not to be considered as a formal diagnosis.

• **If you or the doctor is still concerned** about your child's development:

o *If your child is under 3 years of age – Call your state's Early Intervention provider for evaluation and services that can help your child. You don't need a doctor's referral. Find your state's early intervention contact information at* www.cdc.gov/ncbddd/actearly/parents/states.html

o *If your child is 3 years or older - Call your local, public elementary school or school district and ask to speak with someone who can help you have your child evaluated, even if your child does not go to that school. Follow up with a written request for evaluation. For a sample parent letter requesting evaluation and letter writing tips, visit* www.parentcenterhub.org/evaluation-2/

o *Ask the doctor if you need to take your child to a specialist who can take a closer look at your child's development. If you do, ask the doctor for a referral and contact the specialist right away. Doctors your child might be referred to include:*

  ➢ Developmental pediatricians. These doctors have special training in child development and children with special needs.
  ➢ Child neurologists. These doctors work on the brain, spine, and nerves.
  ➢ Child psychologists or psychiatrists. These doctors know about the human mind.

- o *If your appointment with the specialist is many weeks away, remember you can call back every week to see if an earlier appointment has opened*
- o *Contact the Department of Health or the Early Childhood Administrator in your state about additional intervention services that may be available. Early Childhood Development State and Regional contacts can be found at* www.acf.hhs.gov/ecd/state-and-regional-contacts
- o *Find more information, including what to say when you make these important calls, and what to do while you wait to have your child seen, and how to get support for your family at:* www.cdc.gov/Concerned. *You can also access the SPAN Parent Advocacy Network's tip sheet, What to Do While Waiting for the Results of your Child's Evaluation, at* www.spanadvocacy.org/search/node/waiting%20for%20evaluation

- **Connect with local community resources** such as advocacy/family organizations (for example: SPAN Parent Advocacy Network in New Jersey) in your state who can provide support for you to navigate the early childhood system to access services, in addition to information about parent workshops, support groups, recreational programs, etc. Parent Training and Information Centers are found at www.parentcenterhub.org/find-your-center/and Family Voices/Family-to-Family Health Information Centers are found at: http://familyvoices.org/affiliates. For Sample flowcharts highlighting the resources and next steps for parents, visit: https://rwjms.rutgers.edu/boggscenter/projects/Act_Early.html
- **Getting help early for your child often means being persistent.**
- **Children with special health care needs should also be monitored and screened for developmental delays** and, depending on their condition, they may need more frequent monitoring and screening. •

ABOUT THE AUTHOR:

Deepa Srinivasavaradan is the CDC's "Learn the Signs. Act Early." Ambassador for NJ and the State Parent Lead for NJ's Early Childhood Initiatives – Help Me Grow, Early Childhood Comprehensive Systems Impact, & Home Visiting CoIIN 2.0. She is also a NJ LEND Family Fellow and the Southern Regional Coordinator of the Family to Family Health Information Center at SPAN Parent Advocacy Network: www.spanadvocacy.org

References

https://www.cdc.gov/ncbddd/autism/new-data.html
https://www.cdc.gov/ncbddd/actearly/index.html
https://www.healthychildren.org/English/family-life/health-management/Pages/Well-Child-Care-A-Check-Up-for-Success.aspx

MILESTONES MATTER: LET'S TALK ABOUT THEM!

MILESTONES AT 4 MONTHS
☑ Begins to babble
☑ Responds to affection

MILESTONES AT 6 MONTHS
☑ Likes to play with others
☑ Responds to own name

MILESTONES AT 9 MONTHS
☑ Has favorite toys
☑ Understands "no"

MILESTONES AT 1 YEAR
☑ Tries to say words you say
☑ Waves "bye-bye"

MILESTONES AT 2 YEARS
☑ Begins to run
☑ Begins to sort shapes, colors

MILESTONES AT 3 YEARS
☑ Knows name and age
☑ Climbs and runs well

Get free milestone checklists for these ages and more at **www.cdc.gov/Milestones** or by calling 800-CDC-INFO (800-232-4636).

Learn the Signs. Act Early.

Developed in partnership by the University of Missouri and the US Department of Health and Human Services, Centers for Disease Control and Prevention.

PART I

A ROAD RICH WITH WISDOM

INSIGHTS ON INCLUSION FROM A PARENT, ADVOCATE & FOUNDER

BY KIM HUMPHREY AND SEAN LUECHTEFELD

Editor's Note

"Included. Supported. Empowered." is a three-year storytelling and public awareness-raising initiative designed to celebrate the successes of individuals with intellectual and developmental disabilities, and to raise up the important role providers play in making those successes possible.

The Included. Supported. Empowered. team got the chance to sit down with Kim Humphrey at a recent gathering of the Maine Association for Community Service Providers. Kim is the mother of an exceptional child with autism named Daniel, and founder of Community Connect Maine, a growing group of parent-advocates in the state who are vigilant in their fight to ensure Mainers of all abilities have access to the high-quality supports they need and deserve.

This article contains part one of the two-part conversation we had with Kim, which has been lightly edited for clarity and tone.

INCLUDED. SUPPORTED. EMPOWERED.: Tell me a little bit about your son, Daniel, and his experience with an autism spectrum disorder.

KIM HUMPHREY: Close to three decades after he was diagnosed, Daniel, at 30 years old, is thriving. The last 10 years have been the most stable of his life. He is non-verbal with severe autism. He uses only basic functional communication. Because communication is so limited, he at times exhibits aggression to express frustration or pain. However, he has learned—with staff prompting—to de-escalate himself, which is a major achievement. I am thrilled that he is in an environment that provides enough to allow him to continue to grow, learning skills even beyond his years in the school system.

Since returning from an excellent out-of-state residential school almost ten years ago, Daniel has lived with another young man with autism in a well-run group home. They live near a college where he volunteers weekly delivering excess food to a nearby soup kitchen. During the week, he serves 12 Meals on Wheels clients who look forward to his visit.

In addition to contributing to his community, he takes care of his daily household chores, including doing his laundry, selecting his meals and picking up groceries. He still makes time for a little drumming, jumping on the trampoline, walking in his neighborhood, working out at the local YMCA and hanging out with peers as he competes in Special Olympics. Neighbors who have included him in annual summer picnics have remarked about how they enjoy his presence as they peer out their window to see him walking around the block or jumping in his front yard. My son's frequent radiant smiles say it all. I couldn't be prouder of him.

ISE: When did you first realize Daniel was on the autism spectrum?

KH: He wasn't diagnosed until he was six, although we knew a great deal well before then.

The day Daniel was born, the pediatrician told us he was "perfect." Of course, Dan's dad and I agreed. Looking back, I remember his 19-month-old sister, Kristin, pointed out when she saw her little brother in the hospital basinet for the first time: "He has a tongue!"

While he did have a tongue, we realized a few years later that his language was not developing. We were shattered when we discovered that learning to talk was going to be difficult, but we didn't know the full story at that point. Daniel was initially diagnosed by an expert pediatric neurologist with congenital dysphasia just before he turned two-and-a-half. The doctor said it was a garden-variety language disorder that Daniel could overcome by age five – albeit with intense intervention.

We were informed at that time that it might be autism. However, it didn't matter because the intense intervention for congenital dysphasia was the same treatment he would need if it was autism. Because progress was slow, we knew it was autism long before his official autism diagnosis occurred at age 6.

ISE: What are some of the supports and services Daniel has received over the years?

KH: Right after he was diagnosed and to this day, Dan responds best in a structured environment that includes activities that are engaging to him. Speech and occupational therapy help to unlock his ability to communicate and accomplish useful tasks. Sensory integration strategies built into his day as preferred activities (jumping, rocking, sitting in bean bag chairs, playing with squeezable toys) were used in his school years. He did well with a broad applied behavioral analysis approach, which worked best when the training tasks were functional. He learned in small, tedious steps the skills that come naturally to so many of us.

> **“WHAT IS AMAZING IS THE HUGE DIFFERENCE IT MAKES WHEN DANIEL RECEIVES THE SUPPORT HE NEEDS. WITH CONSISTENT, WELL-TRAINED PROFESSIONALS SUPPORTING HIM, HE LOVES JOINING IN COMMUNITY ACTIVITIES. BUT WITH GAPS IN CARE, HIS SKILLS DETERIORATE.”**

What is amazing is the huge difference it makes when Daniel receives the support he needs. Over the years, my family and his team learned what programs work well and what would fail him. If he had well-trained staff, no gaps in care, excellent transitions, and around-the-clock learning and supervision, he made slow but steady progress. On the other hand, when this level of support was unavailable, he would learn new aggressive behaviors like kicking, biting or pulling hair. With consistent, well-trained professionals supporting him, he loves joining in community activities. But with gaps in care, his skills deteriorate.

In other words, with appropriate care, Daniel has dignity. Without it, Daniel is uncivilized.

ISE: So often, we hear families talk about the need for consistency in their loved ones’ lives, but we also know there is a huge dearth in the number of Direct Support Professionals out there to work with folks like Daniel. Has that ever impacted your family?

KH: Absolutely. While Maine had some wonderful providers, it lacked the steady workforce required for Daniel to make progress. So, when he was 11 years old, Dan left his family home to live in a residential school for autism in Massachusetts. A year later, we tried to bring him back home to create a group home nearby by applying for a Home and Community-Based Services (HCBS) waiver, which would have funded a group home to be operated by a provider agency. Though Daniel qualified, there was no funding in the waiver program for him. It was not until he graduated at age 20, eight years later, that he received the HCBS waiver. He was then able to return to Maine, and he moved into the group home in Lewiston where he still lives today.

THE EXTRA MILE: Daniel makes working out at the local YMCA part of his busy routine; “Some providers were courageous, creative and clever about leveraging much-needed services. These people were critical to the success he has experienced. It was not unusual to observe a young professional succeed in teaching Daniel, then go on to have a highly successful career. I started thinking of my son as a career launcher.”

ISE: Wow – eight years? No family should have to wait that long to have their family together in one place.

KH: Exactly.

ISE: So tell me about the impact Dan’s support providers have had on him and on your family.

KH: I felt extremely lucky when quality professionals would reveal new ways of healing Daniel. Some providers were courageous, creative and clever about leveraging much-needed services. These people were critical to the success he has experienced. It was not unusual to observe a young professional succeed in teaching Daniel, then go on to have a highly successful career. I started thinking of my son as a career launcher.

We also came upon people with high levels of expertise that could intervene in a crisis, perform a functional analysis assessment or recommend an in-depth strategy that would work. Without some of these people, my son would be functioning at a much lower level today. There are very few people who had the highest level of expertise that he seemed to require. When my son graduated from high school, an adult service provider commented to me that my son's skill level was higher than people they served that had similar characteristics—and I think that's thanks to the many wonderful providers we were fortunate to work with.

> **"PEOPLE WITH DISABILITIES AND THE FAMILIES SUPPORTING THEM DESERVE TO HAVE THE OPPORTUNITIES THAT ARE OPEN TO THE REST OF THE WORLD."**

ISE: In 2015, you started Community Connect Maine, a coalition of parent-advocates. What inspired you to start this group?

KH: It's simple: people with disabilities and the families supporting them deserve to have the opportunities that are open to the rest of the world. This ought to happen without being subjected to the choice of lifelong advocacy marathons or living without needed supports. When policymakers understand the collective stories of people living with the disability community, positive changes can happen. That is the basis of the motivation behind starting Community Connect Maine. •

Kim shares more about Community Connect Maine, her work as an advocate and organizer, and her family's incredible story in Part 2 of this conversation in Exceptional Parent magazine's April issue. Stay tuned!

ABOUT THE AUTHORS:

Kim Humphrey is Founder of Community Connect Maine. She can be contacted at khumphrey.phadv@gmail.com.
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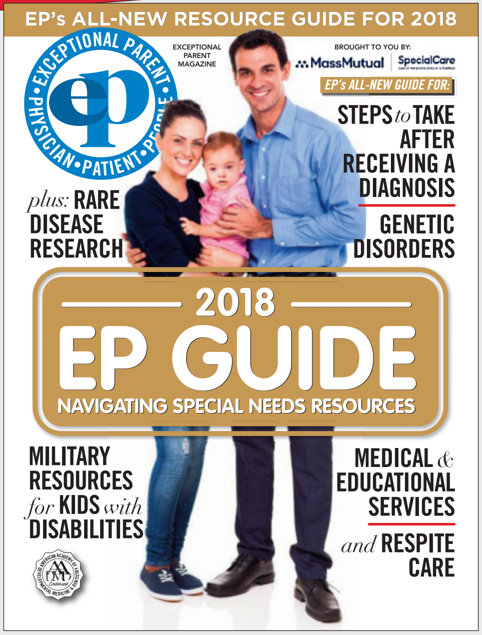

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THWACK!

Be gone PANDAS!

This is merely my account of our journey with it. Your journey may differ. PANDAS can appear in the form of a sudden unexplained behavior and it seems to come with strep, but can also come with Lyme or ticks. There are many families who have encountered this with children who have autism or other immune challenges.

BY LAURA GEORGE

I still remember that sound from that day several years ago. I heard it as I put my hand on the classroom doorknob that was next to my classroom. I never knew that such a simple sound would evoke a memory, a story and an unwanted journey to prayerfully overcome years later. It is this sound that causes one to hauntingly remember confusing experiences, an unwanted diagnosis and a deep desire to wish that with strength it could be overcome.

My daughter was your typical, average kid. She was incredibly bright and had an amazing ability to grab details where they were never expected to be seen; like the time she caught a street misspelled three different ways. Her memory was amazing and she was full of life always approaching it with zest. She was entering her tween years; doing well in school and teaching herself drawing skills at an advanced adult level.

This sound, *"Thwack!"*, would forever change her and me. For days prior she had been aggressive, losing her memory and moodier than a child at age ten should be. I had been sharing with other parents my frustration at her behavior and myself for not being a better parent. I continued to twist the handle on the door hearing that sound again, followed by immense sobbing. "Laura, I just don't know what to do with your daughter! She is refusing to follow instructions, claiming that she doesn't understand, and has thrown both her shoes across the room! Doesn't she understand that this behavior is inappropriate at school?" I looked at my daughter who was sitting on the floor in a manner reminding me of a two-year-old's temper tantrum.

The following day I took her to our family doctor. I asked him what was I doing wrong. After all, this was my first child and I am a young widow. Of course, I'm going to make mistakes but I did not think I was doing that badly. After all, she was a child with good grades! She is my courteous, well-behaved child; I was still trying to tell myself. Our family had been going to this doctor for a long time, long enough for him to remember seeing my daughter in diapers. Maybe he could tell me what I was doing wrong and I could fix it. Instead, *"Thwack!"*, he said something else. "Your daughter needs to be tested for strep!" I was surprised! She has no fever, sore throat, runny nose; nothing that suggests she is sick. The next thing I knew he came in with a cotton balled stick to take a throat sample. My daughter bucked, screamed, cried, and threw a fit to the point that the entire front lobby of his small office could hear her. After the test, she said, "Mom, why did they take that? My throat was fine!"

SCARY NOISES: This sound, *"Thwack!"*, would forever change her and me. I continued to twist the handle on the door hearing that sound again. My daughter had thrown both her shoes across the room, and was sitting on the floor in a manner reminding me of a two-year-old's temper tantrum.

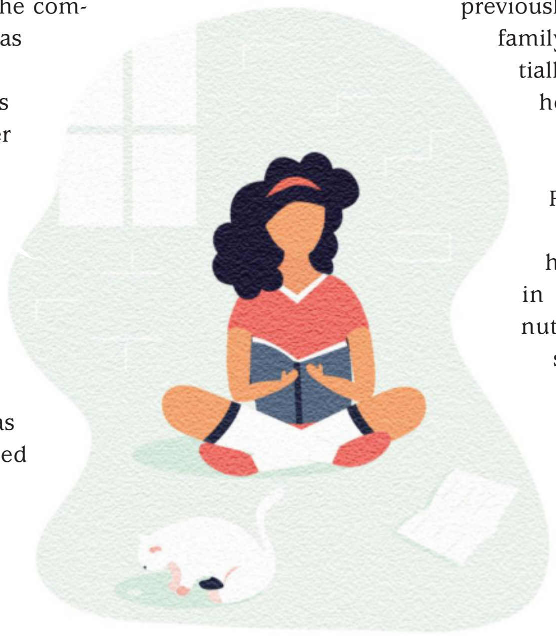
After a period of time, the doctor came back into the room. "Mrs. George, your daughter has strep. In fact, I went through my records and discovered that she was also diagnosed with it in my office exactly one year ago at the exact same appointment time." *Thwack!* I am now suddenly speechless, silent and very confused. He then follows with, "Your daughter I suspect has pandas. Not the animal, but instead P.A.N.D.A.S. which stands for Pediatric Autoimmune Neuropsychiatric Disorder Associated with Streptococcus infection."

In the next 300 days, she was formally diagnosed with strep no less than eight times and on antibiotics each time. My education on the topic would be acquired from the medical community, along with online research and support groups (see below). The strep toxin goes go down to the kidney and comes back up residing in the brain and swelling it. Think of it as a headache to be manually placed inside the brain except that it can play in any room freely. This happy, cheerful child would mentally deteriorate rapidly in front of me and sometimes with frightening clarity. Her above average grades in school would drop so deeply that I often wondered if she would graduate to the next grade. Logic and the ability to focus, putting ideas together, turned into frustrating, scattered and incoherent concepts. Sitting down to work on homework was a strain and sleeping the day away was preferred.

Her once-simple life changed into one filled with doctor appointments. Some would simply dismiss her with a written prescription. One such event was a doctor who simply decided that even though her diagnosis was an autoimmune disorder messing with her brain, she obviously could not sit still and thus put her on a medication that had color dye in it—something we mentioned many times she was allergic to. The medication made her nightmarishly aggressive incoherent episodes even worse. At one point we said to the doctor, "How is it that a medication that is supposed to make one feel better, make both the patient and family so incredibly awful? We both want her off of it now!" He decided to decrease her medication. Yet our actual life preserver would come in the form of a school request that noted that children on that medication were not doing well. My child promptly took herself off the medication and a few days later her symptoms were reduced.

There were many different types of symptoms that she endured. Loss of appetite, picky eating, aggression, circular conversations that there was no ability to stop, memory loss, inability to take supplements or medication, fear of sleeping alone, lack of organization and the list goes on. Her aggression usually came out during her hallucinations and one time I got hit in the back of my head, *"Thwack!"* with a book. In the beginning, they were only for a few moments, sometimes they would last for an hour. The most frustrating thing for me is that I usually did not realize they were occurring until after I saw that her behavior was not making sense. Some hallucinations were that she was somewhere else; some were that she saw things in the air; others made her think that she was in a time or place different to reality. The worst hallucination that I remember her having was at bedtime one night when she thought that she was locked up in a hospital ward. She did not know who I was. She kept asking to be returned home to her Daddy, Mommy and two dogs in Chicago. We live in Georgia and my husband passed away several years ago. *That was heartbreaking.*

As if all the above was not hard enough to endure, she was also subjected to societal misconceptions. One school told her that she would not be accommodated in the fall because of her autoimmune disorder. Another moment was a ten o'clock night visit by the police and Department of Family and Children Services who were conducting an investigation based on a complaint. The complaint was that I was taking her to too many doctors and not taking her to the doctors for treatment. *(Yes, that is the truth!)* It was later proven with assistance from a politician's office that the complaint was false, unfounded and, subsequently, both my child and I were cleared of any wrongdoing. For two months the entire event sent her emotional state plummeting even further and made me all the more concerned for her overall well-being.



CAUSE FOR HOPE: She has not endured hallucinations in over a month. Her appetite has picked up and her grades are starting to return to normal levels prior to her getting this disorder. Even the discussions of going to be with her peers have returned.

In retrospect, my former caregiving experiences with my husband proved to be the greatest source of strength. Though my child saw many doctors, took many tests, and gave up a lot of blood, we managed to narrow them down to a concentrated team. As mentioned previously, there was her family doctor (who initially diagnosed her), her pediatrician who has lot of experience with PANDAS, her chiropractor who has a background in neurology and nutrition, and her social worker. I never asked, but instead informed them that we would all work as a team, each supporting the other's recommendations or need for information. It is a recommendation I would make to anyone walking down the PANDAS path. For my daughter, it ultimately was the smartest decision I could make. Family

HIDDEN INVADERS : RESOURCES FOR FAMILIES WITH PANDAS

SEPPA
Southeastern PANS/PANDAS Association

SEPPA: Southeastern PANS/PANDAS Association

www.seppan.org

NIH

NATIONAL INSTITUTE OF HEALTH

www.nimh.nih.gov/health/publications/pandas/index.shtml

PANDAS NETWORK
ADVOCACY, SUPPORT & RESEARCH FOR PANDAS, PANS, AE

PANDAS NETWORK

http://pandasnetwork.org

AUTISM SPEAKS
It's time to listen.

AUTISM SPEAKS

www.autismspeaks.org/expert-opinion/what-pandas-how-it-different-autism

PANDAS PHYSICIANS NETWORK
PPN
A DIVISION OF THE FOUNDATION FOR BRAIN SCIENCE AND IMMUNOLOGY

PANDAS PHYSICIAN NETWORK

www.pandasppn.org

International
OCD
Foundation

INTERNATIONAL OCD FOUNDATION

https://kids.iocdf.org/professionals/md/pandas and friends were added to the team. Often, I called them when I needed support, sanity or a laugh when I only felt like crying.

There was also an additional special team member. It was a brand-new dog that we obtained from the county dog rescue program. After having him in our home for one month with no training, he started alerting that she was having seizures. Immediately we placed him into training classes. We decided his purpose would be to eventually accompany her in public for seizure alerting. For the short term though he would be the team member who would comfort her as she came out of her hallucinations and wake her up when she fell into her deep periods of sleep. He was my first assistant and still serves in that capacity.

Other therapies included dietary, educational and reward-based planning. Making changes to her diet proved very helpful in helping her to regain her focus and she was placed on a diet-free of chemicals, decreased sugar intake and a more natural diet. It is really hard to follow when the child is a picky eater and focuses solely on one type of food to eat. At one of her schools, we were lucky to have the assistance of a teacher who was also an intervention specialist. She constantly and creatively worked around my child's abilities or lack of abilities to her complete her work. Rewards at home would consist sometimes of small things such as food items, or movies and be motivators for completing one day's worth of homework on time, waking up on time, taking supplements or other daily living tasks.

Less than one year ago, she had her tonsils and adenoids removed, which is an additional popularly recommended therapy. The idea is that the two are germ catchers and if they are removed then it will slow down or possibly stop the repetitive reinfection of strep. Our experience has been that at this point in time she has not caught it again. She has not endured hallucinations in over a month. Her appetite has picked up and her grades are starting to return to normal levels prior to her getting this disorder. Even the discussions of going to be with her peers have returned. However, we clearly understand that for the time being PANDAS is a life- long diagnosis.

Like a bug, my daughter and I collectively say, *"Thwack!* Be gone PANDAS! You are not welcome in our home! You are not welcome anywhere at any time! Quick, someone go get the fly swatter!" •

***Author's note:** There are many facets to PANDAS. This is merely my account of our journey with it. Your journey may differ. PANDAS can appear in the form of a sudden unexplained behavior and it seems to come with strep, but can also come with Lyme or ticks. There are many families who have encountered this with children who have autism or other immune challenges. It is my strong recommendation that if you suspect your child has this, get both the stick and blood strep tests completed followed by a conversation with your doctor. Then find a support group to associate yourself with to get additional medical and community resources.*

— Writing the last words on this, I just learned that she has strep again; number ten in two-and-a-half years!

ABOUT THE AUTHOR:

Laura George is an Emergency Management Disability Liaison and sits on the National Center for Independent Living Emergency Preparedness Committee as well as other national, state, and local committees. 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 also 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 and dog (assistant), Turkey.

Understanding Treatment for PANS and PANDAS

A GUIDE FOR KIDS

WHAT CAUSES PANS OR PANDAS?

Your body's immune system is like a security system that helps protect you and keeps you healthy. Sometimes, certain people's immune systems get confused when they're trying to fight an illness. Doctors think that PANS and PANDAS are caused by that response.

WHAT ARE PANS AND PANDAS?

PANS and PANDAS are illnesses that change the way your body and mind act.

These illnesses can make you feel worried, sad, or even mad—**but it's not your fault.**

Medicine and therapy help kids with PANS or PANDAS get better.

Doctors don't know why some kids get PANS or PANDAS and others don't.

Learn more at pandasnetwork.org

DON'T EVER...

BY KIMBERLEE RUTAN MCCAFFERTY

PHOTO PROVIDED BY KIMBERLEE RUTAN MCCAFFERTY

If you are just beginning your autism journey with your son or daughter, I imagine you are feeling at least a bit (understatement of the year) overwhelmed. Perhaps you've been able to secure that elusive appointment to get your child a proper diagnosis. Maybe you have passed through that gauntlet and are already lining up meetings with Early Intervention for both you and your kid. Perhaps you're at a later stage and are in the midst of evaluations with your child's school district to get him or her enrolled in what you hope will be an appropriate (and excellent) program.

I imagine that wherever you are in this process, whether during it or after it, you are very, very tired.

I am fifteen years into our autism journey with two children on the spectrum, but I can remember those days like they were yesterday. It seemed for years we were living from one doctor's visit to the next, one evaluation/meeting to the next. It was a relentless round of hurry up and wait, until finally we moved and got our son, Justin, into his local school district.

> Nobody can predict your child's future when they're very young, not even the most brilliant doctor or the most experienced therapist. Don't ever let anyone rob you of hope that your child will one day be happy too.

And yes, I too was very, very tired.

We were fortunate in that most of Justin's therapists and teachers were wonderful, however, most people do not deal with dozens of practitioners without having at least one bad apple in the bunch.

For us, it was an Early Intervention provider who informed me with absolute certainty that my twenty-month-old would never speak or live independently. In truth, she turned out to be right.

But that's not the point.

I will tell you this. At the tender age of eighteen months, my eldest son was diagnosed with moderate to severe autism. He had no words, had frequent meltdowns, relentless insomnia, gastrointestinal issues, sensory issues, and was the pickiest eater on the planet. This was 2004, and a diagnosis at this age was generally unheard of, but we were fortunate that a developmental pediatrician was able to recognize his issues for what they were so we were able to start various therapies with him. He was not even two when he started with ABA and speech therapy, barely walking when this particular therapist graced our doorstep.

She had no right to say what she said. There is absolutely no way anyone can predict the trajectory of your child's future when they're this young. And while my gut instincts told me Justin might remain at the more severe end of the spectrum, the elusive possibility of him having some semblance of functional speech and some measure of independence kept me going in those dark days when I was my son's primary therapist. With that one sentence his therapist robbed me of hope and plunged me into days of despair before I was able to realize that she wasn't omniscient, and was far from having all the answers.

She never should have said what she did. And I wish I'd had the energy to tell her that to her face.

Fourteen years after that chilling moment, my son does have a few words but, more important, he can communicate beautifully with his iPad. He will never live independently, but is wonderful at getting his needs met by himself, excellent at the execution of completing a task. He eats (even a few veggies!), sleeps, and no longer has many sensory issues.

Best of all, he is one of the happiest children I know.

Ten years ago, our second child was diagnosed with regressive autism, and at first his trajectory seemed to mirror his brother's. Zach was eighteen months when he experienced two back-to-back illnesses which seemed to rob him of speech, appetite, and extinguish the light in his eyes that made him our boy. I remember thinking at the time that one of his therapists could have said the same thing about him that they did about our older boy but fortunately, all held their tongues.

And ten years later he no longer has special education status, has friends, made the distinguished honor roll in his first marking period of middle school and, best of all, loves his life.

To this day, both of my sons still surprise me with their skill acquisition, their ability to adapt to different environments, and their ebullient souls. Fifteen years ago, I could never have predicted I'd be at this point with my two boys, and my hopes for their happy, safe and productive futures were what kept me going during our darkest days. Nobody can predict your child's future when they're very young, not even the most brilliant doctor or the most experienced therapist.

Don't ever let anyone rob you of hope that your child will one day be happy too. And never, ever give up in that pursuit.•

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.

Everyone has a role to play in the inclusion revolution and ending discrimination against people with intellectual disabilities. Strong Minds is one way Special Olympics breaks down the barriers to health for people with intellectual disabilities.

STRONG MINDS

PREPARES FOR THE WORLD STAGE

BY JAMIE VALIS, PHD

Grace Hamilton is ready. She has been preparing physically and emotionally for months with her basketball team. The 2019 Special Olympics World Games in the United Arab Emirates await.

The world will set its sights on Abu Dhabi as Hamilton and other top athletes from 192 countries will showcase their talents. Many competitors are preparing their minds as well as their bodies for this adventure of a lifetime. In such a thrilling environment, athletes will need to focus and actively manage the inherent stress that comes with competition on the world stage.

Hosted for the first time in the Middle East, the 2019 Special Olympics World Games will take place on March 14-21. The Games will be the world's largest humanitarian and sporting event of 2019 with 7,000 athletes competing in 24 sports and an estimated 500,000 spectators.

Emotional well-being is critical to performing, on and off the field. Unfortunately, emotional wellness is an area that is sometimes overlooked for athletes, including Special Olympics athletes. While many know the importance of physical fitness and a healthy body to achieve their goals, even the most-physically fit individuals cannot achieve their best when they are ill-equipped to manage the stress that comes with competition.

Studies have found that many individuals with intellectual and/or developmental disabilities have not had the opportunity to practice good coping skills in a variety of settings. Most common coping strategies employed by adults with intellectual and/or developmental disabilities are passive, and not active strategies. According to Alice Boyes, Ph.D., in Psychology Today, "Avoidance

PHOTOS PROVIDED BY STEPHANIE CORKETT/SPECIAL OLYMPICS

BODY AND MIND: *(Opposite page)* Athletes have the opportunity to develop active strategies for maintaining emotional wellness under stress during Strong Minds; *(above, clockwise from top)* Brandy *(far left)* is excited to teach her teammates about emotional well-being and performing at one's best on and off the field; More than 1,100 Special Olympics athletes and 50 clinical directors have joined Strong Minds' efforts; Grace Hamilton *(left)* and Cáit Donnelly encourage emotional wellness in competition and everyday life; Strong Minds features an opportunity for Special Olympics athletes to learn how to develop adaptive coping skills.

coping creates stress and anxiety, and ravages self-confidence."

Special Olympics is working with athletes around the world to educate them about emotional wellness and empower them to use active coping strategies, which are associated with increased well-being.

In 2017, after several years of international piloting, Special Olympics launched a new focus on emotional wellness called Strong Minds. Strong Minds is the eighth discipline of Special Olympics Healthy Athletes®, made possible by the Golisano Foundation. It shows athletes how to develop adaptive coping skills and maintain emotional wellness in competition and everyday life. The content is derived from evidence-based models of self-regulation, social-emotional learning and mindfulness-based stress reduction.

Athletes learn coping strategies like deep breathing, thinking positive thoughts, releasing stress, and connecting with others, and after trying them out, they identify the strategies they plan to use in the future. Trained volunteers then provide visual aids for incorporating these individually-tailored techniques into their lives.

FAMILIES CAN DOWNLOAD RESOURCES SUCH AS THE

STRATEGIES FOR STRESS

AND

TIPS FOR STRESS

FOR FREE!

"[Strong Minds] relaxes me right down, I can feel all the stress and negative energy just going out through my fingertips - I can feel it just going down," reports Hamilton as she prepares for World Games.

Competition provides a natural opportunity to develop active strategies. To date, more than 1,100 Special Olympics athletes and 50 clinical directors have participated in Strong Minds. Athletes, families and volunteer professionals are embracing Strong Minds.

Brandy Peterson, a Special Olympics athlete and Health Messenger from Montana, shares, "My goal is to educate athletes, family members, coaches, volunteers and the community of our newest Healthy Athletes discipline Strong Minds. I really love doing this and working with the athletes on emotional wellness."

Special Olympics Ireland began offering Strong Minds in June 2018, catching the attention of the Minister for Health who visited Healthy Athletes. With 91 athletes slated to compete, Special Olympics Ireland continues to offer Strong Minds offerings to the delegation preparing for World Games. Strong Minds events have included workshops with athletes, whole team exercises, and coaches and management team involvement with much success.

“Strong Minds has had such a positive effect. It helps everyone to realize these exercises can not only be used in sporting environments but also are relevant to everyday life,” shares Cáit Donnelly, the Health & Wellbeing Coordinator of Special Olympics Ireland.

Ireland is not alone in its focus on emotional wellness and physical fitness. In other areas, teams are actively preparing for World Games beyond the training field. For example, Special Olympics USA, with more than 200 competing athletes, will incorporate Strong Minds training into its send-off celebration in Newark, N.J. Also, at the previous World Games in Austria, athletes such as James Richardson, a long-time Special Olympics athlete from Germany who medaled in the 5,000m and 10K cross country ski events, participated in the Strong Minds pilot. Richardson left with tools he could use: "[Strong Minds] helped me find a way to put my positive thoughts into words that I can then use to help me control stress when needed."

Strong Minds is an important new area of training for Special Olympics athletes, and its future is bright as plans include engaging health leaders in Strong Minds training, incorporating visual imagery into the field of play, and developing additional resources for athletes, caregivers and coaches.

In 1997, Special Olympics began offering free health screenings and education to Special Olympics athletes in a welcoming, fun environment called Healthy Athletes. Now, more than 270,000 health professionals and students have delivered over 2 million free health screenings to people with intellectual disabilities. These providers take these skills back to their practices and provide higher quality health care to people with intellectual disabilities – not just Special Olympics athletes – in their communities. In addition to Strong Minds, Healthy Athletes provides free health screenings in podiatry, physical therapy and fitness, audiology, vision, dentistry, better health and well-being, and sports physical exams.

Everyone has a role to play in the inclusion revolution and ending discrimination against people with intellectual disabilities. Strong Minds is one way Special Olympics breaks down the barriers to health for people with intellectual disabilities. You can demonstrate your commitment to creating a fully inclusive world by taking the Inclusion Pledge right now at **JoinTheRevolution.org** •

For more information about Special Olympics, Healthy Athletes and Strong Minds at **http://www.specialolympics.org/health**

ABOUT THE AUTHOR:

Jamie Valis, PhD, is Senior Manager of Health Training, Special Olympics International.

F O AM . TO YOUR FAMILIES

ILITARY
SECTION

MILITARY LIFE

PUZZLES & CAMO

ARMY
NAVY
AIR FORCE
MARINES

THE EXCEPTIONAL FAMILY MEMBER PROGRAM

A PROGRAM FOR FAMILIES WITH SPECIAL NEEDS

EXCEPTIONAL FAMILY MEMBER PROGRAM QUICK REFERENCE GUIDE

When your family member has special needs, you have an extra roster of must-do's to be a good guardian of your family. The Exceptional Family Member Program, EFMP, (http://download.militaryonesource.mil/12038/MOS/ResourceGuides/EFMP-QuickReferenceGuide.pdf) offers many services for military families. Here are just a few of the ways it can help guide you to the resources your family needs to thrive.

WHAT IS THE PROGRAM ABOUT?

It's all about helping your family navigate the medical and educational system, so you can have more peace of mind about your family member's care. We assist by:

- *Identifying and enrolling family members with special medical or educational needs.*
- *Finding out what services are available at your present or new duty station.*
- *Supporting your family with information, referrals and non-clinical case management to access services.*

Each military service branch has EFMP resources. Here are links by branch:

- *Army Exceptional Family Member Program*
  www.myarmyonesource.com/familyprogramsandservices/familyprograms/exceptionalfamilymemberprogram/default.aspx
- *Navy Exceptional Family Member Program*
  www.public.navy.mil/BUPERS-NPC/SUPPORT/EFM/Pages/default.aspx
- *Marine Corps Exceptional Family Member Program*
  www.usmc-mccs.org/services/family/exceptional-family-member
- *Air Force Exceptional Family Member Program*
  www.usafservices.com/home/spousesupport/specialneeds.aspx

You may also enroll at MilitaryINSTALLATIONS (https://installations.militaryonesource.mil). Visit Military OneSource's Exceptional Family Member Program to find out even more. www.militaryonesource.mil/family-relationships/special-needs/exceptional-family-member

EFMP OFFERS TWO IMPORTANT KINDS OF HELP

The EFMP helps families in two big ways: by making sure special needs are considered during assignments, and by easing access to assistance wherever you are.

- ***Assignment coordination:** While military mission is always the driving force behind a service member's assignment, the Exceptional Family Member Program helps make sure that family members' documented needs are considered during relocations.*

This is important because access to appropriate medical and educational services may be limited in overseas and remote locations. With assignment coordination, you can be more assured that your family member's needs will be considered, so you can focus more clearly on mission-related responsibilities.

- ***Offering families support:** This part of the program helps families identify and access programs and services. There are two ways to access support, through Family Support services on installations or by calling Military OneSource for a special needs consultation.* www.militaryonesource.mil/products#!/detail/298

Family Support providers on the installation can put you on the path to empowerment by:

- *Providing information and referral services for both military and community services*
- *Helping you find and navigate programs in new locations*
- *Giving "warm handoffs" to the Exceptional Family Member Program at new locations*

HERE TO HELP: Special Needs Consultations through Military OneSource can help you understand topics such as the military health care system, TRICARE, and special needs trusts/estate planning.

- *Finding ways to bridge gaps in programs, services and supports*
- *Informing you about available local school and early intervention services*
- *Providing non-clinical case management, including individualized services plans*
- *Offering opportunities for families with special needs to connect*
- *Helping families understand what is offered, how to determine eligibility and how to apply for benefits and entitlements.*

Special Needs Consultations through Military OneSource can help you:

- *Understand topics such as the military health care system, TRICARE, and special needs trusts/estate planning.*
- *Find services and navigate the wide and sometimes complex array of resources, benefits and care available to you*
- *Manage calls with health care and other service providers by staying on the line with you and helping you get the information you need.*
- *Connect you to online resources including The Special Needs Parent Tool Kit, Education Directory for Children With Special Needs, The Department of Defense Directory on Early Intervention, Special Education and Related Services in OCONUS Communities and Special Care Organizational Record toolkits for elders.*

HAS YOUR FAMILY ENROLLED?

You should enroll if you have a family member with special medical or educational needs – a spouse, child or dependent adult – who:

- *Requires special medical services for a chronic condition such as asthma, attention deficit disorder, diabetes, multiple sclerosis, etc.*
- *Receives ongoing services from a medical specialist*
- *Has significant behavioral health concerns*
- *Receives early intervention or special education services through an individual family service plan or individualized education program.*

Contact a Military OneSource special needs consultant if you have any questions about eligibility. www.militaryonesource.mil/special-needs1

HOW DO YOU GET STARTED?

- *Visit or call your local installation's Military and Family Support Center. Some installations also have EFMP Enrollment and EFMP Family Support centers. Find your nearest center here.* https://installations.militaryonesource.mil
- *Obtain paperwork from the Exceptional Family Member Program medical point of contact at your local military treatment facility.*
- *Contact Military OneSource at 800-342-9647 and ask for a referral to a special needs consultant.*

LEARN MORE: IMPROVE YOUR FAMILY'S STRENGTH AND PEACE OF MIND

To enroll, you'll need to complete forms to document medical and educational needs. You'll find answers to your enrollment questions, forms, contact information and much more in the EFMP Quick Reference Guide.

You can also learn more by subscribing to The Exceptional Advocate, an e-newsletter for families with special needs. Start today to improve your family member's quality of life and to help your family thrive.

– Military One Source

8 TIPS FOR MILITARY PARENTS RAISING CHILDREN WITH SPECIAL NEEDS

Research shows raising a child with special needs can test a marriage. As a military family you have a strong foundation to work from, but the ability to depend on one another and teamwork are key.

With determination, communication and the tips below, you can keep your relationship strong and your family thriving. Your spouse will be your strongest ally and your greatest strength while you raise your children and in the many years after. That said, you both have access to extra help to strengthen your relationship and nurture your children through the Office of Special Needs, Military OneSource and many other DOD programs.

To get started, contact your local Military Family Support staff for more information. Also, see how the Exceptional Family Member Program Resources, Options and Consultations, EFMP ROC, can help your family, and try out Military OneSource's flexible and education-based consultation series Building Healthy Relationships to build your communication skills.

KEEP YOUR RELATIONSHIP STRONG : EIGHT TIPS

1. **Both you and your partner need to acknowledge and understand your child's diagnosis from a doctor you both trust.** You'll never be on the same page for care if your spouse doesn't believe your child's diagnosis – or if they think there's an unidentified problem.
2. **Consider participating in ongoing family counseling to learn better ways to interact with and guide your child as they grow up.** Through regular counseling, your family can become a better team – parents, child and siblings, together.
3. **Don't only see your spouse as a parent.** Remember, your marriage began when you chose your spouse as a life partner with individual qualities that made you love him/her, over and above his/her ability to transport children back and forth to school or medical appointments.
4. **Spend at least 20 minutes every day in "adult" conversation without once mentioning your children or anything child-related.** Talking to each other as fellow adults who love each other can keep your marriage strong and healthy, outside of your shared parenting responsibilities. If one partner is deployed, then become daily pen pals, reserving a third of your letter for non-kid topics.
5. **Be aware of caregiver burnout – and offer relief whenever possible.** Being a military family means that "fair" parenting schedules aren't always possible, due to deployment and mandatory assignments. One spouse may get the bulk of the caregiving responsibilities. Still, the service member parent must remember that while they can leave their assignments at work, they will never stop being a parent – and they must find ways to support their partner-parent to prevent caregiver burnout that could negatively affect the marriage.
6. **Keep routines.** Routines help increase home stability and predictability for children with special needs, which is especially helpful if there's a single primary caregiver. If you're away due to deployment, remember your family's schedule and do your best to accommodate it with your communications, as well as your reintegration back into the family environment.
7. **Don't be afraid to reach out to friends and family.** When dealing with special medical and/or education needs, a military couple runs the risk of isolation, which can make marital problems worse. Don't hesitate to reach out to friends and family for help and a break when you need it. Chances are, they want to help – they just aren't sure how.
8. **Use the resources at your disposal.** To support overall mission readiness, the Department of Defense provides many resources for military families with special needs. Many of these services are completely free to use and none will negatively impact your military career.

SPECIAL EDUCATION PROGRAMS AND RESOURCES FOR MILITARY FAMILIES

Families with special needs have a wide range of programs and services available for both family members with special needs and their caregivers.

Here is a sampling of the various resources and tools available to you through the U.S. Department of Education's Office of Special Education Programs, or OSEP.

YOUR OSEP POINT OF CONTACT FOR SPECIAL EDUCATION PROGRAMS

Connect directly with your state's OSEP point of contact (www2.ed.gov/policy/speced/guid/idea/monitor/state-contact-list.html) for questions related to special education services. This list can also be useful for families planning an upcoming move to a new state. Be sure to contact the customer service point of contact first, who will then connect you with the person who can answer your specific questions. And, if you're still not sure who you should contact, it's never a bad idea to start by contacting your local EFMP Family Support staff or reach out to an EFMP Resources Options and Consultations, or EFMP ROC, consultant who can point you in the right direction. www.militaryonesource.mil/confidential-help/specialty-consultations/efmp-roc

THE INDIVIDUALS WITH DISABILITIES EDUCATION ACT

The website for the Individuals with Disabilities Education Act, or IDEA, (https://sites.ed.gov/idea) offers a lot of information to help students, parents, educators and service providers gain a better understanding of the act and how it applies to early intervention and school-age services in Parts C and B, respectively.

On the IDEA site, you can gather information and resources to help further guide you through special education programs, especially grant-funded free public education for children through age 21, as well as early intervention services for toddlers and infants through age 2.

Plus, you can search for specific toolkits or explore an IDEA-based resource library stored within an easily accessible online database at the IDEAs That Work website. https://osepideasthatwork.org/node/175

BLOGS AND WEBINARS THAT SPEAK TO FAMILIES LIKE YOURS

The Office of Special Education and Rehabilitative Services Blog has stories and insights from other families with special needs (https://sites.ed.gov/osers/) who have perhaps experienced struggles and successes similar to your family's. The blog also features interviews by industry specialists and policymakers and is a must-read for any caregiver of individuals with special needs.

The Military Families Learning Network, or MFLN, also hosts regular live webinars discussing everything from finances to federal employment opportunities for the military community. For families with special needs, they also have resources specifically concerning early intervention strategies for military families. Head over to the MFLN website to watch prerecorded webinars and listen to podcasts made specifically to help families like yours. https://militaryfamilieslearningnetwork.org/family-development

SOUNDS LIKE A PLAN: On the IDEA site, you can gather information and resources to help further guide you through special education programs.

TRANSITIONING STUDENTS

In May 2017, OSEP updated A Transition Guide to Postsecondary Education and Employment for Students and Youth with Disabilities, which helps children with special needs and their families prepare themselves for life after high school. In this guide, you can find transition-specific planning and services, as well as potential education and employment options for your child. www2.ed.gov/about/offices/list/osers/transition/products/postsecondary-transition-guide-may-2017.pdf

These resources are just the start of what OSEP can offer you and your child with special needs, so you can make sure they start off with every advantage and succeed in school and in life. Remember, too, that if you need some help figuring out the IDEA resources, or need recommendations on which program is right for your child, your local EFMP Family Support staff and Military OneSource is happy to help, however we can. www.militaryonesource.mil/confidential-help/specialty-consultations/education/plan-your-future-with-a-military-onesource-education-consultant

– Military One Source

SHELLY HUHTANEN

Real

I walked back to my room and sat on the bed listening to him scream. It reminded me of his regression three-and-a-half years ago, when we moved to Fort Benning. He kept screaming and seemed to get louder, and the pitch seemed to get higher and higher.

Autism has a way of keeping us humble and reminding us that we need to appreciate the victories, even the small ones. Last week, my son had a rough night. He started screaming before bed and was inconsolable. I tried to talk to him and see if I could help him find the words to describe his feelings. After everything I could think of failed, I became detective trying to feel all over his body looking for clues. Did he have a fever? Did he have any fresh scrapes due to a fall I didn't witness? Was his stomach tight? I felt nauseous at the thought of having to add another food item that bothered his stomach. All came up negative. I couldn't figure out why he was screaming.

I stood back and finally asked, "Do you need time alone? I can give you some time if you feel you need it." Broden looked up and told me to shut the door. I honored his request. I walked back to my room and sat on the bed listening to him scream. It reminded me of his regression three-and-a-half years ago, when we moved to Fort Benning. He kept screaming and seemed to get louder, and the pitch seemed to get higher and higher. I peeked my head into Hayden's room. Hayden, his older brother, was trying to do his homework at his desk. I apologized for Broden and told him to hang in there. Hayden looked at me and shrugged.

I thought we were past this. I haven't witnessed this type of behavior in so long. It was almost as if I had forgotten how taxing it was to have Broden scream uncontrollably and to not be able to figure out what was causing it. I hate feeling helpless. I told myself to not forget this feeling so I would appreciate the days when we weren't battling behavior.

I walked down the hall and leaned my head against the door to see if I could tell if he was starting to calm down. Moments later the phone rang. It was Mark. He could hear Broden screaming once I answered and asked what was going on before saying hello. "I don't know. I can't get him to calm down. I'm just trying to give him some time," I said. Mark wanted to be there, but couldn't. I could feel the guilt through his voice as he said goodbye so I could focus my attention on Broden.

I went back into my room and sat on the bed listening to every howl coming from his room and then there was silence. He stopped. I could see Hayden at his desk from my bed. Once the screaming stopped, Hayden turned his head and we looked at each other. Was he going to start screaming again or was it over? I tiptoed to his room and leaned my ear against his door. I could tell from his breathing that he had spent all the energy his body had in the last 30 minutes and he was exhausted. I slowly opened the door and looked inside. His face and eyes were red. He was trying to slow down his breathing to stay calm and his pajamas were soaked from tears.

I went over to his bed and leaned down towards him to place my hand on the top of his head and I rubbed his chest saying, "I'm here. It's ok." After a few minutes I asked him if he was ready to go to bed and if he was ready to sing his bedtime song. After he said yes, I made a point to continue our bedtime ritual like we do every night. My hope was that this would give him comfort. I leaned down and kissed him on the forehead and told him I loved him. I turned off the lights and shut the door for the last time that night.

We made it. We got through it. Moments like this remind me how much I love him. He continues to remind me how powerful love is. You love someone so much you look beyond the behavior, no matter how trivial it can be, because desperately you want to show them that they are so much more. Autism did not win that night.

Autism can be nasty, but it also can strip you from anything that is not worthy to hold on to. When I think of autism I think of the moment when the rabbit becomes real in the Velveteen Rabbit. "You become. It takes a long time. That's why it doesn't happen to people who break easily, or have sharp edges, or who have to be carefully kept. Generally, by the time you are Real, most of your hair has been loved off, and your eyes dropped out and you get loose in the joints and are very shabby. But these things don't matter at all, because once you are Real you can't be ugly, except to people who don't understand."

> "Once you are Real you can't be ugly, except to people who don't understand."

Autism has showed me that I don't break easy and it has worn down my sharp edges. I would have to say the worry and stress has made my eyes droopy and I'm sure my hair isn't as shiny as it used to be, but it doesn't matter. The love for my son is real. The realness will always win. •

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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