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JUNE 2019
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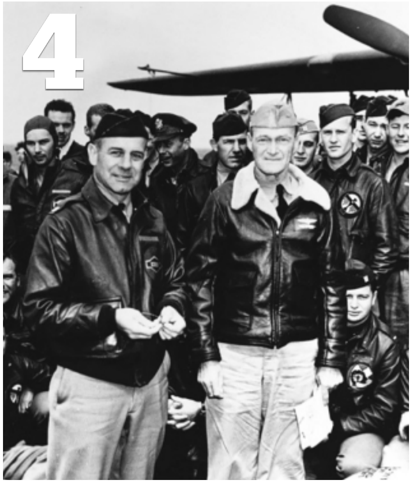

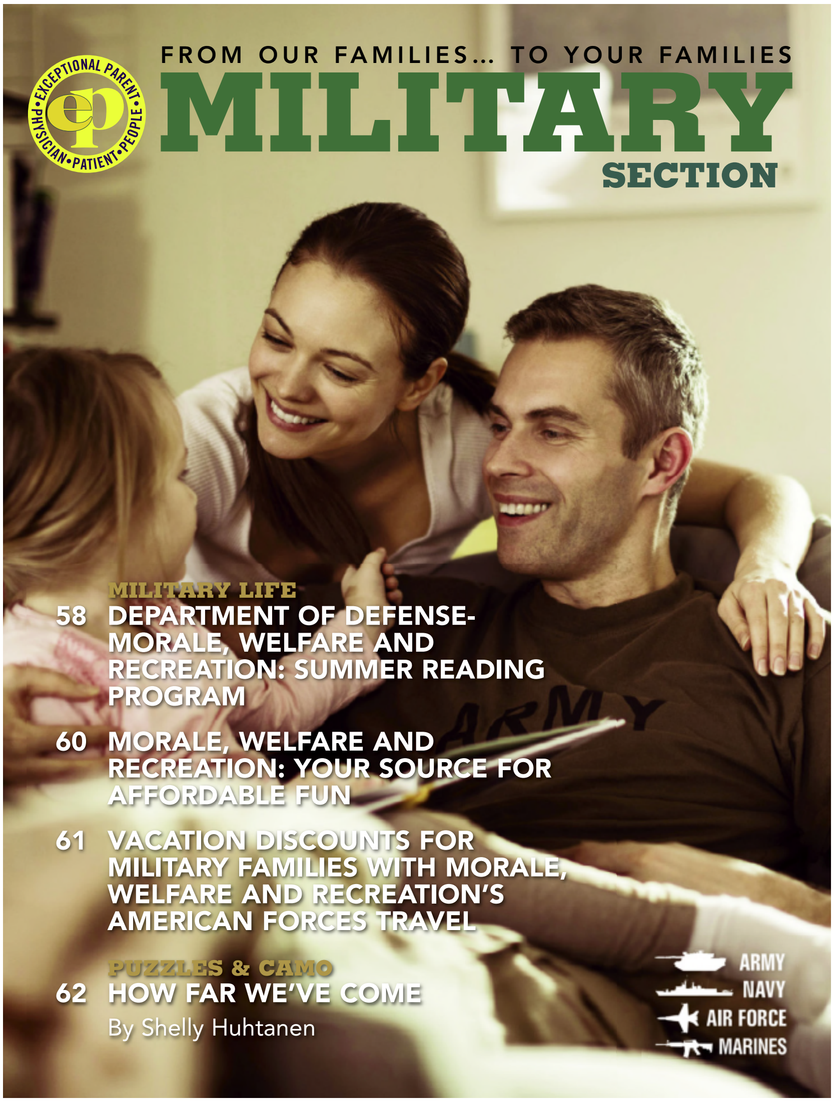
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Information and Support for the Special Needs Community

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

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.

Revenge, Retribution and Retaliation

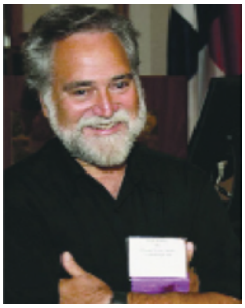
Exceptional parents don’t have the time or the energy for revenge, retribution or retaliation. Their efforts are singularly dedicated to insuring that their children are given opportunities to explore their potential, indulge their talents and feel welcomed and included.

“They started it, and we finished it.”

While one might think this was uttered by a six-year-old in a sandbox quarrel, it was a remark made by the last member of Doolittle Raiders.

On December 7, 1945, the Japanese caught America sleeping and bombed Pearl Harbor in a sneak attack that President Franklin Roosevelt termed, “A day that will live in infamy.” In addition to America losing many servicemen and ships from the attack, American lost something else. They lost their feelings of security, omnipotence and invincibility. They were shocked, paralyzed and impotent; but only for several months.

“They started it, and we finished it,” was the simple explanation provided by Dick Cole, a retired U.S. Air Force Lt. Colonel who was a crew member of the Doolittle Raiders. Cole died recently at age 103, the last of the Doolittle Raiders.



The Doolittle Raid took place on Saturday, April 18, 1942. It was an air raid on Tokyo and served to reignite America as it entered into the war with Japan. The raid was planned and led by U.S. Air Force Lieutenant Colonel James Doolittle.

The Doolittle Raid was conducted against all the odds. The attack was launched from U.S. Navy aircraft carriers from the Pacific Ocean. The raid involved

PHOTO COURTESY WIKIMEDIA COMMONS

sixteen bombers; each with a crew of five men, all volunteers, and the only information given was that it would be an "extremely hazardous" secret mission.

The planes did not have enough fuel to reach Japan, carry out their bombing mission and land safely in China. Despite efforts to remove weight from the plane, including removal of protective steel plates from the airplane, removal of the gun turrets, and scrapping all the radio equipment and trading the bombsights for a twenty-cent makeshift replacement, it was obvious that the planes would have to be ditched before reaching a safe airfield. They tried to increase the fuel carrying capacity of the plane by installing an additional fuel tank with 160 more gallons plus using collapsible neoprene auxiliary fuel tanks in every nook and cranny of the plane.

TARGET TOKYO: Take off from the deck of the USS HORNET of an Army B-25 on its way to take part in first U.S. air raid on Japan on April 1942. The surprising and daring raid was on military targets at Tokyo, Yokohama, Yokosuka, Nagoya, and Kobe.

Whatever increase in the flying range was achieved by the reduction of weight and the additional fuel tanks, the specially-constructed heavy bombs negated the added range. There was no debate on whether they should drop bombs or leaflets.

The bombing raid caused negligible material damage to Japan, but it had major psychological effects. American morale was raised and it gave the Japanese second thoughts about the ability of the Japanese military to protect the home islands.

According to Richard Joyce in *Eighty Brave Men,* "15 aircraft reached China, but all crashed, while the 16th landed in the Soviet Union. Of the 80 crew members, 77 initially survived the mission. Eight airmen were captured by the Japanese Army in China; three were executed. Fourteen complete crews of five, except for one crewman who was killed in action, returned either to the United States, or to American forces."

Doolittle was awarded the Medal of Honor and the entire mission members received the Distinguished Flying Cross. The Doolittle Raiders held a convention every year from the late 1940s to 2013. There they renewed their friendships and celebrated their membership in an exclusive club that no one else could join.

Revenge is thought to be an opportunity for defeating an opponent who has defeated you in the past.

Retribution comes from the Latin "retribuere" meaning to pay back; while retaliation implies the return of like for like.

The Doolittle Raid checked all three boxes. After the war, the Japanese leaders admitted that the attack on Pearl Harbor had "awakened the sleeping giant."

Since the beginning of the Disability Rights Movement, parents have used the metaphor of war to describe their experiences. They often cite they were "outgunned" by the system, "outmaneuvered" by the other side, "outflanked" by allied groups and were derailed by hidden landmines.

Exceptional parents don't have the time or the energy for revenge, retribution or retaliation. Their efforts are singularly dedicated to insuring that their children are given opportunities to explore their potential, indulge their talents and feel welcomed and included.

One thing exceptional parents are not caught doing is "sleeping."•

ANCORA IMPARO

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

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

CONNECT AND DISCOVER

Join EP's Facebook Community

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

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

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

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

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

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

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WHAT'S HAPPENING

THE DISABILITY INTEGRATION ACT GAINS MOMENTUM WITH SUPPORT OF NEW STATE DELEGATIONS

The Disability Integration Act (DIA) continues to gain momentum as ADAPT and other disability rights advocates work with House Leadership to pass the bill during the week of the 29th Anniversary of the Americans with Disabilities Act on July 26, 2019.

The additions of Senator Thomas Carper and Congressman Richard Neal mean that the Delaware and Massachusetts congressional delegations join those from Colorado and Vermont in their unanimous support for the bill and the right of elderly and Disabled Americans to live in freedom instead of being forced into unwanted institutionalization.

The bipartisan, bicameral legislation which is designed to ensure the rights of people with disabilities to live in the community already enjoys the support of every major national disability organization. The bill has widespread support among aging, social justice and faith-based organizations, including AARP.

> "We're going to make history with 'Disability Freedom Day' by passing DIA when thousands of Disabled Americans are on the Hill!"

Since its introduction in January, DIA has secured a total of 139 co-sponsors in the House and 26 co-sponsors in the Senate. Organizers from ADAPT see the support for the bill growing as entire delegations declare their support for the legislation. "We are so proud that all of Delaware's legislators support our right to be free," said ADAPT Delaware organizer Daniese McMullin-Powell. "When people understand what DIA does and why it is needed, they line up to support it."

CALL TO ACTION: Protesters from ADAPT block the sidewalk near the White House in Washington, DC., organizing to ensure that people with disabilities can live in the community rather than be forced into nursing facilities and other institutions.

Congressman Neal's co-sponsorship means the bill only needs the support of 91 more Democrats in the House in order to bring it to the House floor for a vote this July. "Having the entire Massachusetts delegation support the bill keeps us on schedule for that important vote on the week of July 26th", said Massachusetts ADAPT organizer Rhoda Gibson. "We're going to make history with 'Disability Freedom Day' by passing DIA when thousands of Disabled Americans are on the Hill!"

"In this age of partisan politics, we are seeing legislators from both sides of the aisle DIA is an opportunity for bipartisan work in Congress," said ADAPT organizer Bruce Darling. "We are going to pass this bill not because it serves one party's interests, but because no one can deny that Disabled Americans deserve to live in freedom. Seeing entire state delegations support the bill only convinces us of that even more."

Groups like ADAPT which have worked for years secure the constitutional and civil rights of disabled Americans are pushing Congress to pass the legislation now "We have waited 29 years for our freedom we are tired of waiting we need DIA passed now," said ADAPT organizer Dawn Russell.

ABOUT ADAPT

For decades ADAPT has worked to secure for Disabled Americans the same rights and liberties enjoyed by their non-disabled neighbors. ADAPT strategies include using civil disobedience if necessary as a tool to gain public attention, so that they can change laws, policies, and services affecting persons with disabilities. Learn more about ADAPT's history and activities at www.adapt.org, on social media with the National ADAPT Facebook and Twitter pages. Also, under the hashtag #ADAPTandRESIST.

PHOTO PROVIDED BY ADAPT

WHAT'S HAPPENING

MARIA TOWN NAMED AAPD'S PRESIDENT AND CEO

The Board of Directors of the American Association of People with Disabilities (AAPD) announced that Maria Town has been selected as the new President & CEO.

Maria Town, a well-recognized disability rights advocate, will begin her new position on July 15, 2019. APD Board Chair, Ted Kennedy, Jr., said he is excited about the future of AAPD with Town at the helm. He went on to say that he is "incredibly grateful to our current CEO, Helena Berger, for her leadership and dedication to AAPD. She has created an environment that will allow the new CEO, Maria Town, to have maximum impact at AAPD in 2019 and beyond."

MARIA TOWN: "I am honored to contribute to the progress of inclusion & equity nationwide."

Town is currently the Director of the City of Houston Mayor's Office for People with Disabilities, where she serves as the primary liaison between the more than half million people with disabilities in the greater Houston area, the Mayor, Houston City Council, and other key city, state, and national leaders. Town quickly became an expert on emergency response having begun the position shortly before Houston felt the impacts of Hurricane Harvey.

Prior to that, she served as the Obama White House Senior Associate Director & Disability Community Liaison in the Office of Public Engagement. While there, Town increased the White House reach to the disability community by more than 700%. She also engaged with leadership from the nation's premier disability and civil rights organizations, including AAPD, to provide White House Senior Advisors with daily briefings on key issues related to Americans with disabilities, seniors, cabinet agencies, and the Obama Administration's place-based initiatives.

Upon being named President & CEO, Town stated, "I am incredibly honored to be the next CEO of AAPD. I look forward to working alongside our committed board, staff, and stakeholders to ensure that AAPD represents and engages our diverse community in the collective fight for equal access, integration, and full inclusion for Americans with disabilities."

Town is the recipient of many awards and honors including the Henry Viscardi Achievement Award, Texas Governor's Committee on People with Disabilities Martha Arbuckle Award, Susan Daniels Mentoring Hall of Fame Honoree, and an AAPD Paul J. Hearne Leadership Award Finalist. She began her professional disability rights career as a disability advocate in a policy advisor role at the Office of Disability Employment Policy at the Department of Labor. She received her Bachelor of Arts degree from Emory University.

ABOUT AAPD

AAPD

AAPD is a convener, connecter, and catalyst for change, increasing the political and economic power of people with disabilities. As one of the leading national cross-disability civil rights organizations, AAPD advocates for the full recognition of rights for the over 60 million Americans with disabilities. AAPD's programs and initiatives have been effective in mobilizing the disability community through communications advocacy; cultivating and training new and emerging leaders with disabilities through leadership development programs; increasing the political participation of Americans with disabilities and elevating the power of the disability vote through the REV UP (Register! Educate! Vote! Use your Power!) Campaign; and advancing disability inclusion in the workplace through the Disability Equality Index (DEI) — the nation's leading corporate benchmarking tool for disability equality and inclusion. To learn more about AAPD, visit www.aapd.com.

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MDA CELEBRATES FDA APPROVAL OF ZOLGENSMA FOR TREATMENT OF SPINAL MUSCULAR ATROPHY

The Muscular Dystrophy Association (MDA) celebrated on May 24th the decision by the U.S. Food and Drug Administration (FDA) to grant approval of Zolgensma (onasemnogene abeparvovac-xioi), the first gene therapy for a neuromuscular disease.

Zolgensma is a one-time intravenous (into the vein) infusion for the treatment of pediatric patients less than two years of age with spinal muscular atrophy (SMA) with bi-allelic mutations in the survival motor neuron 1 (SMN1) gene, including those who are pre-symptomatic at diagnosis.

SMA is the leading genetic cause of infant death. Zolgensma is designed to target the genetic root cause of SMA by delivering the survival motor neuron gene (SMN), which is missing or mutated in SMA. Zolgensma will be made available in the United Statesand will be marketed by AveXis, a Novartis company.

LIFE-ALTERING: Zolgensma is designed to address the genetic root cause of SMA by replacing the defective or missing SMN1 gene to halt disease progression with a single, one-time infusion.

Approval of the therapy marks another historic achievement for the SMA community. Now, in addition to Spinraza – the first SMA disease-modifying therapy, which was approved in December 2016 for SMA – patients will have access to another promising therapy.

For decades, MDA has funded research aimed at the discovery of genes causing neuromuscular disease and has supported work to develop therapies that address the root cause of disease. Zolgensma is only the second gene therapy approved by the FDA to treat any disease, placing the field of neuromuscular disease at the forefront of genetic medicine. "Zolgensma is poised to be another life-altering therapy for the SMA community," says MDA President and CEO Lynn O'Connor Vos. "It represents a breakthrough toward the promise of safe and effective gene therapies, and it may catalyze the development of other gene therapies to treat a range of rare neuromuscular diseases."

Zolgensma may be the first of many gene therapies targeting the genetic root cause of disease, highlighting the importance of years of investment by MDA and others into gene identification and research unlocking the cause of disease. In addition, MDA has funded landmark research focused on developing and refining gene delivery tools and has supported the work to establish protocols for safe and effective gene therapy clinical trials. While this may be the first gene therapy for treating neuromuscular disease, the increasing pace of drug development holds immense promise for the future of the field. In the past decade alone, seven therapies for treating neuromuscular diseases have been approved by the FDA.

The Muscular Dystrophy Association is committed to transforming the lives of people affected by muscular dystrophy, ALS, and related neuromuscular diseases. This is done through innovations in science and innovations in care. For more information visit mda.org •

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The Gonge Go Go Rollers is a two-pedaled transport device that was created with the idea that children can give it rough treatment without damaging it. The design features a unique quality without sharp edges or areas which could pinch the feet. The wheels, the steel shafts and the pedals form a unified whole, which provides sturdiness and strength. Children can pedal their way around, while developing important gross motor skills and hand-eye coordination. It consists of plastic wheels and pedals with steel axle of 14 millimeter in diameter and rubber tyres. It is for the age of four to 12 years. Maximum load can be 50 kilograms.

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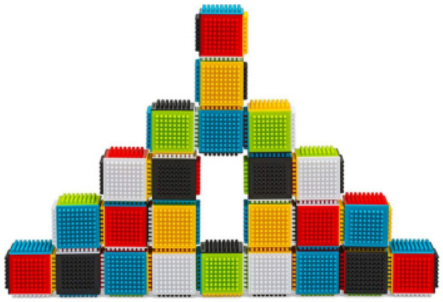

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TEN FOOT JUMBO PARACHUTE

The 10 Foot Jumbo Parachute is an activity designed for those individuals ages three and up, with autism and sensory processing disorders, to promote cooperation, coordination and more. The 10-foot nylon parachute features 12 handles and includes a storage bag. It is recommended for age 3 and up

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

NEW PRODUCTS

WOOD LACING SNEAKER

The Melissa & Doug Wood Lacing Sneaker is a toy designed for children with fine motor disabilities ages 3 and up to teach them eye- hand coordination and fine motor skills as they learn how to tie a bow. The wooden shoe is made to size for little fingers and heavy enough to stay in place on a table, so that kids lacing and tying for the first time don't get frustrated. This fine motor skill also encourages independence and helps build self-esteem.

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JUNE IS ALZHEIMER'S AND BRAIN AWARENESS MONTH

10 WAYS TO **LOVE YOUR BRAIN**

START NOW. It's never too late or too early to incorporate healthy habits.

Growing evidence indicates that people can reduce their risk of cognitive decline by adopting key lifestyle habits. When possible, combine these habits to achieve maximum benefit for the brain and body.

BREAK A SWEAT

Engage in regular cardiovascular exercise that elevates heart rate and increases blood flow. Studies have found that physical activity reduces risk of cognitive decline.

HIT THE BOOKS

Formal education will help reduce risk of cognitive decline and dementia. Take a class at a local college, community center or online.

BUTT OUT

Smoking increases risk of cognitive decline. Quitting smoking can reduce risk to levels comparable to those who have not smoked.

FOLLOW YOUR HEART

Risk factors for cardiovascular disease and stroke – obesity, high blood pressure and diabetes – negatively impact your cognitive health.

HEADS UP!

Brain injury can raise risk of cognitive decline and dementia. Wear a seat belt and use a helmet when playing contact sports or riding a bike.

FUEL UP RIGHT

Eat a balanced diet that is higher in vegetables and fruit to help reduce the risk of cognitive decline.

CATCH SOME ZZZ'S

Not getting enough sleep may result in problems with memory and thinking.

TAKE CARE OF YOUR MENTAL HEALTH

Some studies link depression with cognitive decline, so seek treatment if you have depression, anxiety or stress.

BUDDY UP

Staying socially engaged may support brain health. Find ways to be part of your local community or share activities with friends and family.

STUMP YOURSELF

Challenge your mind. Build a piece of furniture. Play games of strategy, like bridge.

Visit alz.org/10ways to learn more.

alzheimer's association®
THE BRAINS BEHIND SAVING YOURS.®

HEARTSIGHT CHRISTINA LLANES MABALOT

A Fathers' Legacy

To this day, I hear Papa's voice in my dreams, saying: "You may not see very well, but you can speak and write. Cultivate those skills and society will pay attention to your success, not to your disability."

"Work your visual impairment to your advantage." These were my father's words of wisdom.

While most people think that having a disability is unfortunate, my father, Antonio, believed that it could be the catalyst for finding and developing one's gifts. That is, acknowledging what one can't do could positively result in intentionally identifying and maximizing what one can do best. He explained how most people without disabilities usually stumble across their areas of expertise far along in their lifetime. Some have articulated how they would have cultivated their gifts or talents early on, had they known they had such talents. But since they didn't perceive or experience disabilities or disadvantages, they didn't deem it necessary to focus on skill sets that could actually be their assets.

Papa, as I call my dear father, had said that it's one thing for someone to have a visual impairment, but it's unfortunate for that person not to see where one is going in life. Papa set me on the right track. He recognized my potential for speaking when I was yet a toddler, so he directed my steps. He used to tease me about how I started talking as soon as I was born. My father believed that this could one day lead to a public speaking career for me. As a matter of fact, he wanted me to follow his footsteps and become a lawyer someday. He built my foundation. He read me stories and bought me classic books with fonts large enough for me to read. He likewise advised me to try my hand at writing.

"Public speakers can only be as good as the content of their message," he used to say.

My father delegated me as his personal secretary as soon as I could dial phone numbers on our rotary phone. A corporate lawyer, he had a long list of people for me to call to set appointments or provide updates about transactions. This was my very first on-the-job training, and it made me feel skilled and confident.

My siblings weren't treated differently. One day, my brothers asked my father how the clock operates. To my mother's shock, my father handed them a desk alarm clock to take apart and discover its workings. They didn't stop there. Their next object of interest was the transistor radio. My brothers must have dismantled every device that ran on batteries and electricity that one day there was no working device in the house. On the bright side, they were eventually building their own radios and stereo components following diagrams from a book that my father provided. This was how their skills in Information Technology evolved.

LASTING LEGACY: "While most people think that having a disability is unfortunate, my father believed that it could be the catalyst for finding and developing one's gifts."

Papa made studying so much fun. Every year, he gave a price for the one who got the highest grade-point average. This was how I acquired my first radio/cassette recorder. He also built me a personal study desk with a fluorescent light more prominent than the table. He drove us to and from school every day. We would play all sorts of silly games while stuck in the rush hour traffic to kill the monotony. One of us would always put dibs on the tastiest snack papa bought, leading to senseless arguments. What made these scenes enjoyable was that Papa joined these squabbles to inject humor.

Thanks to my father, my visual impairment has been the drive that's led me to develop my speaking and writing skills in the best possible way. I have to admit that I let him down when I didn't pursue Law as a profession, but when he realized that Special Education was my passion, he learned to respect my career path.

To this day, I hear Papa's voice in my dreams, saying: "You may not see very well, but you can speak and write. Cultivate those skills and society will pay attention to your success, not to your disability."

My father's words of wisdom are an enduring legacy that has shaped who I am today, as well as the lives of my students and my children. It is where I derived my slogan: "Discover the best in your child." I hope to pass it on to various communities, especially to persons with special needs, and down to succeeding generations.

MY CHILDREN'S FATHER

The day I met my husband, Silver, at a national officers' training conference organized by the Disabled People International was when my outlook on the sector of persons with special needs broadened. I had always been connected with agencies that provide services for the population with special needs, but Silver championed special needs organizations at the grassroots level. I have a visual disability and Silver is mobility impaired. Our cultures amalgamated, and the rest is history. I had found a friend and a partner, not only in advancing the cause of the special needs community, but also in chasing my dreams in life.

PHOTOS PROVIDED BY CHRISTINA LLANES MABALOT

PACKAGE DEAL: The author's husband, Silver; with his wife and children Paulo and Jen. "Silver was accepting of the fact that our kids could inherit my congenital condition, aniridia. Most of his friends and family objected to his decision, but their protests fell on deaf ears."

LOVE CONQUERS ALL BARRIERS

I could hardly believe my ears when Silver assured me that he was accepting of the fact that our kids could possibly inherit my congenital condition, aniridia. I discouraged him, but he didn't change his mind about marriage and raising a family. Most of his friends and family objected to his decision, but their protests fell on deaf ears. I guess we both drew comfort from the fact that my first child was sighted and never thought that we'd actually have a child with special needs.

"It's a package deal," Silver said in assurance.

Society often thinks that parents with special needs who are actively involved in the special needs community would be ready when and if children with special needs are born to them. This was not true in our case. We both fell into different levels and manifestations of depression when Jem, our child with visual impairment, was born. But even when Silver was yet in that state of mind, he never let Jem out of his sight. She was the apple of his eye. In fact, he overprotected and even spoiled her. It's not that Silver didn't know any better, but I guess, when one's role expands from being just an advocate to becoming a parent of a special needs child, rules tend to be overlooked. This has made it so easy for me to end arguments over Jem's misbehavior. I'll usually just say, "Well you spoiled her…"

Silver passed on to our kids his own father's parenting skills. He fondly recalls how his dad used to carry him on his shoulders when they'd go places. He did the same with Jem. Wherever he went, Silver had the baby carrier strapped on to him so he could take Jem along. Some of the meetings included band practices. Silver, a singer and musician by heart, regularly led worship at church. Jem took on her father's talents. As a matter of fact, Paulo, our son, also acquired Silver's love for singing and playing musical instruments. During the family's leisure time, they jam and sound like pros while I cheer them on and try hard not to sing along, much as I want to, lest I introduce cacophony into the mix.

That Silver is a workaholic is an understatement. In fact, he doesn't drop what he's doing until a task is completed, even if it means staying up all night. He's almost like a machine. An engineer by profession, he built and remodeled the houses we lived in. He's also the manager in our finances, chief operations officer and administrator in our organizations, master of the barbecue grill, a chef in the kitchen, king of the backyard, the do-it-yourself handyman and – are you ready for this – my makeup artist. Very well-meaning, Silver wants to train his children to be like him. In doing so, he ends up seeming like a taskmaster. But I highly doubt if anybody could ever work precisely the way he does. There is a universe of differences in personality types and working styles within our family.

Two men… two fathers… two generations. My father was a man of words, my husband is a man of action.

My father gave me lenses from which I could perceive my visual impairment from a winner's perspective. My husband partnered with me to make me an actual winner. Both men made me who I am today. This continuing legacy of fatherhood will be passed on to our children, and to our children's children.•

HEARTSIGHT

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

Does a child with a disability = a divorce?

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

"Every relationship is hard, and the challenges of co-parenting can increase the amount of stress on a marriage. When a child has special needs, like cerebral palsy, additional issues can arise out of whom primarily carries the burden and the different ways each parent handles the emotions involved. It is a sad truth that couples with children (who have) special needs face a much higher divorce rate than the rest of the married population… **the exact rate still appears to be unclear…**" [1] (emphasis added)

"New studies debunk the frequently quoted statistic that 80 percent of parents with autistic children are divorced." [2]

"While it is positive to hear that an oft-cited report that 80% of parents of a child with autism get divorced has been since debunked, (sic) there does exist a gap between marriage success of parents who do and do not face challenges with their child's development. On the issue of the autism spectrum disorder, the numbers were re-examined in a different study that found a 10% increase in the chance of parents getting divorced (sic) if their child was diagnosed. While this is not the 80% more likely, it's still a disappointment." [3]

RESEARCHERS HAVE FOUND THAT:

- *Among couples with children without any disabilities, the risk of divorce was lowest for couples with one child and increased with each successive child.*
- *The risk of divorce for parents of children with developmental disabilities remained unchanged with increasing family size…Other children in the family may be a vital support system for parents coping with the care of a child with a developmental disability.*
- *Divorce rates were not elevated, on average, in families with a child with developmental disabilities. However, in small families, there was a significantly higher risk of divorce relative to a general population comparison group.* [4-6] (Note: In the long-term study, population included primarily high school white graduates from Wisconsin.)
- *There is no consistent evidence of an association between a child having autism spectrum disorder (ASD) diagnosis and that child living in a nondivorce family. Once we control for co-occurring psychiatric disorders, our results show that a child with an ASD is slightly more likely than those without ASD to live in a nondivorce household.* [7]

AADMD

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.

It just seemed reasonable to assume that since parenting a child with a developmental disability involves greater marital stress, there would likely be an increase in the divorce rates in these families. (Note: There has been a general undertone that, in the present time, divorces are easier and single person parenthood is more acceptable. The reality is the rates and number of divorces have decreased since 2000.[8])

	Number of divorces	Rates per 1,000 total population
2016	827,261	3.8 *
2000	944,000	4.0 **

* 44 states + D.C.
** No report on number of states

PROTECT YOUR MARRIAGE – SUGGESTIONS

"All marriages have ups and downs. Tossing in kids can intensify whatever strengths or weaknesses are already there. Add a kid with a disability, and well, the stress is amplified. Even though they love their kid like crazy, the worrying and advocating and fighting with insurance companies or schools can wear parents down over time, and make them more snappish with one another. Sometimes, physical exhaustion from caring for a child who doesn't sleep well at night wears parents down. Sometimes, one parent puts so much energy into helping the child that they don't have much left at the end of the day for their spouse. Sometimes, couples feel a disconnect because they disagree about what is best for the child."[9]

- *Do not just become "parent-partners." When parents' only connection to each other is through or about the child, it can cause problems… spend 20 to 30 minutes each day connecting to each other, with no talk of the children allowed. That helps you remember the person with whom you in fell in love.*
- *Parents may have different ideas about what their expectations should be for their child, or the best course of treatment. One parent may grieve the child's diagnosis and the other may not. It's important to not just tolerate, but embrace your partner's point of view.*
- *Whether it's asking your partner to pitch in more with the household chores, or putting him in charge of wrangling with your insurance company, ask for help sooner than later.*
- *Get creative when it comes to romance. Look for imaginative ways to be romantic at home and make use of the time when the kids are in school for dates.*
- *Parents may need to rethink their roles so that caring for the child is not exclusively one person's responsibility. Couples that are raising kids with disabilities often feel depleted, or put upon, she said, when one parent does all of the caregiving. Sharing the responsibilities and giving credit for effort can help make you feel more like a team.*[9]

Another approach: To solidify their marriage, parents of children with disabilities must dedicate time to each other. If the relationship deteriorates, they can take action to improve it. For instance: communicate the mutual concerns openly and find solutions together or go into a marriage counseling program.

MAKE UP OR BREAK UP: Divorce and children with disabilities is difficult. Parents can take action to avoid a divorce; children with disabilities cannot. Parents must dedicate time to each other to solidify their marriage - if the relationship deteriorates, they can take action to improve it.

Divorce and children with disabilities is difficult. Parents should avoid divorcing because of their children with disabilities. The children deserve better. Parents can take action to avoid a divorce. Children with disabilities cannot. [10]

OK, YOU TRIED AND FAILED

So, what happens to the child with disabilities after the divorce? Divorce usually means children lose daily contact with one parent – most often fathers. Decreased contact affects the parent-child bond and researchers have found many children feel less close to their fathers after divorce. Divorce also affects a child's relationship with the custodial parent – most often mothers.

"… research has found that kids struggle the most during the first year or two after the divorce. Kids are likely to experience distress, anger, anxiety, and disbelief. But many kids seem to bounce back. They get used to changes in their daily routines and they grow comfortable with their living arrangements.

Others, however, never really seem to go back to "normal." This small percentage of children may experience ongoing—possibly even lifelong—problems after their parents' divorce." [12]

"When there is a child with special needs involved in a divorce, issues of child custody, visitation, and support and property division are significantly more complex to negotiate. (emphasis added) As part of your divorce, make sure you consider globally what your child's special needs are and have your attorney walk you through a 'day in the life' of caring for your child." [13]

- *Child support charts (for divorces) often do not address the extra expenses of a child with special needs.*
- *Uncertainty about the nature and cost of future care makes it difficult to estimate disability-related expenses in a divorce agreement.*
- *In the divorce agreement, care must be given to unique issues that arise in the child's transition into adulthood, such as guardianship, eligibility for quasi- government or private agency benefits, employment, recreation and social skills, independent living, or custodial care.*
- *Typically with developing children, child support and custody end at age of majority or when they graduate from college. Divorcing parents of children with special needs who have severe impairments face the reality of life-long care-giving and, perhaps, co-parenting.*
- *Alimony and child support payments need to consider the child's eligibility for public benefits as both a minor and adult.*
- *It is essential that your family law attorney collaborates with a special needs attorney and an experienced financial adviser to eliminate risk of losing the child's entitlements.*
- *Effectively channel support obligations and parenting plans in the divorce settlement to provide for more quality of life expenditures for the child.* [13]

> "When there is a child with special needs involved in a divorce, issues of child custody, visitation, and support and property division are significantly more complex to negotiate. As part of your divorce, make sure you consider globally what your child's special needs are and have your attorney walk you through a 'day in the life' of caring for your child."

And this is only a partial listing of the considerations when a divorce involves children with special needs! Now that you have a clearer picture of the whole story, **must a child with a disability = a divorce?** •

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POSITION ANNOUNCEMENT

Community Provider Agency serving approximately 1,200 individuals with intellectual and other developmental disabilities as well as a variety of co-occurring conditions in Southeast Tennessee and North Georgia is seeking candidates for the Executive Director position.

The Agency's main offices are located in Chattanooga, Tennessee, employing approximately 900 staff and providing a variety of home and community-based services in accordance to State and Federal guidelines. Annual budget – approximately $37 million dollars. The agency has operated for 66 continuous years as a respected community provider serving 11 counties in Southeast Tennessee and 9 counties in North Georgia. The agency is governed by a 25-member board of directors that works with several affiliate organizations designed to further the mission of the agency. In addition to Medicaid Waiver-funded day and residential services which offer a myriad of community integrated training and living experiences to promote independence, the agency also provides specialized school age services for local education agencies in Hamilton and surrounding counties, Intermediate Care Facilities for 80 individuals with intellectual disabilities who have complex needs, a Family Support program designed to assist individuals with a variety of disabilities, a comprehensive health and dental clinic, a robust transportation system comprised of approximately 160 vehicles, ongoing research opportunities, sensory programs, enrichment services (e.g., art, music, recreational activities, Special Olympics), a training center for aging, dementia and longevity, and dedicated resources for evaluating emerging technologies applicable to community inclusion. Orange Grove has Long standing and active relationships with colleges and universities offering student attachments in various disciplines, including special education, social work, medicine, dentistry, nursing, health promotion, psychology, exercise physiology, public health, physical and occupational therapy, computer science and bioengineering.

Candidates should have experience in nationally accredited provider agency administration, including HCBS Waiver programs, MCO-funded services and ICFIID-funded services. Generalist background with broad knowledge of organizational planning and administration, including finance, personnel, operations, non-profit management, and development. Candidates should also have experience in working with a board of directors' governing structure, and supervision of management level personnel. Experience in organizational financial management. Experience in dealing with emerging regulatory and policy changes issued by State and Federal agencies affecting the organization, such as HCBS guidelines and technology practices for the implementation of Protected Health Information among others.

Educational requirements include a Bachelor's degree in an area related to the purpose of the agency and a minimum of seven years of full-time paid professional experience in a management or supervisory capacity in a field related to the purpose of the agency, or a Master's degree in an area related to the purpose of the agency and a minimum of five years of full-time paid professional experience in a management or supervisory capacity in a field related to the purpose of the agency, or a Doctoral degree in an area related to the purpose of the agency and a minimum of three years of professional experience in a management or supervisory capacity in a field related to the purpose of the agency.

Candidate should possess a unique background of experiences in and an energetic commitment to:

- Maintaining person-centered services in a diverse field of funding streams by consistently advocating for and promoting a quality driven system that incentivizes measurable organizational outcomes.
- An in-depth understanding as to how the landscape of community services for people with disabilities is changing and a vision as to the best organizational approach necessary for sustained growth and improvement.
- Guiding organizational change by drawing upon demonstrated experience in leading an organization through necessary "out of the box" adaptations in order to properly position it for a successful MCO environment.
- Leading specialized teaching and therapeutic services as well as organizing alternative school age services that benefit contracting local education agencies and best prepare students for the least restrictive educational environments.
- Guiding and supporting development activities as well as grant requests in a collaborative fashion drawing upon agency partnerships which further diversify an organization's funding sources while simultaneously ensuring adequately resourced and self-sustained programs.
- Educating the general community, local, State, and Federal governments, MCO's, legislators, advocates, donors, and other key stakeholders with regard to the critical needs of individuals served and thereby creating the necessary improvements to overall services.
- A vigilant perspective of quality management coupled with a perpetual drive for service improvement that surpasses expectations of national accreditation, MCO, State, and Federal regulation compliance, as well as donor anticipations that distinguishes the agency as a superior service provider.

Compensation/Benefits: commensurate with experience/qualifications; major medical health plan/dental-vision.
Paid time off/holidays.
Additional benefits negotiable.

Applications/resumes accepted June 1, 2019 - June 30, 2019.
Position selection to be made in August 2019 with duty assumption/transition in October 2019.
Send resume to:
Email: execsearch@orangegrove.org
Additional Organizational Information is available at www.orangegrovecenter.org

HORSE SENSE: Lisa Gatti, Founder and CEO of Pal-O-Mine Equestrian. “Horses can heal in so many ways.”

PAL-O-MINE EQUESTRIAN

Where Horses are Central to Growth, Learning and Healing

In 1995, Lisa Gatti, an avid horse lover, competitive rider and special education teacher, began a therapeutic horseback riding program for individuals with disabilities and other vulnerable populations. She had one horse, a small group of students and rented space at a local equestrian center.

A lot has changesd since then. Her organization, Pal-O-Mine Equestrian, a 501(c)3 nonprofit, located on Old Nichols Road in Islandia, New York, has evolved considerably from its beginnings. Its mission however has not: To facilitate growth, learning and healing with a myriad of populations using horses as the foundation. The difference is that now Lisa, as Pal-O-Mine’s CEO, oversees a sizeable team of dedicated and highly credentialed professionals, ranging from certified equine specialists to licensed social workers and registered nurses and licensed teachers and riding instructors.

PHOTO BY ELLEN LEAR/COURTESY OF PAL-O-MINE EQUESTRIAN

In addition, there are facility, program and barn staff who make up part of this team, not to mention the volunteer coordinator who oversees the 80 volunteers weekly who give of their time, selflessly and unconditionally. There is also a herd of 20 therapy horses, as well as farm animals and other livestock to complete the team.

The programs, too, have grown as have Pal-O-Mine's facilities and footprint. Its students, from children and adults with developmental and physical disabilities, to survivors of abuse, our military and their families and underprivileged and at-risk youth, are making tremendous strides. Pal-O-Mine continues with conviction toward the finish line in A Race We Will Win.

What They Are Saying

Looking around at Pal-O-Mine today—with its 13 acres and multiple buildings, including those for classrooms, educational and vocational programs, barn, indoor arena and organic and sensory gardens—it is difficult not to be captured by the energy of the instructors and their students as they grow in courage, confidence and life skills, bonding with their human and equine teachers. Regardless of their disability or circumstance—whether they have an autism spectrum disorder, neurological disorder, cerebral palsy, multiple sclerosis, Down syndrome, spina bifida, an emotional or genetic disorder, traumatic brain injury or other disorder—Pal-O-Mine's programs are designed to help each individual improve in the areas they need most. And, they do improve.

One parent spoke about her son, saying, "My son, Timothy, has multiple physical disabilities, but is completely mentally normal. He works very hard to change this in whatever small way he can, and thanks to his riding at Pal-O-Mine, his ability to do small things for himself is improving much to the delight of his therapists." Still another parent said, "My son has been riding since he was four years old. I cannot find enough positive words to describe the staff and volunteers that work here. Horses and Pal-O-Mine have had such an incredibly positive influence on my son's life that we are forever grateful." One student, perhaps, said it best, "My journey has been long and arduous. I searched and searched, and found you…You all helped me regain my life. There's always work to do to keep growing…"

Pal-O-Mine
Equestrian
Est. 1995

Pal-O-Mine Equestrian began in 1995 as a therapeutic horseback riding program for individuals with disabilities and other vulnerable populations. Our mission is to provide a comprehensive therapeutic equine program using horses to facilitate growth, learning and healing. Our populations include children and adults with disabilities, those who have been abused or neglected, the military and the impoverished.

HORSES MAKE LEARNING FUN: A student from a local school district attends Pal-O-Mine as part of an Equine Assisted Learning Program where academic, social and behavioral goals are met.

TRUE PALS: With the exception of Adaptive Riding, all of Pal-O-Mine's programs are unmounted and involve activities on the ground with the horses, which provides opportunities for individual and group discovery through experiential learning.

For parents of children with special needs, it may be difficult to understand the impact a qualified professional, alongside one of Pal-O-Mine's horses which include many breeds – Paints, Belgium Draft, Appaloosas, Haflingers, Minis, Quarter Horses, Palominos, Norwegian Fjord, and Appendix – can have on their child. But the impact is real and measurable in the growth in trust, self-esteem and new life skills gained.

Programs that Empower

Pal-O-Mine provides a variety of programs which include: Adaptive Riding and Unmounted Horsemanship, Equine Assisted Psychotherapy, Equine Assisted Learning, Hippotherapy, Military and First Responder Wellness Programs and Corporate Leadership Workshops. Each of these programs has specific objectives rooted in an educational, emotional, growth and learning foundation. Pal-O-Mine Equine Assisted Learning (EAL) Programs, for instance, use unique approaches to create positive and constructive learning experiences for children and adolescents who are at risk of failing in the traditional academic setting. These EAL sessions incorporate guided and safe horse interactions, positive interactions between students, animals and adults, along with grade-level appropriate reading, writing, art and math skills. The program follows the practices and guidelines of the Equine Assisted Growth and Learning Association (EAGALA), and many of Pal-O-Mine's instructors are EAGALA-certified.

The Equine Assisted Psychotherapy (EAP) program also follows the model prescribed by EAGALA, the leading international EAP training and certifying organization. Pal-O-Mine currently has seven Licensed Mental Health Professionals and nine Equine Specialists who are certified in the EAGALA model.

Additional Programs

- **Hippotherapy,** a treatment strategy provided by licensed and specially trained occupational therapists, physical therapists or speech-language pathologists who use the movement of the horse, whose gait provide multidimensional movement, to help address and improve function;
- **Animal Assisted Speech/Occupational Therapy** enhanced with the assistance of Pal-O-Mine's horses, ponies, miniatures horses, miniature donkeys, goats, sheep, chickens, bunnies and cats;
- **Individual, family and group therapy** focusing on issues such as grief, trauma, abuse, and eating and substance disorders;
- **Military and First Responder Wellness,** also using the EAGALA EAP model to treat veterans and their families who suffer from the effects of Post Traumatic Stress Disorder (PTSD), such as anger, depression, anxiety, nightmares, irritability, addiction and other debilitating conditions, as well as those with traumatic brain injury.
- **Corporate Leadership and Team Building Workshops;**
- **Alternative to Incarceration Program** for school aged youth specifically designed to reduce the recidivism rate and allow for completion of high school.

A Race We Will Win

With its student population continuing to grow and no holding back on the reins of its expansion, Pal-O-Mine has embarked on its most ambitious capital improvement campaign since its inception. Launching officially at Pal-O-Mine's 2019 "Day at the Races," at Belmont Park, the day before the Belmont Stakes, its "A Race We Will Win" campaign has a goal to raise $3 million over a three-year period to fund various essential capital improvements across its property and facilities. These include building renovations and system installation projects such as an office expansion, indoor arena improvements, energy-efficient lighting, accessible inclusive playground for humans and horses, new fencing, golf carts for multiple purposes, roof and window replacements, and other infrastructure and equipment needs.

According to Lisa, whose achievements include the 1996 and 2000 United States Team Leader for the Equestrian Paralympic Games in Atlanta, Georgia and Sydney, Australia, and Member of the Board of Directors of EAGALA, as well as a Member of the Board of Autism Communities of Long Island, "The last few years have been especially dynamic for our organization. We have seen tremendous growth in our programs and facilities. We have been fortunate to have many very loyal and generous contributors who have helped us reach this stage in our growth. Now, we want to reach out to the broader private and corporate communities for their support so we can provide our vital programs to more individuals with disabilities, as well as our military and their families, adjudicated youth and those who are survivors of trauma. We are confident this will be A Race We Will Win for all of those we serve today and into the future."

Learn more about Pal-O-Mine Equestrian at: www.pal-o-mine.org •

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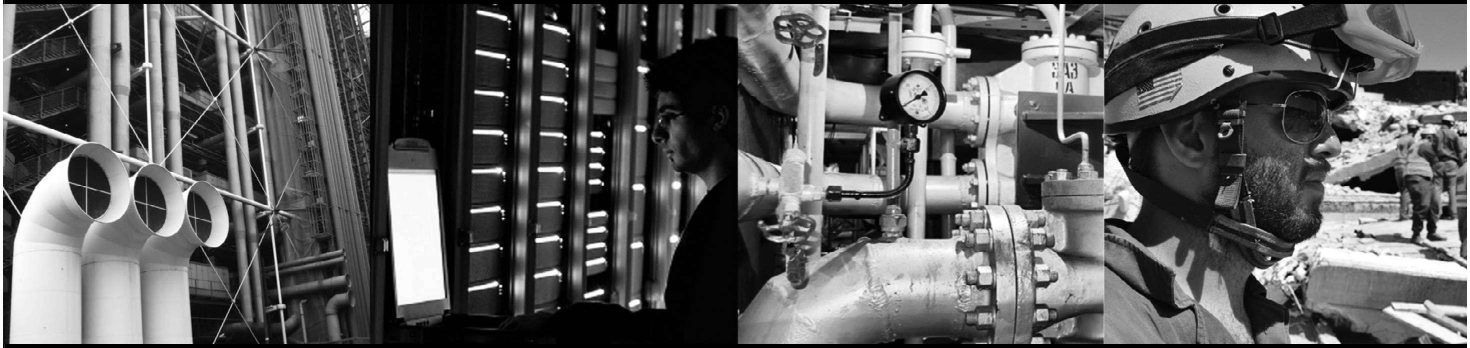

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THE ANNUAL ISSUE
SUMMER FUN!

A PARENT'S GUIDE TO PICKING THE BEST CAMP FOR YOUR CHILD TH SPECIAL NEEDS

BY LAUREN AGORATUS, M.A.

Every child with a disability has different needs, even those with the same diagnosis. Families may be at a loss to find summer activities for their children with special needs.

When thinking about summer activities for their children with disabilities, families should consider whether their child is eligible for extended school year services, which might be appropriately provided in a camp. They should also consider whether their child with disabilities could benefit from an inclusive summer camp experience.

IS THE CHILD ELIGIBLE FOR EXTENDED SCHOOL YEAR?

Some children are eligible for an extended school year (ESY) so they can maintain the skills they have learned. This is an IEP (individual educational program) team decision, and parents are part of the IEP team. If families have difficulty accessing ESY services for their child, they can contact the Parent Training and Information Center in their state for free help *(see Resources, next page)*. Regarding coordination of ESY and camp, consideration should be given to the following:

- *If the child doesn't have ESY, when is camp available?*
- *If the child does have ESY, can camp be considered the ESY placement? If not, can the child attend camp the remaining weeks? Many camps now have a "regular" and "ESY" camp schedule, or pay week-by-week, to cover the summer.*

WOULD A TYPICAL SUMMER CAMP BE APPROPRIATE, WITH ACCOMMODATIONS?

Many children with disabilities could have a successful experience at a typical summer camp, with the appropriate accommodations. In general, under the Americans with Disabilities Act, summer camps are required to make "reasonable" accommodations to include children with disabilities. This might include making special dietary provisions, training staff to address allergies, or identifying buddies to provide additional support, among other accommodations. The ADA provides that, "No individual shall be discriminated against on the basis of disability in the full and equal enjoyment of the goods, services, facilities, privileges, advantages, or accommodations of any place of public accommodation by any person who owns, leases (or leases to), or operates a place of public accommodation."

For more information, check out, "Inclusion of Children with Special Needs in After-School and Summer Programs: A Guide for Families and Professionals," at **www.njsacc.org/pdfs/childrenspecialneedsbooklet_WEB.pdf**. The American Camp Association also has a guide, Let's All Play: Helping to Make Inclusive in Summer Camps a Success, at **www.acacamps.org/resource-library/camping-magazine/lets-all-play-helping-make-inclusion-summer-camps-success.**

HOW TO FIND A CAMP

The American Camp Association also has a family guide as well as "find a camp" listing. Many organizations for specific disabilities may also have suggestions. Lastly, other families and family organizations, such as Family to Family Health Information Centers and

PITCHING CAMP: At camp, beyond arts-and-crafts and other skills, children learn by socializing with other children. By choosing the best camp for their child with special needs, families will enhance their child's summer experience.

Parent-to-Parent USA affiliates, might have recommendations in their geographical area *(see Resources, next page)*.

QUESTIONS FOR CAMP DIRECTORS

Families will naturally be concerned with how their child's needs can be met at camp. Communication is key for families to have a positive camp experience. Parents can ask basic questions over the phone before deciding to visit a camp. Questions they can discuss with camps when visiting could include:

- *For children with medical needs, is there a "camp nurse"?*
- *Can the child self-administer medication?*
- *How are children transported to/from camp?*
- *Is there consideration of special diets? Food allergies?*
- *How does the camp accommodate children with special needs?*
- *Is this a day or overnight camp?*
- *Does the child need one-to-one assistance? Many camps offer this.*
- *Will the child be engaged with typical peers?*
- *How does the camp address challenging behaviors?*
- *Are there backup plans in place for children at risk of dehydration, sun sensitivity, or heat exhaustion?*

HOW TO PAY FOR CAMP

Besides private pay, in many states the state agency that provides services to children with disabilities or special healthcare needs offers some help paying for camp, in some cases, even including aides. In addition, there may be a county Office on Disabilities offering additional financial assistance. Lastly, many civic groups such as the Elks, Kiwanis, or Jaycees offer free camp for children with special needs *(see Resources, below)*.

Camping is often seen as a rite of passage to growing up for all children. Beyond arts-and-crafts and other skills, children also learn by socializing with other children. By choosing the best camp for their child with special needs, families will enhance their child's summer experience.

ABOUT THE AUTHOR:

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

SEND A KID TO CAMP : A GUIDE TO PICKING A SUMMER CAMP

EXTENDED SCHOOL YEAR

WRIGHTSLAW

www.wrightslaw.com/nltr/13/nl.0430.htm

UNDERSTOOD.ORG

Extended School Year Services: What you Need to Know

www.understood.org/en/friends-feelings/child-social-situations/summer-camp-summer-school/extended-school-year-services-what-you-need-to-know

Summer Learning Programs for Students with Learning and Attention Issues

www.understood.org/en/friends-feelings/child-social-situations/summer-camp-summer-school/summer-learning-programs-for-kids-with-learning-and-attention-issues

PARENT TRAINING AND INFORMATION CENTERS

www.parentcenterhub.org/find-your-center/

www.parentcenterhub.org/esy-services-beyond-the-school-year-for-students-with-ieps

FINDING A CAMP

AMERICAN CAMP ASSOCIATION

www.acacamps.org/campers-families

PARENT-TO-PARENT

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FAMILY-TO-FAMILY HEALTH INFORMATION CENTERS

http://familyvoices.org/affiliates

NATIONAL ASSOCIATION OF COUNCILS ON DEVELOPMENTAL DISABILITIES

https://nacdd.org/councils

CIVIC GROUPS

ELKS

www.elks.org/states

KIWANIS

https://locator.kiwanis.org/FindAClub

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https://usjcfoundation.com/programs/current-programs


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THE ANNUAL ISSUE
SUMMER FUN!

SCREEN SMART

YOUR DIGITAL TOOL KIT TO STOP SUMMER LEARNING LOSS

Giving children the chance to talk about the stories they see on screens is simple but beneficial. You'll find that they start to connect what they're learning in school to screen time at home and make better viewing choices.

BY NICOLE DREISKE

Summer learning loss is looming for millions of children as school-free days seem to invite endless, often mindless, screen time. In addition to camps and outdoor activities, parents often craft ingenious solutions for "summer setback". One dad told me that his wife went online and found resources matched to each of their three kids' learning levels.

"She printed them out and the kids do one hour of schoolwork every day before they go out to play. Last year they were ahead when they went back to school." Another parent said that every year they have their kids create a list of ten books they want to read over the summer. But screen time can be part of the solution, especially if it's not used as a "reward". Let's look at some handy ways for parents to help their kids develop healthy tech habits and boost learning over the summer. I start with the three "C's":

- *Co-view*
- *Communicate during screen time*
- *Connect the stories kids see on screens to the stories they read in books*

HOW TO HELP YOUR CHILD BE MORE SCREEN SMART

To get the ball rolling, parents just need to call on their "storybook skills" while children are using digital devices.

1. Schedule co-viewing (or co-gaming) for 15 minutes twice a week. Pick a series your child loves, or a short video based on a book, like those produced by Rabbit Ears or Weston Woods. Many are available at your local library! Any story-based app or game will work, too.

TIP: *Pick content that you know for your first co-play or co-viewing experience.*

2. Use your "storybook voice." During screen talk, relax into the same tone and tempo you use when reading a story aloud to a child. This allows you to encourage, coax, and tease out responses. Just like reading story at bedtime, the idea is to enjoy the shared space and the cuddling, using a playful and caring tone.

3. "Prime" the mind before viewing - With a few simple words you can prime children to use higher order thinking when engaging a screen.

This helps them make the most of their screen time so they don't watch mindlessly. Good priming gets kids excited about this fun, new way of using screens.

The key is to make it sound fun (storybook voice!) so they're interested in watching screens with their minds awake.

The first time, you say: "Today we're going to do something special and watch/play together! We're going to look for what we like, what we don't like, and why." After that you build on experiences by referencing things you've seen together.

TIP: *If you need to make dinner and want to allow some solo screen time, "prime" by letting your child know you'll be talking with them later.*

4. Interact and talk during screen time the way you do when reading a book to a child. Screen time is too often solitary and sedentary. But when we watch or play with screens together, we give our children wonderful new ways to connect with us. They react, share and express themselves so they're active, instead of passive. This also means they're learning to be critical thinkers and observers, not just consumers of content.

Share ideas and point out details. During story time with a book, children ask questions about the colors, shapes, and characters. Let them point out details. You can comment, perhaps tying real life experiences to the book. If a child points to the picture of a kitten and says, "Kitty!" you might say, "Yes, and where did we see a kitten this week? What color was it?" Use that same kind of interaction during co-viewing. Every word counts in childhood and the more words shared with parents, the better!

TIP: *Add words like "character," "plot" and "setting" when you're pointing out details. Your child will quickly learn what the words mean by the way you use them, or by asking you!*

Ask questions. You can P&Q (pause and ask questions) or ask questions while the program is running. "What just happened there?" "What time of day is it now?" "Why do you think the character did that"? "What kind of animal is that?" "Where are they now? What's the setting?" "How do you think they'll solve that problem?" Children can easily answer your questions while watching, but don't hesitate to use the pause button to give them enough time to answer.

TIP: *When a child asks you what happened, you can turn the question back – "What do you think happened here?" It's fun to replay in slow motion and look for details!*

5. Play, Draw, Co-Create. Guide energy out of screen time and into art! Children can draw their favorite character in a new setting. They can change a part of the story they didn't like. "If you didn't like that ending, how would you end the story?" If you loved a special setting, make up your own story pretending you're in that setting.

TIP: *Don't just act out the scenes from a video, let the play or artwork unfold from the child's own imagination.*

6. Media reports. Once or twice a month ask your child to write or "screen talk" a media report. It's just like a book report, and if they're too young to write, they can perform their media report while you video it! Age-appropriate book report templates are easy to find online.

Giving children the chance to talk about the stories they see on screens is simple but beneficial. You'll find that they start to connect what they're learning in school to screen time at home and make better viewing choices. Just turn on children's minds before turning on screens, and then talk with them. Over time, they get smarter and show more empathy. That's a big return on a small investment.•

ABOUT THE AUTHOR:

Nicole Dreiske, Executive Director of the International Children's Media Center, is an educational innovator whose techniques for "healthy tech habits" have reached more than 500,000 children. She is the author of *The Upside Of Digital Devices: How to Make Your Child More Screen Smart™, Literate and Emotionally Intelligent,* winner of the National Parenting Center's Seal of Approval.

SAFE ONLINE GAMES

FOR KIDS ON THE SPECTRUM

BY JACKIE SCHWABE

Stuart Duncan, who has a child with an autism diagnosis, wanted a safe place for his son to play. Autcraft, which he founded in 2013, became the first Minecraft server created for children with their neurological divergence considered from the start.

Summer is right around the corner and we are all looking for a safe place for our kids to play. If they can't play outside, we want to be sure they will be safe online. Online can be trickier than outside because it is difficult to monitor what others are saying or doing.

Fortunately for parents with children on the spectrum, there is a solution to the problem.

Autcraft was founded in 2013 by Stuart Duncan. Stuart has a child who has an autism diagnosis and he wanted a safe place for his son to play. Later, Stuart advised that he too has an autism diagnosis. Autcraft became the first Minecraft server created for children with their neurological divergence considered from the start, instead of being an afterthought – created for them, by them.

The founder is known in the game as AutismFather. He created the game as a response to parents who did not know if their children could play their favorite game with others without the threat of bullying and discrimination. He isn't a passive founder either. Autcraft is administrated by adults that include others with an autism diagnosis and parents and/or family members of someone on the spectrum. There are also additional staff members that include what they call "Helpers" – which are people of all ages that prove to be responsible, positive and helpful with people, "SrHelper," which are adults that demonstrate some knowledge of the game as well as having respect, responsibility, and helpfulness, and even "Buddies" who are people of all ages that are supportive and helpful to others.

WHAT ARE FEATURES THAT MAKE IT SAFER?

While there are a number of great things that come from just having all the various staff members that are helping the players, there are a few important features about Autcraft that also ensure the children's safety. Here is a list of some of the more important features:

- *Bullying, killing, stealing, and similar misdeeds are not tolerated.*
- *Swearing is not tolerated.*
- *There is a support system inside the game to get admin help.*
- *Players builds are protected using WorldGuard. You have to ask an admin for protection.*
- *All kills, blocks places, blocks broken, items dropped, picked up and more are tracked so that the administrators can see exactly what happens anywhere in the game.*
- *A few mini-games have been setup, including hide and seek, mob arenas, and more.*

All of these features were put in place to help make the game more enjoyable to those with an autism diagnosis.

FAIR GAME: Autcraft was created as a response to parents who did not know if their children could play their favorite game with others without the threat of bullying and discrimination.

HOW CAN MY CHILD PLAY?

The best thing you can do is to start at https://www.autcraft.com/setup. This is a wiki that describes each step that needs to occur to get started. There is also a link to the rules in the game at https://www.autcraft.com/rules. Note that the rules page also includes game play guidelines. If you have used social stories in the past to assist your child with what to expect, going over the rules and gameplay guidelines with them ahead of time will help make a smoother transition for them, especially if they have already played Minecraft. If they have played Minecraft before, there are rules here that they didn't have before.

The most important concept for Autcraft and AutismFather is the safety of the players. That means that Autcraft is a whitelisted Minecraft server for children and adults that have an autism diagnosis and their families. In order to play with the others, you or a family member must own a computer version of Minecraft and you need to register and apply to be put on the whitelist, which you can do here. Visit https://www.autcraft.com/whitelist. Since the applications are reviewed, the waiting time for assessment of your application is approximately two weeks.

HOW CAN WE SUPPORT AUTCRAFT?

It has been the founder's mission to help as many children with an autism diagnosis as possible, so he accepts pledges in any amount that you are able to give. You can find out more information on his Patreon page www.patreon.com/autismfather.

Autcraft is a dedicated Minecraft server designed specifically for players on the autism spectrum, as well as their family and friends. Created by Stuart Duncan after hearing the frustration of other parents whose children were bullied, Autcraft has taken numerous steps to ensure a safe and enriched experience for players within the server. Autcraft is the perfect sanctuary for families with autism to learn to engage and cooperate with others, aided by a staff of knowledgeable and understanding admins.

The interesting thing about the Patreon page is that for each level of support, he makes an attempt to continue to give back to the community. For example, if you donate $6 or more you will get a postcard from AutismFather to say thank you. For donations of $10 or more you get to place your name at spawn on a sign so that all the visitors to the serve can see who is helping keep the whole place running. You can also get a special Patreon Rank which includes some extra commands and permissions to help streamline game play. Higher donations include things like coffee mugs and other game-related perks. There is even access to the Discord server with only a $10 pledge.

While all of this is great, the Patreon site itself is full of positive support for the community and campaigns like #TakeBackOurIdentity to support the larger community of those with an autism diagnosis. The Patreon page also has content that is for Patreon members only, so they can feel part of an exclusive club.

WHY DO I SUPPORT AUTCRAFT?

I have four children. My daughter has an autism diagnosis, and to be completely transparent, she doesn't play Autcraft or Minecraft. However, my other three children do play Minecraft. In general Minecraft is a great way to see your kids learn how to work together and build things. It is fun to see them create new worlds and defeat the Creepers (those are the bad guys). Sometimes they even invite their sister to come join them, and on rare occasions, she does.

BUILDING CONFIDENCE: Summer is right around the corner, and we are all looking for a safe place for our kids to play. Autcraft is a place where your children will be looked after by a team of staff that understand their unique challenges.

I watch the kiddos play Minecraft once in a while or listen over their shoulder to their favorite YouTube star, Dan TDM, who talks all about Minecraft. It is a great game and there are some really positive people within the community. However, there are also those that are not very pleasant. Some of our kids have had their castles broken by others and had items they dropped for later pick up by other kids. And while most of the time, my children are able to deal with the loss, I am positive that not all children with an autism diagnosis would be able to handle these things. In fact, AutismFather mentions one of the reasons for the safety rules of the game is to keep others from doing things like this – for often, they result in broken computers or keyboards when our children are not able to react.

That isn't all though. We had a personal incident with my oldest child just in the last few months. It didn't relate to Minecraft, but it did relate to cyber-bullying and had some very negative consequences for all the children involved. The Autcraft server isn't just a safe place to keep our kids from having their special items stolen, it is a safe place for inappropriate language and topics that many of us know will then be repeated unmercifully, over and over again, for what might seem like eternity.

WHAT ABOUT ONLINE SAFETY?

It is great that AutismFather took the time to create a world that is safe just for children with an autism diagnosis. However, I also respect greatly the efforts that he has taken to encourage online safety for all children. AutismFather advises that everyone should discuss the dangers of strangers on the internet as much, or more so, than strangers that they meet face to face.

He suggests that you don't allow your children to add every person they can on a friends list. They have the ability to add friends in Discord, Xbox, Facebook and, well, everywhere. It is dangerous for them to join a new community and start to ask every person they meet to friend them somewhere. It is also their desire to have many friends, but even on whitelisted servers, you never know if someone is who they say they are. With that said, monitor their friends list.

AutismFather also suggests avoiding private one-on-one conversations online. Join larger channels, or semi-private channels, or groups, so that others can also see what is said and what might be going on wrong. If anyone asks something inappropriate, there is a witness. If you are able, join the conversations, or at least be able to see them if you think something might be going on. AutismFather feels so strongly about this that he actively refused to have any private conversations, even with parents. Note that this applies to social media as well. Private conversations are no place for children.

GO OUTSIDE AND PLAY OR GO INSIDE AND PLAY – JUST BE SAFE

Yep, summer is right around the corner, and we are all looking for a safe place for our kids to play. Autcraft is a place where your children will be looked after by a team of staff that understand their unique challenges.

Most of all this summer, let your kids have fun with the games they are able to play and want to play. Just keep in mind some of the online internet safety tips, like never having private conversations, and always being respectful of others online. Have a great summer! •

If you would like to learn more about Autcraft you can find links to over 20 articles as well as a research study on the topic at https://www.autcraft.com/media. In addition, you can visit Autcraft on Facebook at @AutcraftServer, Twitter at @Autcraft, and YouTube at @StuartD2.

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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STUDY: THE FAMILY DOG

Researchers designed an adapted physical activity, animal-assisted intervention where the family dog would serve as a partner with the child in physical activities designed to help improve overall physical activity, motor skills and quality of life.

COULD HELP BOOST PHYSICAL ACTIVITY FOR KIDS WITH DISABILITIES

BY MICHELLE KLAMPE

The family dog could serve as a partner and ally in efforts to help children with disabilities incorporate more physical activity into their daily lives, a new study from Oregon State University indicates.

In a case study of one 10-year-old boy with cerebral palsy and his family's dog, researchers found the intervention program led to a wide range of improvements for the child, including physical activity as well as motor skills, quality of life and human-animal interactions.“These initial findings indicate that we can improve the quality of life for children with disabilities, and we can get them to be more active,” said Megan MacDonald, an assistant professor in OSU's (Oregon State University) College of Public Health and Human Sciences and corresponding author on the study. “And in this case, both are happening simultaneously, which is fantastic.”

The researchers detailed the child's experience in the adapted physical activity intervention program in a case study just published in the journal Animals. Co-authors are Monique Udell of the OSU College of Agricultural Sciences; Craig Ruaux of the OSU College of Veterinary Medicine; Samantha Ross of the OSU College of Public Health and Human Sciences; Amanda Tepfer of Norwich University and Wendy Baltzer of Massey University in New Zealand. The research was supported by the Division of Health Sciences at OSU.

Children with physical disabilities, such as cerebral palsy, spend significantly less time participating in physical activity compared to their peers and are considered a health disparity group, meaning they generally face more health concerns than their peers.

Researchers designed an adapted physical activity, animal-assisted intervention where the family dog would serve as a partner with the child in physical activities designed to help improve overall physical activity, motor skills and quality of life. The family dog is a good choice for this type of intervention because the animal is already known to the child and there is an existing relationship – and both the dog and the child will benefit from the activities, MacDonald said.

Researchers took initial assessments of the child's daily physical activity, motor skills and quality of life before starting the eight-week intervention. A veterinarian examined the dog's fitness for participation and the human-animal interaction between the dog, a year-old Pomeranian, and the child was also assessed.

Then the pair began the eight-week intervention, which included a supervised physical activity program once a week for 60 minutes and participation in activities such as brushing the dog with each hand; playing fetch and alternating hands; balancing on a wobble board; and marching on a balancing disc.

“The dog would also balance on the wobble board, so it became a challenge for the child – if the dog can do it, I can, too,” MacDonald said. “It was so cool to see the relationship between the child and the dog evolve over time. They develop a partnership and the activities become more fun and challenging for the child. It becomes, in part, about the dog and the responsibility of taking care of it.”

> ***“The findings so far are very encouraging. There's a chance down the road we could be encouraging families to adopt a dog for the public health benefits. How cool would that be?”***
>
> **– Megan MacDonald**

The dog and the child also had “homework,” which included brushing the dog, playing fetch and going on daily walks. The child wore an accelerometer to measure physical activity levels at home.

At the conclusion of the intervention, researchers re-assessed and found that the child's quality of life had increased significantly in several areas, including emotional, social and physical health, as assessed by the child as well as the parent. In addition, the child's sedentary behavior decreased and time spent on moderate to vigorous activity increased dramatically.

“The findings so far are very encouraging,” MacDonald said. “There's a chance down the road we could be encouraging families to adopt a dog for the public health benefits. How cool would that be?”

The researchers also found that the relationship between the dog and the child improved over the course of the therapy as they worked together on various tasks. The dog's prosocial, or positive, behavior toward the child is a sign of wellbeing for both members of the team, said Udell, who is director of the Human-Animal Interaction Lab at OSU.

“A closer child-dog bond increases the likelihood of lasting emotional benefits and may also facilitate long-term joint activity at home, such as taking walks, simply because it is enjoyable for all involved,” she said.

This study is one of the first to evaluate how a dog's behavior and wellbeing are affected by their participation in animal-assisted therapy, Udell noted. From an animal welfare standpoint, it is promising that the dog's behavior and performance on cognitive and physical tasks improved alongside the child's.

Though the case study features only one child, the research team recruited several families with children with disabilities and their dogs to participate in the larger project, which was designed in part to test the design and methodology of the experiment and determine if it could be implemented on a larger scale.

Based on the initial results, researchers hope to pursue additional studies involving children with disabilities and their family dogs, if funding can be secured. They would like to examine other benefits such a pairing might have, including the sense of responsibility the child appears to gain during the course of the intervention.

“We're also learning a lot from our child participants,” MacDonald said. “They're teaching us stuff about friendship with the animal and the responsibility of taking care of a pet, which allows us to ask more research questions about the influence of a pet on the child and their family.”

ABOUT THE AUTHOR:

Michelle Klampe is a news writer with OSU News and Communications. Megan MacDonald, an assistant professor in OSU's College of Public Health and Human Sciences and corresponding author on the study. OSU College of Public Health and Human Sciences is the first accredited college of public health in Oregon, the college creates connections in teaching, research and community outreach while advancing knowledge, policies and practices that improve population health in communities across the state and beyond.

Most industries – from transportation to commerce – are now being revolutionized by advances in information technology. Hospital care is just beginning to leverage IT to do a better job for inpatients. Why not use these technologies to optimize the health of adults with IDD?

SOLVING OLD HEALTHCARE PROBLEMS WITH NEW TECHNOLOGY

THE RIGHT CARE NOW PROJECT

BY SUSAN ABEND, MD FACP

It can be very challenging to find good healthcare if you are an adult with an intellectual and developmental disability (IDD). In fact, many people stay with their pediatrician as long as they can because finding an adult doctor who is familiar with IDD is so difficult. While there are doctors and clinics that specialize in the care of adults with IDD, there are not very many. Unless you live nearby one and can wait for an appointment, they're not generally an option.

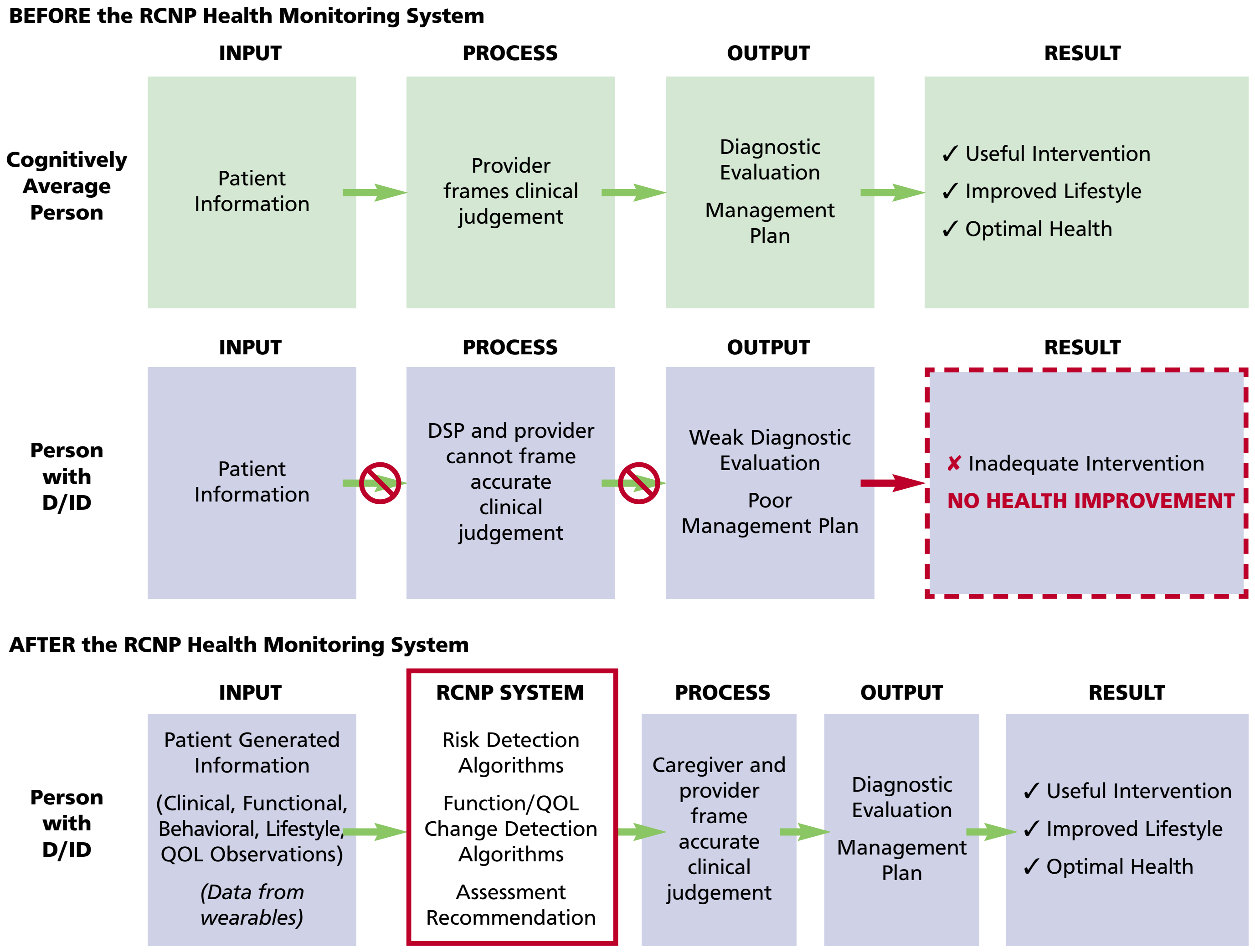
Most people need to rely on local primary care doctors for their health needs, yet many surveys have shown that the majority of doctors don't feel they have the training, information and skill to treat patients with IDD properly.

Why is this the case? There are many theories, and many barriers to good care have been identified. People with IDD are now living longer, and the general medical community has only recently come to realize that adults with IDD often have complex needs that require specialized knowledge. Unfortunately, a medical curriculum that teaches evidence-based practices is not yet widely available. To make matters worse, the average practitioner is under increasing time constraints and has often not been trained to work with someone who may have difficulty communicating his/her needs. It has also become harder to get the information needed to create a good care plan: staff members who accompany patients may not know them well, and may not have good training: In the U.S, direct service providers (DSPs) are experiencing a job vacancy rate of more than 9%, and the average support agency experiences a turnover rate of about 45% every year. It's a tremendous challenge to be sure that the people supporting adults with IDD know them well, can communicate properly with their providers, and are trained to recognize a change in health before a crisis develops.

These obstacles to good care have had unacceptable consequences for those with IDD: Adults with IDD are more than twice as likely as average individuals to have unmet health needs. They receive fewer preventative health services, have more hospitalizations, are at higher risk of dying of illnesses like pneumonia, and have higher rates of diabetes, obesity and high cholesterol. These healthcare inequities are so great that the American Medical Association (AMA) and the American Academy of Developmental Medicine and Dentistry (AADMD) have advocated for legislation that persons with IDD be designated as a Medically Underserved Population.

However, a group of us who have worked to provide excellent, multispecialty care for adults with IDD have realized that if there are tools to help caregivers and practitioners overcome these communication and skill barriers, then all adults with IDD can get proper care from the provider of their choice. Armed with these tools, adults with IDD will no longer have to depend on a sys-

FIGURE 1: The RCNP Monitoring System collects and processes information regularly so DSPs and providers have all the information they need to provide high quality, effective care



D/ID- Developmental and Intellectual Disability; DSP- Direct Service Provider; QOL- Quality of Life tem that may not meet their needs.

We realized that most industries – from transportation to commerce – are now being revolutionized by advances in information technology (IT). Hospital care is just beginning to leverage IT to do a better job for inpatients. Why not use these technologies to optimize the health of adults with IDD? We created a nonprofit organization to do just that: The Right Care Now Project (RCNP). With generous support from eClinicalWorks, one of the largest electronic health system companies in the U.S., our team – an internist, psychiatrist, neurologist, nurse, behaviorist and consumer, all with many years of experience and a deep understanding of healthcare for adults with IDD – has developed a system to help make sure that all adults with IDD can get expert care from all their providers.

You Can't Fix What You Can't Find

Caregivers and DSPs are exposed to a wealth of information every day that give clues about the health of adults who can't communicate directly. Currently, however, there's no consistent way to be sure each caregiver knows what information is important to record, to give to doctors at a visit, or to use to call for a doctor's attention. The backbone of the RCNP Health Monitoring System is a method for collecting, interpreting and distributing this important information – data that can be used by practitioners to figure out if a person has an active problem and/or needs an assessment to prevent a future problem or crisis. We created a computer cloud-based system where caregivers can log in to a website and work with the adult with IDD to easily answer specific questions about health, function, activities, quality of life, and their medical care. Caregivers can be trained to use the system in about an hour, and the questions take about 35 minutes to complete. The caregiver enters this information every three months, and this quarterly information is then automatically fed through algorithms, or short computer programs, that can pick up changes in health, or patterns that indicate that medical attention is necessary. The system can currently detect over 100 health issues that are common in those with IDD but are often overlooked or inadequately treated because providers don't have access to the information.

ABOUT RCNP

The Right Care Now Project has been developed by physicians dedicated to making healthcare for adults with autism and intellectual disabilities accountable and effective. The Right Care Now Project is dedicated to assuring that all adults with autism or ID have access to appropriate, timely care. It does this by developing care standards and novel monitoring systems informed by its research, service and educational activities. www.rightcarenowproject.org

Nudging, Teaching and Tracking

The information in the system creates three important tools that alert caregivers and doctors that important medical attention is necessary, and what to do next. With these tools, people can get the care they need from a system that now can meet their needs. *(see Figure 1).*

1) ***The Health Risk Report:*** *This is a notification generated after each quarterly data-entry session that gives the caregiver, DSP and/or guardian/advocate a list of potential health issues that need to be addressed. Each time the system flags a problem, that problem is listed on the person's report, along with recommendations for what the caregiver should do next, and how to alert the provider of the issue. Problems that appear in consecutive quarterly reports are flagged and sent to caregivers/DSPs as Risk Alerts. This tracking helps prevent issues from being ignored.*
2) ***The Health Summary Passport:*** *This report, accessible anytime, communicates to doctors and other providers the important information necessary to give proper care. It includes specific descriptions of the person's baseline function, changes in function, new or ongoing physical or behavioral problems they may be experiencing, their health and medication history, and also includes recommendations for the provider to assess and manage the issues flagged by the system. For practitioners not familiar with the health issues common in people with IDD, it is a roadmap to guide proper assessment and referrals. For those providers who are skilled but need the important information that is often not available at the visit, the Health Summary Passport is an invaluable source of data to create a plan for evaluation and treatment.*
3) ***The Quality Report:*** *The Right Care Now Project Health Support System can also inform organizations who care for a group of people how well they are doing to make sure their clients have optimal care and health. It gives the organization information on over 40 indicators of good care and health. From the percentage of people who have gotten preventative care, to the percent with falls or pneumonia, the report can guide the organization to make sure they're doing everything to fix problems and prevent crises. It also allows them to identify the individuals affected by care issues, so they can perform direct supervision, to be sure all issues are addressed.*

Because the RCNP system is built on eClinicalWorks electronic health record (EHR) technology, its information can be shared directly with EHRs used by each person's doctor. However, unlike a doctor's office EHR, which is controlled by providers and functions like a billboard, the RCNP system is interactive and prompts timely action. Guardians and advocates can also use the system to understand health issues that need attention and to help make sure that all health needs are addressed quickly and effectively.

We have designed the RCNP Health Monitoring System to empower adults with IDD to overcome the information and communication barriers that have long prevented them from getting the care they deserve. It is our hope that everyone will get the care they need from all their providers, regardless of their location or their ability to access a special clinic. No one should have to get care from their pediatrician well into adulthood, and all of us have a right to timely, effective healthcare. •

ABOUT THE AUTHOR:

Susan Abend, MD, FACP is the Chief Executive Officer of The Right Care Now Project.
www.rightcarenowproject.org

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The public badly needs exposure to this segment of the autism population, the one that nobody writes the "feel-good" stories about. The one that makes some of us uncomfortable. The one that will never star in a television series.

FOR OUR CHILDREN WITH SEVERE AUTISM, SPEAK LOUD, SPEAK PROUD

BY KIMBERLEE RUTAN MCCAFFERTY

A couple of weeks ago, while procrastinating from what I should have been doing and scrolling through Facebook, I saw a post that immediately caught my interest. It was from the National Council on Severe Autism (NCSA) which I had never heard of, and the title read "Suffering in Silence: The Dark Side of Autism."

PHOTO PROVIDED BY KIMBERLEE RUTAN MCCAFFERTY

SPEAKING OUT: I want the world to see him as I do, a kind-hearted, intrinsically happy almost-man, and I also share the fear I've felt when dealing with my son's meltdowns, my anxiety for his future. I do this in part so that some other parent out there going through this will not feel so alone.

> ***I actually put down my chocolate for better scrolling access,and I never put down my chocolate for anything.***

I read the article by a mom out in California who spoke about an incident she had lived through with her 11-year-old severely autistic son, one which culminated in the California Highway patrol pulling up behind her as she parked her car on the highway and hoped to quell the rage her son was displaying toward her so she could safely leave. Both her love and fear for her son came through in every sentence, as well as her heartache in knowing that an attempt to take him ice skating could end this way.

I personally have a 15-year-old severely autistic son with accompanying OCD, tics, and intellectual disability. Justin and I have a profound connection – this is a child who kisses me even when he doesn't want anything and hugs me on a frequent basis. We have a bond that through insomnia, aggression, refusing to eat, soul-sucking OCD and, last year, also a terrible movement disorder, has remained true and strong.

I write a blog about him, Autism Mommy-Therapist, because I want the world to see him as I do, a kind-hearted, intrinsically happy almost-man, despite his challenges. And yet I also share about his incidents of aggression, the fear I've felt when dealing with my son's meltdowns, my anxiety for his future. I do this in part so that some other parent out there going through this will not feel so alone. I also do this for my own mental health, because it's important that I have an outlet to share my experiences with my severely autistic child.

ABOUT THE NCSA

NCSA NATIONAL COUNCIL ON SEVERE AUTISM

The NCSA focuses on the burgeoning population of children and adults affected by severe forms of autism or related disorders. This population includes those who, by virtue of any combination of cognitive and functional impairments, require continuous or near-continuous, lifelong services, supports, and supervision. Individuals in this category are often nonverbal or have limited use of language, have intellectual impairment, and, in a subset, exhibit challenging behaviors that interfere with safety and well-being.Learn more at www.ncsautism.org

And I do this in the hopes that more parents will share their stories, and this underserved segment of the autistic population will finally get the attention, and the services, they deserve.

Stories of high-functioning autistic children and adults are easy to find. As the mother of a 12-year-old on the mild end of the spectrum, I want him represented too. However, my eldest son is nothing like the protagonist on *The Good Doctor,* and yet he also deserves to have his story told. The public badly needs exposure to this segment of the autism population, the one that nobody writes the "feel-good" stories about. The one that makes some of us uncomfortable. The one that will never star in a television series.

Autism acceptance is not just for the high functioning. Those of us with children and adult children on the more severe end of the spectrum need to tell their stories and have them be heard. Many of our children are silenced by the inability to speak or communicate through a device.

Their realities should not be silenced too.

I am thrilled with the creation of the NCSA. This is a platform for families with severe autism to finally have a strong voice. I am actively for any organization which can help my kids, and hopefully, with time, we will see NCSA as a major contributor to the goal of realizing safe, happy and productive lives for those severely affected.•

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.

CHOOSING LIFE FOR A CHILD WITH DOWN SYNDROME

BY EMILY BRITTINGHAM

Amid the growing rate of abortion in fetuses with Down syndrome, Dr. Rick Rader, EP Magazine's Editor in Chief, and I sought to bring some positive attention to families who have chosen to keep or adopt a child with Down syndrome and explore with them the array of emotions, challenges, and blessings that have come with that choice.

PHOTOS PROVIDED BY EMILY BRITTINGHAM

As the abortion rates in the United States climb to 80 and 90 percent, it is important to support families who have been given a Down syndrome diagnosis. Lisa and Bekah assert that it is interaction and education that can prevent and lower these abortion rates.

I was given the opportunity to interview two women about their experience raising children with Down syndrome. Lisa is a mother to five children, and her third child, Jordan, was born with Down syndrome. Bekah is the mother of Millie, her adopted daughter with Down syndrome, and Josie, her biological daughter. There are four questions in this article that I asked Lisa and Bekah, but the rest of the interview was led by these two women who shared their honest journey of raising children with Down syndrome.

What do you think the abortion rate for fetuses with Down syndrome is?

I started each interview by asking what each mother thought the current rate of abortion for fetuses with Down syndrome is in the US.

Lisa: Lisa stated that in the 70's, the abortion rate was 90%, which was then followed by a decline in the 80's and 90's due to a show on television featuring a child with Down syndrome, *Life Goes On*. Lisa correctly predicted the current rate to be between 80% and 90%.

Bekah: When I asked Bekah what she believed the abortion rate to be, she stated that she didn't look up the statistics because they were too upsetting to her, and that as the abortion rate climbs, Bekah fears that Millie won't have any friends that look like her.

Why did you decide to keep/adopt your daughter?

Lisa: When I asked Lisa why she chose not to terminate her pregnancy, she informed me that she never went through testing

BEYOND COMPARE: *(Opposite page)* Bekah and Millie; Bekah said that she has known since she was a child that she would adopt a child with Down syndrome. *(Above)* Bekah expressed that the biggest difference in raising her two girls has been watching Jojo, who was born without any medical problems, not need her as much as Millie did.

FIRST COMES LOVE: Jordan *(third from right)* poses with her family on sister Peyton's wedding day; Her mother describes her as her own best advocate and ambassador because people have positive experiences when they meet her. Lisa has met with mothers who have been given a fetal Down syndrome diagnosis and brings pictures of Jordan to show how beautiful life is with her in their family.

beyond standard prenatal screenings because there is a high rate of false positives and an increased risk of miscarriage with testing (Spencer 2003). Lisa had a typical pregnancy with normal sonograms. It wasn't until after birth that Lisa and her husband were told that Jordan had Down syndrome. When I asked Lisa what went through her mind when she was told that Jordan had the physical markers indicating Down syndrome, she stated that her thoughts felt "uncontrollable" and that she was appalled by them. Lisa describes those thoughts as a "piano playing" because they played over and over in her mind. Lisa said that she looked in the mirror and thought that even though she was now the mother of a child with special needs, she didn't look any different. It was in that moment that the Lord gave her peace of mind and orchestrated a "profound spiritual experience" by reminding her that He would show who He is through Jordan. Lisa said that she then walked to the nursery and knew that she would do anything to protect her baby, that Jordan has a purpose.

Bekah: Bekah and her husband adopted Millie and brought her home as soon as she was released from the hospital. I asked Bekah why she chose to adopt a child with Down syndrome, and she said that she has known since she was a child that she would adopt a child with Down syndrome. Bekah's aunt had a close friend whose son has Down syndrome, and Bekah was able to spend time with him while growing up. Bekah stated that when she was around him he "taught her so much". Bekah's aunt always celebrated him and made Down syndrome "nothing to fear." This is what initially fueled her desire to adopt a child with Down syndrome. Bekah and her husband made the choice to adopt after they had been married for three years, and it took another year to adopt Millie. To read more about the details of their adoption story you can visit Bekah's blog, Behnke Farms. Bekah and Millie's biological family have an open adoption, and Millie video chats with her birth family once a month. Millie's birth parents also attend all of her birthday parties and join Millie and her family on vacation once a year. I asked Bekah if she could divulge why Millie was chosen for adoption and if it was hard to "share Millie" with her birth parents. Bekah explained that keeping Millie away from her birth parents would be withholding love from her and that what is important to know is that Millie's biological family didn't choose adoption because they don't love her, instead it is the opposite. For Bekah what's most important is that they love her and chose to give her life. In Bekah's words, "that is an unbelievably big love." Bekah spoke about the bond she and Millie's birth mother share, stating that it extends beyond Millie and that they are truly friends. As a result, Millie will know all of her history, and the people who have contributed to it, which makes her who she is.

How has raising a child with Down syndrome been different than raising typical children?

Lisa: Lisa's biggest concern upon giving birth was the health problems Jordan might face and that she might be letting her children down. Instead, Jordan has thrived without any major health problems. Lisa's kids "adjusted beautifully" to having a sister with Down syndrome. Lisa stated that she felt like it was an advantage for her children to have a sister with Down syndrome because her children were able to meet and interact with other children who have special needs and were not afraid of them. Instead it gave them a "depth of character." Lisa expressed that the biggest difference between Jordan and her other children were the milestones, as Jordan took longer to reach them than her other children. For example, Jordan chose not to walk until she was 2.5 years old. Jordan also received speech therapy, and Lisa expressed that language is Jordan's biggest area of delay. Jordan chooses not to speak when she can get her point across in other ways. However, Jordan has experienced many typical milestones. She is a junior in high school, works at a local Mexican restaurant and consignment store twice a week, and is looking into a college program at West Georgia for adults with disabilities.

CHARACTER COUNTS: Jordan's siblings adjusted beautifully to having a sister with Down syndrome. Her mother believes it was an advantage for her children to have a sister with Down syndrome and that it gave them a depth of character.

Bekah: Bekah and I talked about the recent shift in her life from raising a child with Down syndrome to raising their newest daughter, Josie (Jojo). Millie was born with a heart defect and low muscle tone. As a result, she needed an NG feeding tube along with open heart surgery. Jojo, on the other hand, was born without any medical problems. Bekah expressed that the biggest difference in raising her two girls has been watching Jojo not need her as much as Millie did. Millie is still largely nonverbal and will communicate through signs and small phrases or simple words. Bekah shared that Jojo, who is nine months old, has passed milestones that Millie was achieving at 17 months old. Bekah described these differences with the phrase, "Babies with Down syndrome keep a little longer," a phrase that a friend shared with her. Bekah also talked about how Millie can become overwhelmed easily and will be reluctant to use her voice. Like Jordan, Millie chooses not to talk. Bekah reminds Millie that "her words matter" and that she "cares about what [Millie] has to say." Bekah also added that "raising any two children is so different. Every child is so different. We have made it our goal to celebrate each child for [who they are]. We want to soak in every part of that child's best and celebrate them fully for who they are. God made them perfectly. We celebrate His creativity."

What would you say to mothers who are considering aborting their child with Down syndrome?

Lisa: Lisa would ask moms to educate themselves and to spend time with a family that has a child with Down syndrome. She would also ask mothers to research the high false positive rate in prenatal screening for Down syndrome and tell the mothers that a Down syndrome diagnosis is not a death sentence. Instead, having a child with Down syndrome is the exact opposite. Lisa describes Jordan as, "her own best advocate and ambassador" because people have "positive experiences" when they meet her. Lisa has also been given the opportunity to meet with mothers who have been given a fetal Down syndrome diagnosis and brings pictures of Jordan to show how beautiful life is with her in their family.

Bekah: Bekah would tell new mothers with a fetal Down syndrome diagnosis, "Congratulations!" She would also ask moms to "slow down, research, and look at the information and advice from their own lens" rather than looking at it from the eyes of people who do not have children with Down syndrome or medical professionals encouraging an abortion. Bekah would encourage mothers to ask themselves, "Is there a beauty I haven't seen yet, and will this change my life?" Bekah's answer is yes, life will change in the best way.

As the abortion rates in the United States climb to 80 and 90 percent, it is important to support families who have been given a Down syndrome diagnosis. Lisa and Bekah assert that it is interaction and education that can prevent and lower these abortion rates.

For further information on the statistics behind fetal Down syndrome abortion rates and false positive prenatal screenings, please see the references listed below.

ABOUT THE AUTHOR:

Emily Brittingham received her undergraduate degree in Psychology from Berry College and is currently working towards a degree in Occupational Therapy. She lives in Tennessee with her husband, Hunter, and Goldendoodle, Daisy. Emily works at the Orange Grove Center where she enjoys advocating for, and serving her friends there.

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Think of it this way: If everyone wanted to put such a premium on the ability to walk that it affected one's salary or career track, then people who use wheelchairs would rightfully object. Well, people whose emotions develop differently should be equally upset over how the concept of EI is being applied.

ARE CORPORATE AND EDUCATIONAL USES OF "EMOTIONAL INTELLIGENCE" GROUNDS FOR DISCRIMINATION UNDER THE ADA?

BY MICHAEL JOHN CARLEY

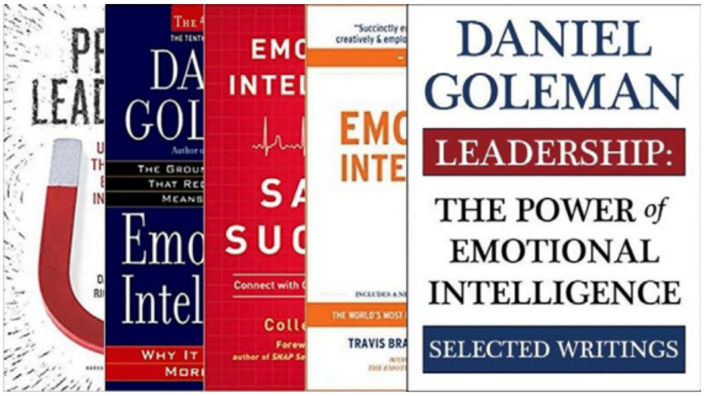
Over the last ten years, both business leaders and educators have increased their usage of "Emotional Intelligence (EI)," a tool that attempts to measure a person's ability to understand not only their own emotions, but also the emotions of others. First introduced in 1990 by psychologists Peter Salovey and John Mayer, EI only really burst onto the scene following the publication of Daniel Goleman's 1995 book (also called Emotional Intelligence*). Originally just a theoretical way to break down the capacity for empathy, EI's modern value resides in the theoretical ability to read an individual's capacity for emotional regulation, and to work with others in a collaborative setting.*

DDespite the variety of arenas in which EI is now employed, the business world has embraced it the most, especially in companies' hiring, employee evaluation, and professional development strategies. The business world, after all, loves metrics, and their embracing of this concept has arguably morphed from "usage" to "reliance" very quickly. In an era where data has never been more sought after, many executives believe there is a direct correlation between employee productivity and a high EI score.

EI herein, is one component of our newfound love of data. And the competition for new information has created a race so large that it has escalated into the need for an even newer category, "metadata" – which can be defined as "data that studies data."

But what has yet to be examined is that low scores on an EI test can then be assumed to reduce a person's chances of obtaining or even keeping a job, and therefore could alter the individual's career track even if they are successfully completing their job requirements. And since many non-apparent disabilities contain life experiences wherein people are often ostracized or left out of "developmentally-appropriate" life markers throughout youth and early adulthood, two conundrums are immediately posed: 1. Is it therefore a violation of the Americans with Disabilities Act (ADA) to subject an employee with a disclosed developmental disability to an EI screening of any kind? And 2. If so, are companies actually even aware that such practices are illegal?

I too, as a data-loving individual on the spectrum, embraced the concept of EI at first, wondering if it could help the spectrum world to improve its ability to decipher non-verbal communication. But I then began to wonder if the rush to embrace such time-saving data was causing us to unwisely bypass necessary examinations regarding context, and/or critical thinking.



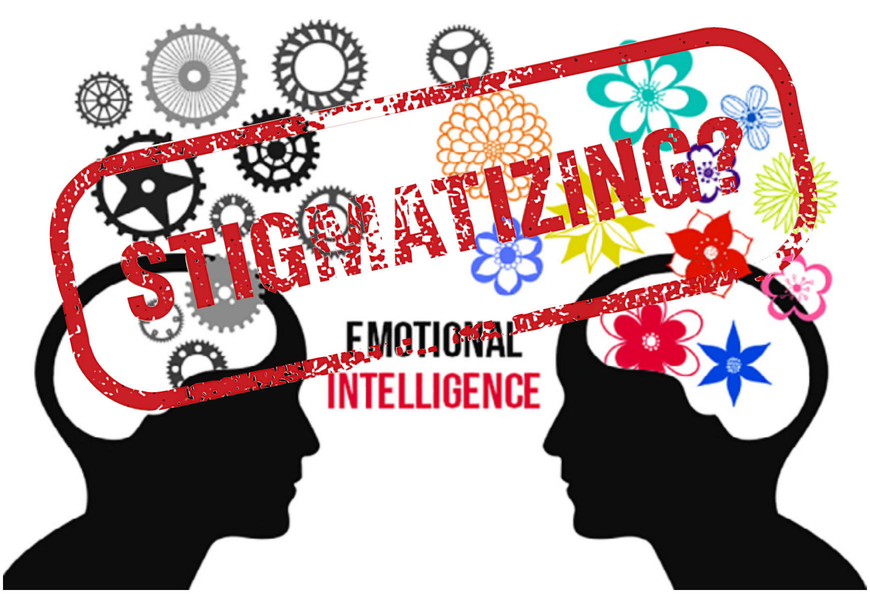
BOOK SMART?: Emotional Intelligence has become a large-selling topic in the business publishing world. The business world's embrace of EI has morphed from "usage" to "reliance" very quickly.

A SHORT HISTORY OF "EMOTIONAL INTELLIGENCE"

Though the idea has been taken to a variety of definitions since even Goleman's book, the original concept of Salovey and Mayer involved four categories:

1. *Perceiving Emotions*
2. *Reasoning with Emotions*
3. *Understanding Emotions*
4. *Managing Emotions*

Soon, tests emerged to rate an individual's capacities for EI, and quickly became enormously popular with (especially large) corporations. Additionally, those who work with these companies in advisory roles evolved in their footsteps. Risk management firms, though initially slow to embrace the concept of EI, have since fallen head over heels with using it both as a sales device to draw business, and as a fix-all training method with new clients. Firms such as TalentSmart have also sprung up, that focus only on products created around the hyperbole of EI – and this strategy appears to have benefited them greatly, as TalentSmart lists over 150 Fortune 1000 clients on their website.[1] Other corporate consulting firms have followed suit, propelled by articles from *Forbes*,[2] *Inc.*,[3] and the *Harvard Business Review*[4] that extol EI's virtues. And lastly, from the many HR, and Corporate Diversity and Inclusion (D&I) conferences I've spoken at, I can certainly attest to the enthusiasm I've seen for the use of EI in the workplace, even to the point of some companies and consultants believing EI to be a foolproof means of overcoming Unconscious Bias – the hidden prejudices we all may have, but are as yet unaware of.



SKEPTICS VIEW: The concept of Emotional Intelligence has not evolved without criticism. Many have called it a "hallucinatory desire" to break down feelings into a math equation, and believe that, by definition, emotions cannot be accurately measured due to their intangible nature.

But EI has not evolved without criticism. Many have outright panned EI, calling it a "hallucinatory desire" to break down feelings into a math equation. Further, cynics believe EI to be a Sisyphean pursuit; in that by definition, emotions cannot be accurately measured due to their intangible nature. Amidst the many tests that have been developed (estimated between two to three thousand, with no licensing mandate or accountability), a decent percentage of these examinations are self-given despite the common knowledge that, to quote a 2014 piece on EI in *The Atlantic*,[5] *"abilities cannot be accurately measured with self-reports."* Even the *New York Times*-owned, but now defunct About.com, ended their definitions of EI with a self-test. Moreover, the emotional capabilities of *the evaluator* must also come under scrutiny, yet is not, when conducting EI exams that are not self-administered.

Despite the cautions, a supposed ability to perceive the thoughts *and* emotions of others, and react to them, has been quantified to the satisfaction of many. And in many large companies, a blanket love affair with EI seems to have caused many employees with disclosed, non-apparent disabilities to be subjected to tests that cause them to appear less capable even (again) when they are satisfactorily meeting all of the requirements of their job. Such separation is important because with neurological conditions like autism spectrum disorders, learning disabilities such as Attention Deficit Disorder (ADD), Attention Deficit Hyperactivity Disorder (ADHD), or many mental health conditions, feelings herein grow differently. In varying levels, emotional regulation is a challenge for anyone with Executive Functioning issues, and overall emotional underdevelopment is often a telltale sign for many of these non-apparent conditions. Emotions herein not only evolve at a different pace, they also can mature at differing levels, and in rarer instances certain emotions may never even surface.

Probably the greatest documented value of EI as a tool exists not in corporations, but in our educational system, where the rising popularity of EI gave birth to the dozens of emotional literacy programs now employed by tens of thousands of schools. Studies reported on in a 2014 *New York Times* article[6] determined that kids who get these programs at an early age were "*more likely to do well at work but also to have longer marriages and to suffer less from depression and anxiety. Some evidence even shows that they will be physically healthier.*" Though author Jennifer Khan's piece was not without skepticism, her article added that, when it came to career and personal success, emotional recognition might factor more so than academic achievement.

And in the aforementioned article in *The Atlantic,* author Adam Grant made a great case that EI is not – as most "corporatespeak" implies it to be – synonymous with personal character. The piece notes how EI projects the ability to manipulate emotions as well as understand them, citing not only Martin Luthur King, Jr., but also Adolf Hitler as extreme examples of this talent. The article also pointed out what some, but not all of the corporations who use EI…understand: that while it's a noticeable benefit to socially-oriented positions such as sales, it has actually been proven to be a detriment in less-social vocations such as scientist, data entry person, financial analyst, or auto mechanic.

Finally, many clinical professionals object not only to the notion that high EI indicates that the beholder of a high test score is a good person, but also that EI is an "intelligence" of any kind. They seem to concur that EI is an entity of its own, outside of brains, good intentions, or even personality.

WHERE CORPORATE USE OF EI IS INDISPUTABLY LEGAL, AND WHERE IT IS QUITE POSSIBLY ILLEGAL

Nothing illegal exists in the use of EI during the hiring and onboarding process, as usually no disclosure of a non-apparent disability occurs before or during these stages by the prospective candidate. Like anything else containing protection under the ADA, disclosure is a must. No one can expect protection or accommodations at any stage of their careers without first having disclosed their condition with their employer, and then subsequently having requested reasonable accommodations.

STRESS TEST: A blanket love affair with EI seems to have caused many employees with disclosed disabilities to be subjected to tests that cause them to appear less capable even when they are meeting all of the requirements of their job.

However, if a disclosure of any developmental disability should occur during these hiring stages, it stands to reason that this changes the legality of using EI during their interview process. By definition, EI discriminates against those with slower emotional development.

But if a disclosed employee is well into their tenure at a particular company – with a position that does not demand great socialization to complete the work – and they are then told that they must partake in one of these quantifiable exams, herein is where the real illegality might appear, especially if the result of the assessment would then be entered into their personnel file. Of the two employment law specialists I talked with (both of whom have written about EI's use in the workplace), neither could answer the question – of legal vs. not legal – directly, leaving me not with the feeling that they didn't know the law, but that this idea of EI contrasting with the ADA was new territory for them as well.

Granted, as one senior human resources leader from the financial services sector stated; *"All tests have the possibility of resulting in a disparate impact against a given population."* A test, after all, is intended to produce a distinction between those who score well, and those who do not, and this will never not be the reality. But certain examinations are known to have biases wherein one population, just based on their cultural upbringing, might score better than those from a more marginalized group – one controversy that immediately comes to mind are the complaints that African-Americans historically have made towards the New York City firefighter exam.[7]

And according to six of the 46 HR and D&I professionals I contacted (interestingly, all of whom requested anonymity) the love affair with EI is blinding their companies to even the concept that this might be illegal. As a result, their companies are implementing across the board testing with their entire employee base. No one I contacted suggested their company was in full knowledge of any legal boundaries and oddly enough, I contacted these individuals about their hiring practices only. They themselves volunteered the correlation regarding existing employees.

Now, one grey area that still remains is if the disclosed employee agrees to take the test, does it then become legal? Herein, there lies further room for legal exploration though it is safe to say that companies would be wise to refrain from asking these employees to participate, and equally wise for the employees, if asked, to politely refuse.

OVERVIEW

The recent criticisms of EI in the aforementioned *New York Times* and *Atlantic* articles are fair and diplomatic. But while they put new scrutiny on the praise bestowed on those with high EI scores, they refrain from criticizing the stigma given unconsciously to employees with *low* EI scores. Again, we who are diagnosed with non-apparent disabilities not only grow differently on an emotional level, but some of us also grow with fewer, or even more, emotions; so that the question of "what emotions exist" must be taken into the same consideration as "when do emotions enter into maturity." And under the current corporate climate, to say that a low EI scores contains no indirect negative consequences to the employee... this is, at best, ignorant.

The problem doesn't persist because companies wish to ignore the ADA, or because anyone's trying to ostracize certain employees. The issue seems to exist due to many factors, including an overconfidence in EI's value as an assessment tool, and also because the Diversity & Inclusion (D&I) strategies of most large companies are surprisingly antiquated. From my consulting experience over 80% of the D&I departments in Fortune 1000 companies should be called "Race & Gender departments," as most barely mention the other traditional aspects of D&I (disabilities, sexual orientation, and veteran status) – this material just isn't even on their radar. Though the greater job is by no means accomplished with racial and gender equality in the workplace, most of the D&I departments I've come across are there only for show, some minor instruction about unconscious bias, and for legal compliance. Whether these D&I leaders wish to shape their strategies towards giving equal weight to every marginalized community – a near impossibility – or not, one professional I spoke with bitterly believed that a lack of accountability contributed to his firm's D&I department remaining "narrow-minded." *"Regarding our directives,* [our D&I executives are] *stuck in 1985 even if our language is present-day… without exception they all believe themselves to be 'Thought Leaders.' And… they resent being asked to expand their thinking."*

Think of it this way: If everyone wanted to put such a premium on the ability to walk that it affected one's salary or career track, then people who use wheelchairs would rightfully object. Well, people whose emotions develop differently should be equally upset over how the concept of EI is being applied.

Finally though, some fault also has to lie with the disclosed employees who have these non-apparent conditions, as it is a very rare instance where these individuals both understand and acknowledge any existing, relative emotional underdevelopment caused by their diagnosis. Granted, an inability to emotionally regulate is no easy element of one's disability to own up to; but to ensure that they are protected, our population would be wise to make foregoing such testing a part of the reasonable accommodations they request in their workplace.

FULL DISCLOSURE: If a disclosure of any developmental disability occurs during hiring stages, this changes the legality of using EI during their interview process. EI discriminates against those with slower emotional development.

CONCLUSION

There are lots of reasons why a seemingly-intelligent culture could buy into the snake-oil medicine of measuring an emotion, many of which we've hopefully discussed. But EI's main attempt to quantify the unmeasurable arguably stems from our collective over-excitement (soon to be over-reliance) on data. The use of data wouldn't be a bad thing if it was universally used to elicit truth, and eloquence. However, the attractiveness of data unfortunately also revolves around data's ability to *superficially* prove truths, or to lie. Data guru, Nate Silver, paradoxically tells us that *very few* people really know how to use data. Well, image and compliance-concerned D&I departments probably don't fall under this category.

A perfect example of the desire to use data to lie was found in my local public school district in Green Bay, Wisconsin. As a school consultant, I try never to turn down a conversation with a special needs parent or teacher from our school community, and none have anything good to say about the leadership currently in place. One study that one district administrator boasted to me about (trying to convince me what a great job they were doing) contained the quagmire that those parents who were too incensed over past injustices… had not taken part in their study.

But instead of allocating their absence to the more truthful "I am not happy" column, their absenteeism was placed into a "Did not participate" column, therefore giving the information the inaccurate stamp of neutrality, rather than disapproval. And this obviously gave the district a false seal of approval from their parents.

No matter how blatant the Green Bay public school district's disingenuousness might have been, the overall effort was successful for them. They were reporting the "positive figures" to school and other community boards that didn't understand data either. Ergo, said boards could not contest the district's inaccurate findings. But as heinous as this might sound to some, I'd guess that the same strategy is utilized by school districts and D&I departments all over the country.

But rather than try to quantify out who has the brains to use data vs. who does not, it's probably more feasible as well as healthy for us maybe instead to question *why* we love data. For starters, the Trump era has blatantly shown us that facts mean infinitely less to the greater populace than they used to, or that we want them to. As a means of coercion, truth has lost the majority of its power. And that's not all bad.

Whether EI is illegal, or useful, or not, it seems at least to be a fabricated construct – bordering on religion – that is clearly at odds with the disability community's ongoing search for acceptance. And if this concept falls on deaf ears, then maybe we should begin to examine whether EI is worse. Is it instead a surprisingly conscious strategy to exclude people with non-apparent disabilities… to paint our lives as being of less value than theirs?•

ABOUT THE AUTHOR:

Michael John Carley is the founder of GRASP, a school consultant, and the author of ***Asperger's From the Inside-Out*** (Penguin/Perigee 2008), ***Unemployed on the Autism Spectrum*** (Jessica Kingsley Publishers 2016), the upcoming ***Book of Happy, Positive, and Confident Sex for Adults on the Autism Spectrum… and Beyond!***, and the column, "Autism Without Fear." In 2000, he and his son were diagnosed with Asperger Syndrome. When re-evaluated in 2014 under DSM-5, he was diagnosed with autism spectrum disorder. For more information on Carley or to subscribe to his updates, go to www.michaeljohncarley.com

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BOOK EXCERPT

In her book, Parents Under Pressure: Struggling to Raise Children in an Unequal America, Karen Zilberstein provides a candid look at how parents contending with poverty, illness, disability, or other constraints are expected to do so much with so little – and the price they and society pay.

PARENTS UNDER PRESSURE

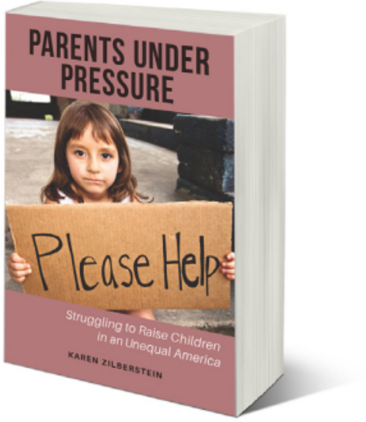
STRUGGLING TO RAISE CHILDREN IN AN UNEQUAL AMERICA

BY KAREN ZILBERSTEIN, LICSW

CHAPTER TWO EXCERPT

The System is Down *recounts the struggles of Victoria and Nathaniel, whose children suffer from multiple disabilities, and delves into the impact of America’s social service systems on families’ income, isolation and health.*

“Most parents push their kids too much,” said Victoria. “You have to be proud of them, just appreciate that they are walking and breathing.” She speaks with the authority of hard-earned experience. Only one of Nathaniel and Victoria’s two children walk, and even then, with a limp, although both can now breathe independently. Achieving that outcome has not come easily.



Title: **Parents Under Pressure: Struggling to Raise Children in an Unequal America**

Author: **Karen Zilberstein**

Publisher: **Levellers Press**
Publication Date**: March, 2019**
ISBN-13: **978-1945473791**
Available at levellerspress.com and amazon.com

When they were infants, the care of Olivia and Autumn, twins born premature and with cerebral palsy, took eighteen hours a day, sometimes more. An apnea monitor, which tracked Olivia’s breathing and heart rate, necessitated vigilant supervision. Steroids to enhance their lung functioning needed to be sprayed through their reluctant mouths. Each baby required feeding every few hours, and their mouths wiped clean afterwards so that they would not develop thrush. With weak musculature, they found digestion difficult, requiring the administration of medications for gastroesophageal reflux disease. Their tiny diapers needed frequent changing, and their monitors had to be unhooked and refastened before and after bathing. They were undersized and fragile, a constant source of concern.

A home health aide helped a few hours a day, but the majority of the care fell to Victoria and Nathaniel. The incessant attention to medical needs, frequent medical appointments, and endless worries created strain. “I had one experience when we had to bottle feed them,” remembered Nathaniel. “You had to support them and hold this tiny little bottle of formula with only about four drops, and they had to suck on the bottle, but you had to position their heads properly. And Autumn was choking. I was terrified. I said, ‘I can’t do this.’ There were all these insane challenges. We were constantly in a state of vigilance over medical issues. We weren’t in this happy afterglow.”

Autumn presented bigger challenges than Olivia. At nine months old, she started banging her head. Victoria and Nathaniel had installed swings for the girls in the doorway of the living room and Autumn would lean out of the swing in order to whack herself on the posts. They would carefully snuggle her back in, secure her in the swing, and pad the posts with pillows, but she continued to bang. Sometimes she banged with such vigor that she scarred herself and shook the house. She also started to rock, vigorously pulsating back and forth. She enjoyed humming, as well, producing a discordant, bitonal, and jarring sound. The banging and cacophonous hum, repeated endless times a day, pelted Nathaniel and Victoria’s nerves.

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Encouraging, but intermittent signs of progress punctuated Autumn’s repetitious behaviors. During her second year, she began to talk and respond. She would sit on the couch and ask for food, videos, or objects, delighting her parents. She progressed to one or two-word commands before her speech completely evaporated. As her skills slipped, so did hopes of a functional childhood. By age three, she had collected a variety of diagnoses: autism, cerebral palsy, gastroesophageal reflux disease, and chronic idiopathic constipation. When her sister started walking, Autumn was still tackling independent sitting. She never mastered toilet training.

IMAGES PROVIDED BY LAUREN HATHAWAY

Autumn's numerous medical conditions necessitated so much care and so many appointments that at times her twin got pushed into the background. Her parents wished they could spend more time talking, coloring, or playing dolls with her. They worried that they did not do enough.

"Because Autumn took so much," they said, "we felt like we didn't have time for other things, even our own relationship. And you feel guilty thinking you want that, because you are basically trying to keep your child alive and functioning and trying to push her forward."

> *"One in six American children live in poverty. One in six struggle with a developmental disability. An estimated 70 percent of American adults have experienced a traumatic event. Despite the overwhelming prevalence of these circumstances, societal expectations and the country's fragmented, under-resourced service systems make it nearly impossible for families experiencing hardship to keep up."*

Along with the daily demands of Autumn's care, a constant flow of unpredictable difficulties cascaded through the family's life, threatening to overrun its banks. Taking the girls anywhere involved a massive production of assembling and carrying equipment: wheelchairs, medicines, special foods, and large diapers and wipes, even when Autumn was full-grown. The equipment itself was vulnerable to malfunction. Autumn rocked so violently that she broke more than one of her wheelchairs. Without it, she could not attend school. In addition, as Autumn grew and put on weight, she became more difficult to manage, and Victoria could no longer lift her. Victoria threw out her back in one attempt, from which she never fully recovered. After the first few years, it thus became clear that Nathaniel's full-time presence at home was sorely needed.

The pressing issue was not just Nathaniel's time and labor, but also how his job affected family finances and services. His income, as well as their limited nest egg, turned out to be a hindrance, pricing them out of certain benefits. When he worked, the girls did not qualify for subsidized state health insurance or for Supplemental Security Income (SSI), the Federal income supplement program started in 1975 to help low-income individuals with disabilities. SSI only allowed $3000 in family savings and cut awards if families owned more. Other services, such as Personal Care Attendants (PCAs), which they sorely needed for Autumn, were only available to those with state health insurance.

Sorting out and applying for benefits took time. A labyrinth of bureaucracies confronted them, agencies and programs with their own twists, turns, obstructions, and dead-ends. Each required a suffocating amount of research, applications, coordination, and, all too often, battles. "It's constant," said Nathaniel, "it's been one challenge after another. While one system is helping, you are locked out of others through economics. Obtaining different programs or services is seen as double-dipping, but really, they cover different things. So, you need to do the research on services, become the experts, and try not to make an enormous mistake at the same time."

Services, however, are often in short supply and hard to procure. A lack of adequate funding perpetuates the problem, reflecting America's confusion about how much the care of distressed families should exist as a private, household concern or a public responsibility, whether individuals with disabilities are valued as assets or demonized as drains on society's coffers.

Throughout history, before industrialization and the primacy of the nuclear family, communal responsibility for children's wellbeing was more often the norm. Cross-culturally, in less wealthy communities, supervision and nurturance of children was augmented by alloparents, who could be fathers, grandmothers, aunts, siblings, or non-relative caregivers. Children's high caloric needs, extended period of dependency, and early weaning, which allows a mother to birth and care for multiple offspring simultaneously, rendered cooperative childrearing a necessity. Parents could not produce adequate resources for themselves and their children without the help of others.

The independent nuclear family, scrambling on its own to provide for children, emerged only recently. As populations increased in the Western world, families divided into smaller units, and resources became allocated unevenly, parental efforts focused more and more on helping their own offspring gain advantage, especially in those segments of society well-resourced enough to sit atop and succeed in the economic food chain.

The trend towards individual, rather than communal responsibility, has been accelerated by public policies and rhetoric. In the early 20th century, as the country faced the devastation of the Great Depression, the government showed greater interest in buttressing citizens' well-being. The Social Security Act of 1935 established a safety net that grew to aid the elderly, unemployed, poor, disabled, veterans, and others. Public benefits peaked in the 1970s, after which a stalling American economy, and policies tilted towards companies, led to reforms and cuts. By the 1980s, political philosophies inflating the message that individual choice, rather than social or public benefit, shapes success began drifting into family life.

"Part of the belief," said sociologist Linda Blum from her office at Northeastern University, "is that it is our responsibility to work on ourselves continuously. We must train our brains and maximize our physical health. When you are talking about kids, those tasks fall on mothers. Individual responsibility for that health maximization is very intense right now. People don't recognize that it's new. And they don't recognize what it is covering up, which is the lack of social and public responsibility."

The end result is that families like Victoria and Nathaniel's, who face demands that exceed their resources, are left isolated and struggling, without the supports they desperately need.•

ABOUT THE AUTHOR:

Karen Zilberstein, LICSW, is a practicing psychotherapist and Clinical Director of the Northampton, MA chapter of A Home Within, a national nonprofit that provides pro bono psychotherapy for individuals who have experienced foster care.

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WELCOME TO MY WORLD!

BY BEN COLLINS

Hello, my name is Ben Collins, and here is my story. I have been working at Special Olympics International in Washington, D.C. for 27 years, in the Marketing and Development Department as Operations Specialist. I sort and deliver the mail for the department, conduct donor calls two times a week to thank donors for supporting our programs, lead interviews and office tours, type Braille nametags, act as the department's co-budget officer, maintain the press kits, participate in Capitol Hill Day to get members of Congress to support Special Olympics, lead the team meetings, and send calendar invites.

PHOTOS PROVIDED BY STEPHANIE CORKETT / SPECIAL OLYMPICS

When I was nine years old, I was diagnosed with retinitis pigmentosa, or RP. I have tunnel vision and night blindness. I can only see shadows and shapes. Because I am visually-impaired, I have to listen very closely to people when they are talking to me. Growing up, when I was in school, I had a vision teacher and a mobility teacher. When I left school, my first job was working at a button factory, called A Major Production. It started out as a temporary position but led to a full-time job. I was there for two-and-a- half years.

At Special Olympics, I use three special needs equipment devices on my desk every day. The first is the visual tech which helps me do the mail every day at my desk. It's like a giant magnifying glass. It magnifies the print, and it works because I can see the shadows of the address label on the mail. The next thing I use is the computer. It's called the JAWS system. When people hear about the JAWS, they think it is a shark, but it's a computer program for people who are visually impaired. The last thing on my desk is a Braille typewriter. It has six keys, and I make Braille nametags for everyone in the office. It helps me find their desks, especially when I am giving tours to new employees.

Commuting to work can be hard for people who are visually impaired. I take public transportation every single day of the week. First, I ride on the bus in my neighborhood, and it takes me to Rockville Metro Station. Then I wait for the Metro. Then I take the red line to Farragut North Station, and every day I listen to all the sounds and voices to figure out where I am going. Everything on the train and the bus is voice-activated, so I can listen to where I'm going. Then I have a 10-minute walk from the station to work. The hardest part of my commute is when I have to cross two streets. When I cross the street, I listen for the traffic or ask somebody when it is safe to cross. I have to listen really hard to the sounds of the traffic. Because crossing those streets was so dangerous for me, I wrote an email to the D.C Department of Transportation, using my voice to try and get crosswalk-warning systems installed on my route to work. The Department of Transportation responded to my email right away and met me outside the street to take photos and talk to me. They promised to install the crosswalk-warning systems and, in a month, they had! My commute is much easier now and I feel safer when I cross the street and go to work.

> "I WISH THAT I COULD TALK TO EVERYONE WHO JUST LEARNED THEY HAVE RETINA PIGMENTOSA OR OTHER VISUAL IMPAIRMENTS, TO LET THEM KNOW THAT LIFE'S AN OBSTACLE COURSE, BUT YOU CAN GET AROUND THE OBSTACLES."

WORLD BEATER: *(Opposite page)* Ben competes in powerlifting with Special Olympics Maryland; *(Below)* Making phone calls at Special Olympics headquarters, and showing off a medal from USA Games (photo credit: Sally Cohen)

ON THE BALL: *(Above left)* Ben throws a bocce ball during a state competition; *(right)* Ben meets with Anthony from the Department of Transportation to discuss crosswalk warning systems for his commute.

I wish that people closed their eyes for five minutes every day, or tried to walk outside to see what it's like for somebody like me. If I didn't have my folding cane, I would run into tables, chairs, trees, walls, or anything on the ground. I wish that people would wear a blindfold to see what it's like for people who can't see at all, and that's why I always say, "Welcome to My World."

This year, I went to the Special Olympics USA National Games in Seattle, Washington. I participated in the sport of bocce for Team Maryland. I won two silvers and a bronze medal. For me, I have to listen to the voices of the officials to tell me where the polena is. A polena is the little ball that is thrown down the playing field to start a game of bocce. The official stands over the polena and he/she asks, "Can you hear me?" If I can't hear him or her, I ask them to say it again. Then I roll the ball. I usually roll the bocce ball against the wall because it is good strategy. Bocce is a game where players need to see where the polena is. I have to picture the field of play in my mind and use the sound of the official to help guide me when I throw the bocce balls. I have been a Special Olympics Maryland athlete for 39 years, and the USA Games was my first time competing outside the state of Maryland. I also compete in powerlifting.

I wish that I could talk to everyone who just learned they have retina pigmentosa or other visual impairments, to let them know that life's an obstacle course, but you can get around the obstacles. Sometimes I get frustrated because it is hard when you can't see anything, but I have a good full life, and you can do anything when you put your mind to it!

Don't underestimate me! •

ABOUT THE AUTHOR:

Ben Collins has been with Special Olympics International in Washington, D.C. for 27 years, with the organization's Marketing and Development Department.

FROM OUR FAMILIES... TO YOUR FAMILIES

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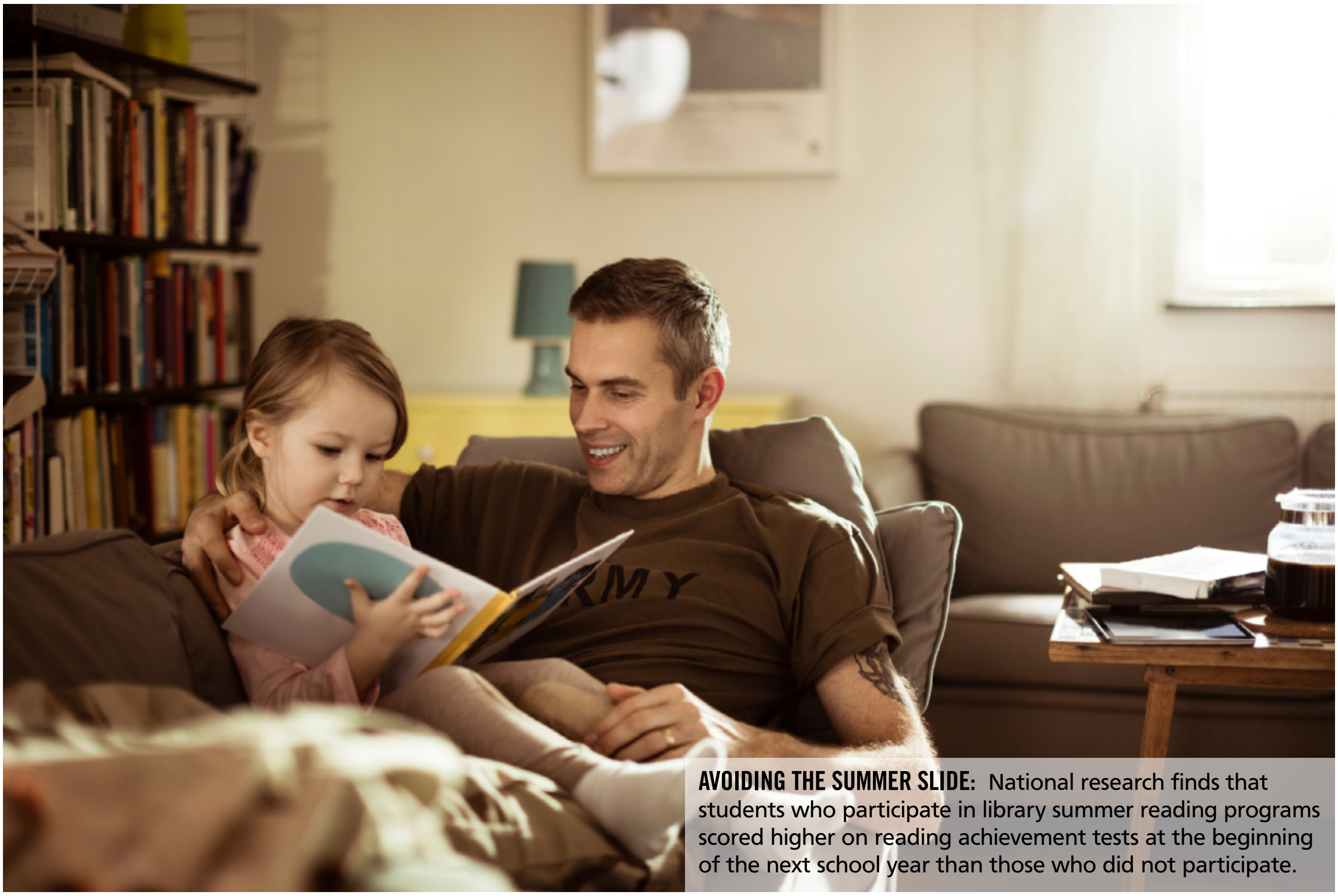


AVOIDING THE SUMMER SLIDE: National research finds that students who participate in library summer reading programs scored higher on reading achievement tests at the beginning of the next school year than those who did not participate.

Morale, Welfare and Recreation develops all kinds of enrichment programs to support force readiness and military community. One such program is the Department of Defense-MWR Summer Reading Program.

The program's theme this year is "It's Showtime at Your Library." Department of Defense-MWR libraries will feature all types of performance, from movies and theater to puppetry, dance, poetry, videos and more. Reading promotes family time for all ages. That's why children, teens and adults can enroll in this year's summer reading program at **www.ila.org/dodsumread** .

ENCOURAGE SUMMER READING

The mission of the Department of Defense-MWR summer reading program, through a contract with the Illinois Library Association iREAD Reading Programs, is to provide the resources and experiences to bridge the summer gap, while inspiring literacy and life-long learning. The benefits of summer reading are clear:

- *National research finds that students who participate in the library summer reading programs scored higher on reading achievements tests at the beginning of the next school year than those who did not participate.*
- *Avid readers of all backgrounds are higher achievers than students who seldom read.*

- *Skillful, critical and prolific reading is one of the most important personal habits that leads to a successful academic career and happy, productive life.*

Plus, reading is fun for the whole family. Reading can lead to priceless conversations, spur a child's imagination and inspire young readers to explore creativity and design new worlds.

Sign up for the Summer Reading Program: contact your local Morale, Welfare and Recreation installation library at **https://installations.militaryonesource.mil/**

EXPLORE YOUR INSTALLATION LIBRARY

The Department of Defense and MWR oversees the management of 207 libraries on military installation (**www.militaryonesource.mil/recreation-travel-shopping/recreation/libraries/explore-the-library**), which provide much more than aisles of books. Check your installation library to see what events are offered. These could include activities, graphics, crafts, reading lists, incentives, films, and more for children, teens and parents. Discover what's in your installation library.

TAP INTO THE MWR DIGITAL LIBRARY

If you're a member of the National Guard or reserve or don't have access to a local installation library, you can still participate in the Summer Reading Program virtually. Learn more at **https://dodvirtualsrp.beanstack.org/reader365**

The MWR Digital Library (**www.militaryonesource.mil/recreation-travel-shopping/recreation/libraries/morale-welfare-and-recreation-digital-library**) can help you support your summer reading goals, giving service members and families access to eBooks, audio books, digital magazines, genealogy resources, digital newspapers, journals, tutoring services and more. The digital library service is a particularly helpful benefit for those military families who may not have access to installation libraries. The digital library service is available through your service branch:

- Army digital library **mwrlibrary.armybiznet.com**
- Marine Corps digital library **mccs.ent.sirsi.net/client/en_US/default**
- Navy digital library. **www.navymwrdigitallibrary.org**
- Air Force digital library **airforce.libraryreserve.com**

– Military One Source

IT'S SHOWTIME : SUMMER READING 2019 AT DOD-MWR LIBRARIES

Visit the following links to learn more about the MWR Digital Library and other library and reading resources:

DEPARTMENT OF DEFENSE: MWR SUMMER READING PROGRAM

www.ila.org/dodsumread

MORALE, WELFARE AND RECREATION DIGITAL LIBRARY

www.militaryonesource.mil/recreation-travel-shopping/recreation/libraries/morale-welfare-and-recreation-digital-library

DOD MWR LIBRARY RESOURCES

www.militaryonesourceconnect.org/achievesolutions/en/militaryonesource/Content.do?contentId=27777

FROM AUDIOBOOKS TO ACADEMIC RESEARCH, THE DIGITAL LIBRARY HAS IT

www.militaryonesource.mil/recreation-travel-shopping/recreation/libraries/from-audiobooks-to-academic-research-the-digital-library-has-it

EXPLORE THE LIBRARY

www.militaryonesource.mil/recreation-travel-shopping/recreation/libraries/explore-the-library

LIBRARIES – THE ESSENTIALS

www.militaryonesource.mil/recreation-travel-shopping/recreation/libraries/libraries-the-essentials

MORALE, WELFARE AND RECREATION: YOUR SOURCE FOR AFFORDABLE FUN

Military life has many demands, so Morale, Welfare and Recreation staff want to help you make the most of your free time. MWR is the military's network of support and leisure programs for service members. On base or off, Morale, Welfare and Recreation (https://installations.militaryonesource.mil) provides lots of ways for you to connect with friends and others for entertainment, rest and relaxation — all at reduced or no cost.

R&R ON THE INSTALLATION

At military installations around the world, you'll find a lot to do and enjoy, including:

- **SWIMMING POOLS:** Cool off and relax with recreational swimming. Sign up for swimming lessons, or join an aquatic fitness class for aerobic, low-impact workouts.
- **BOWLING FACILITIES:** Get a few friends together for a few games or buddy-up by joining a league.
- **GOLF COURSES:** From nine holes to full-scale, PGA-quality links, installation golf courses offer fun and fitness at affordable prices. Some locations also offer driving ranges, putting greens and lessons.
- **RECREATION CENTERS:** Many centers help you connect with family and friends with free Wi-Fi and computer use. Or unwind with billiards, air hockey, foosball, table tennis, Xbox, PlayStations and board games. You'll also find a large library of movies and big-screen TVs to watch them on.
- **TRAILS:** Morale, Welfare and Recreation staff can recommend great local trails where you can hike, bike or take a relaxing walk in nature.
- **AUTO SKILLS CENTERS:** Most installations have Automotive Skills Centers where you can maintain or repair your vehicle. For a minimal fee, you can use work bays, vehicle lifts, and a broad selection of tools, and get advice from certified mechanics.
- **LIBRARIES:** Check out a bestseller, read a magazine article or study for an upcoming test with library resources. Visit your installation library or log on to your Military OneSource account to access the MWR Digital Library from anywhere in the world.
- **MOVIE THEATERS:** See the latest movies at prices lower than those at the commercial chains. Now showing: all your favorite genres and some in 3D.

- **OUTDOOR AND RECREATION RENTAL CENTERS:** Need outdoor gear for a few hours or a few days? Rental centers offer campers, canoes and kayaks, canopy tents, tables and chairs, grills, garden equipment and much more.

See what Morale, Welfare and Recreation offers at your own installation at https://installations.militaryonesource.mil

R&R OFF THE INSTALLATION

Off-base adventures start with your installation's Information, Tickets and Travel office (www.militaryonesource.mil/recreation-travel-shopping/recreation/tickets-tours/information-tickets-and-travel-your-key-to-fun) and the outdoor recreation office. They'll give you the scoop on sporting events, museums, theme parks, aquariums, zoos, historical sites and other attractions, both near and far. They're also good for discount tickets and vacation planning services.

CHECK OUT THESE GREAT OFF-BASE OPPORTUNITIES :

- **LODGING** at recreational facilities, hotels and resorts around the world. Enjoy a cottage on the beach, a mountaintop retreat or a five-star resort with all the luxuries, both stateside and overseas. www.militaryonesource.mil/recreation-travel-shopping/travel/recreational-lodging/vacation-with-military-lodging
- **AMERICA THE BEAUTIFUL PASSES** give you access to more than 84 million acres of national parks where you can hike, climb, ski, surf, stargaze or just relax. www.nps.gov/planyourvisit/passes.htm
- **BLUE STAR MUSEUMS** allow you to soak up history, science or culture between Memorial Day and Labor Day across the country – for free. www.militaryonesource.mil/recreation-travel-shopping/recreation/hobbies/blue-star-museums

Remember, each service branch has its own Morale, Welfare and Recreation program. See what's in store for you:

- Army www.armymwr.com
- Marine Corps. www.usmc-mccs.org/topics/fitness
- Navy www.navymwr.org
- Air Force. www.myairforcelife.com

Morale, Welfare and Recreation is your destination for entertainment, rest and relaxation on or off the installation. Visit your local office for more information or call Military OneSource at 800-342-9647.

– Military One Source

VACATION DISCOUNTS

FOR MILITARY FAMILIES WITH AMERICAN FORCES TRAVEL

There's a new online leisure travel booking website created for members of the U.S. military community: American Forces Travel.

American Forces Travel (www.americanforcestravel.com) is designed to be a one-stop travel booking site. A joint service initiative, it offers military discounts and helps fund other current and future MWR programs.

FIND DISCOUNTS WITH AMERICAN FORCES TRAVEL

American Forces Travel lets service members and their families book their leisure travel and vacations completely online, and at a discount, through its service provider, Priceline Group, Inc. Potential bookings include:

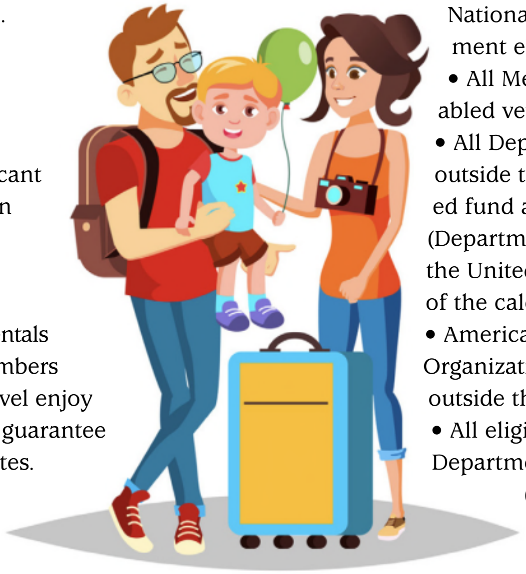
- Flights inside and outside the U.S.
- Hotels all around the world
- Rental cars
- Cruises and vacation packages

Military travelers using American Forces Travel are experiencing significant savings. By booking through American Forces Travel, users get up to:

- 60% off hotel rooms
- 80% savings on cruise packages
- $10-18 per-day discounts on car rentals

In general, military community members booking through American Forces Travel enjoy lower booking fees, have a best price guarantee and get deals on prepaid car rental rates.

Priceline will not charge for bookings or cancelations. While Priceline is waiving all Priceline fees, suppliers may have their own fees, terms and conditions.



SUPPORTING MWR PROGRAMS

Beyond offering travel discounts, American Forces Travel can help members of the military community find many relaxing, fun ways to recharge and stay mission ready. That's because anything booked through American Forces Travel earns a commission that goes directly to MWR programs around the world, at no cost to you. That money helps pay for services you already use, like outdoor recreation, pools, parks and workshops on your installation.

www.militaryonesource.mil/recreation-travel-shopping/recreation/single-life/morale-welfare-and-recreation-your-source-for-affordable-fun

AMERICAN FORCES TRAVEL ELIGIBILITY

Anyone (www.militaryonesource.mil/recreation-travel-shopping/recreation/fun-and-fitness/morale-welfare-and-recreation-programs-and-eligibility) who can use MWR programs and services can use American Forces Travel:

- All active-duty service members from every service branch
- All National Guard and Reserve Component members
- All retired military including those in the National Guard and reserves who are retirement eligible
- All Medal of Honor recipients and 100% disabled veterans
- All Department of Defense civilians serving outside the United States, including appropriated fund and nonappropriated fund employees (Department of Defense civilians serving inside the United States should have access by the end of the calendar year)
- American Red Cross and United Service Organizations-paid personnel currently serving outside the United States
- All eligible family members who have Department of Defense identification cards (www.militaryonesource.mil/military-life-cycle/new-to-the-military/getting-connected/department-of-defense-identification-cards)

To verify eligibility, the website will check the Defense Enrollment Eligibility Reporting System (www.tricare.mil/DEERS). Once you are approved, you can book your next vacation to anywhere in the world, while supporting the MWR programs on your installation. Consider American Forces Travel when arranging your leisure travel.

American Forces Travel is the only official MWR leisure travel site and it is supported under contract by Priceline.com.

– Military One Source

A ONE-STOP TRAVEL BOOKING SITE : AMERICAN FORCES TRAVEL

American Forces Travel is a new Morale, Welfare and Recreation program arising out of a joint service initiative combining the efforts of each of the five branches of service and the Office of the Deputy Assistant Secretary of Defense for Military Community & Family Policy. Because the Internet is now the most popular way to research and book travel, the branches of Service chose to evolve their travel offering. Travel is transforming the way MWR provides online leisure services to Service members and families, empowering them to revitalize, reconnect, be well, and most importantly, be mission-ready. In addition to dramatically enhancing quality of life for the military community, American Forces Travel will inject critical revenue into MWR programs by providing commissions from every booking made.

SHELLY HUHTANEN

How Far We've Come

I was grateful for how far Broden had come, but at the same time I was weeping for the woman in the salon. I wish I could have done more. I wish I could have swooped in and told her a magic solution to make it easier for her, but I knew in my heart there wasn't one. She had to go through it, just like I did.

About ten years ago, I approached a woman getting out of a car that had an autism sticker on her window. It seems like a lifetime ago when autism was still new and I was reaching out to anyone who could tell me something about this world that I didn't know. When I approached her, I introduced myself and told her about Broden. She told me that her son was a lot older than Broden and well into his teenage years. We talked for a few minutes and she encouraged me to take it one step at a time. As she walked away, she turned around and said, "Don't worry. It gets easier. Autism starts to become more familiar and not as scary. Give it time." She looked calm, a feeling that was foreign to me as I grappled with Broden's diagnosis. I asked myself as I got back in my car, "Will it ever get easier?" At that moment, I couldn't see past all of the scary unknowns that had flooded my mind. That day, I couldn't see anything in my life as getting easier.

Last week, I took the boys for their haircut. Jina has been cutting Broden's hair for four years. She is definitely one person I'm going to miss once we move to South Carolina. Due to Jina's persistence and patience, Broden has made great progress over the years. Like a champ, Broden stepped out of the car and walked with his brother into the salon. He walked over to her chair at her station and sat down to wait for her. Once Jina fastened the cape around his neck, I was able to sit down and look at a magazine. I looked up periodically to make sure he was following directions.

When she was finishing up with Broden, another hairstylist looked out the window and said, "Here they come Jina. I think she's trying to get him into the shop." Jina looked up and said, "Broden, you're done. I have another friend who is coming in today for a haircut." Jina peeked out the window, eager to get an update. I finally turned my head to see what they were so interested in seeing out in the parking lot. Right when I glanced over, my heart sank. I saw a woman holding and comforting a boy who was having a difficult time going into the salon. After a few minutes, she was able to pull him into the front door. Once she got him in the salon, he grew more upset and slid to the floor. The boy was inconsolable and it was evident that being in the salon was overwhelming.

> "The mom was already exhausted because it was so much work to just get him into the salon. I felt her pain because I had been there so many times."

I looked over at Broden in the chair and he started to plug his ears due to the boy being loud. Hayden, Broden's big brother, picked up quickly on what was going on and told Broden to follow him out to the car so I could pay for their haircuts. Broden followed my verbal prompt and thanked Jina as he followed Hayden out to the car to wait. After paying, I stood there in the salon looking useless. I wanted to help, but I knew that she knew her son best, just as I know Broden best.

The conversation she was having with Jina reminded me of the same conversations I had had about Broden four to five years ago. "He can't sit in the chair because he gets too upset. Can you cut his hair standing up? I'll hold his arms. Can we take breaks?" I was grateful the mother had found Jina, someone who was kind and caring. I had looked years for someone like her to cut Broden's hair and I was glad that she had found someone.

After standing there for a few minutes, I found myself not being able to leave. I looked out the window and my boys were getting restless. Jina was hard at work on the son's bangs. His mom was holding him from behind and I could see the stress on her face. I could tell that she was already exhausted because it was so much work to just get him into the salon. I felt her pain because I had been there so many times.

As the mother held her son, I walked up to her and put my hand on her shoulder, "Everything is going to be ok. Everything is going to be ok." She looked over at me in disbelief. I said, "Did you see the boy that just left the chair before your son came? He has autism too and we were where both of you are now. It will be ok." She asked how old Broden was, and then told me her son was six years old. I could see her trying to think of the age gap between our boys. She sighed and nodded her head, "Ok."

As I walked to the car, I started to cry. I was grateful for how far Broden had come, but at the same time I was weeping for the woman in the salon. I wish I could have done more. I wish I could have swooped in and told her a magic solution to make it easier for her, but I knew in my heart there wasn't one. She had to go through it, just like I did.

At that moment, I realized that things had come full circle – from the calm and wise woman I met ten years ago to me, who's become wiser through the years, all I could say was, "It's going to get better." •

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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E: threshold@lesley.edu

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