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MAGAZINE
JULY 2019
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THE
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HOMEMAKER
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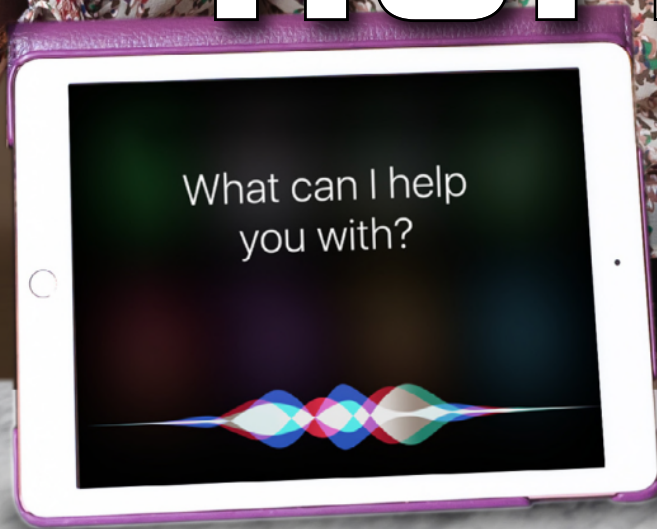
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*Okoro CA, Hollis ND, Cyrus AC, Griffin-Blake S. Prevalence of Disabilities and Health Care Access by Disability Status and Type Among Adults — United States, 2016. MMWR Morb Mortal Wkly Rep 2018;67:882–887. DOI: <http://dx.doi.org/10.15585/mmwr.mm6732a3>

CONTENTS

JULY 2019 VOLUME 49 ISSUE 7



ACCESSIBLE HOMES

- 22 HEARTSIGHT | COVER STORY**
THE EFFICIENT HOMEMAKER WITH VISION LOSS
By Christina Llanes Mabalot
- 28 HOME MODIFICATIONS: THINKING OUTSIDE THE BOX**
By Lauren Agoratus, M.A.

- 30 VANQUISHING THE VEXATION OF HOUSING FOR LOVED ONES WITH PSYCHIATRIC DISABILITIES**
By Tom Pyle, MBA, MS, CPRP



FEATURES

- 34 BON VOYAGE!**
By Cara Gorham Streit, EDD, MSW, LCSW
- 38 A DAY IN THE LIFE OF A MOTHER WITH A HIGH FUNCTIONING ADULT SON WITH AUTISM**
By Sarah Kenney
- BOOK EXCERPT**
41 YOUR POWER OF CHOICE
By Ellen Notbohm

- 45 THINGS WE DON'T THINK OF WHEN CREATING OUR EMERGENCY PREPAREDNESS PLAN**
By Laura George
- 48 WHEN WE ARE OVERWHELMED II**
By Michael John Carley
- 54 HANNAH'S JOURNEY**
By Renee Dease



ON OUR COVER

EP Magazine's Heartsight columnist Christine Llanes Mabalot anchors this month's annual Accessible Homes Issue. By taking us inside her home, she demonstrates how creative strategies and innovative technologies allow her and her family to overcome her vision loss and function like a typical household. Additional articles address the challenges of independent living faced by individuals and families with psychiatric disabilities, and finding resources for accessible home modifications. Photo by Paul Llanes. Coverage begins on page 22.

CONTENTS

JULY 2019 VOLUME 49 ISSUE 7

DEPARTMENTS

ANCORA IMPARO

- 4 **A QUICK SQUIRT TO THE RESCUE**
By Rick Rader, MD

- 6 **WHAT'S HAPPENING**

- 13 **NEW PRODUCTS**

AMERICAN ACADEMY OF DEVELOPMENTAL MEDICINE AND DENTISTRY

- 16 **OVER-PROTECTION OF CHILDREN
WITH DISABILITIES**
By H. Barry Waldman, DDS, MPF, PHD,
Jeffrey Seiver, DDS and
Steven P. Perlman, DDS, MSCD, DHL (Hon)

THE FITNESS PRIORITY

- 20 **LET'S TALK ABOUT BREATHING**
By Kristin McNealus, PT, DPT

- 64 **PRODUCTS & SERVICES**



13



16

MILITARY SECTION

MILITARY LIFE

- 58 **SIX WAYS TO LEAN ON YOUR
MILITARY COMMUNITY TO SETTLE
INTO YOUR NEW HOME FASTER**

- 60 **MEDICAID FOR FAMILY MEMBERS
WITH SPECIAL NEEDS**

PUZZLES & CAMO

- 62 **IT'S NOT ANY EASIER**
By Shelly Huhtanen

FROM OUR FAMILIES... TO YOUR FAMILIES

MILITARY SECTION

MILITARY LIFE
58 **SIX WAYS TO LEAN ON YOUR
MILITARY COMMUNITY TO SETTLE
INTO YOUR NEW HOME FASTER**

**MEDICAID FOR FAMILY MEMBERS
WITH SPECIAL NEEDS**

PUZZLES & CAMO
62 **IT'S NOT ANY EASIER**
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VOLUME 49 ISSUE 7 ■ ESTABLISHED 1971

Editor-In-Chief	• Rick Rader, MD	• habctrmd@aol.com
Managing Editor	• Vanessa B. Ira	• vira@ep-magazine.com
<hr/>		
Publisher	• Len Harac	• LHarac@ep-magazine.com
<hr/>		
Vice President of Business Development & Sales	• Faye Simon	• fsimon@ep-magazine.com
Accounting	• Lois Keegan	• lkeegan@ep-magazine.com
Art Direction & Design	• Leverett Cooper	• lev@foxprintdesign.com
Information Technology Expert	• Ron Peterson	• ron@ep-magazine.com

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Subscriber Services
1360 Clifton Avenue, Ste. 327, Clifton, NJ 07012
subscribe.ep-magazine.com

Customer Service/New Orders
Faye Simon fsimon@ep-magazine.com
or toll free: 800-372-7368 ext. 234

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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.



A Quick Squirt to the Rescue

For years Exceptional Parents have encountered a unique type of rust. Daily they are challenged by frozen notions, corroded concepts and eroding prejudices. They seek ways to free up stalled programs, lubricate crumbling ideology, and penetrate pitting stigmatizations.

It should have been no surprise that the bolt was not coming out without a struggle.

After being in place for over 90 years, holding the rear springs to my 1926 Model T Ford, that bolt was there to stay. After all it had every advantage. The metal had help from hydrated iron oxides and iron oxide-hydroxide. Given sufficient time, oxygen, and water, any iron mass will eventually convert entirely to rust and disintegrate. If left to its own devices, rust has a proclivity to return to the earth.

While the rust on this bolt derailed the progress on my Saturday afternoon restoration project, rust has also played major havoc elsewhere. Rust was an important factor in the Silver Bridge disaster of 1967 in West Virginia, when a steel suspension bridge collapsed in less than a minute, killing 46 drivers and passengers on the bridge at the time. So, rust has the twin characteristics of bonding two pieces of metal together (in the case of my suspension bolt) and totally disintegrating (in the case of the Silver Bridge disaster).

Back in my garage, the first order of business was to get a bigger wrench which didn't work. Getting its attention with several jolts from a large hammer just seemed to amuse the bolt. Before

I went for the torch (rust often surrenders in the face of a glowing and hissing fire) I reached for the WD-40. A few squirts from the can directed the "magic juice" into the bowels of the rusted nut and the threads became saturated. Just for good measure I tapped the bolt with the hammer to encourage penetration of the liquid.

Victory! The bolt was overwhelmed and put up the white flag. Score another win for WD-40.

According to the WD-40 Company, "In 1953, in a small lab in San Diego, California, the fledgling Rocket Chemical Company and its staff of three set out to create a line of rust-prevention solvents and degreasers for use in the aerospace industry.

It took them 40 attempts to get their water displacing formula to work, but on the 40th attempt, they got it right in a big way. WD-40 was born. WD-40 stands for Water Displacement, 40th formula. That's the name straight out of the lab book used by the chemist who developed the product."

This was during the Cold War and the United States was stockpiling and stor-



ing as many missiles as they could produce. One of the problems was preventing rust on the surface of the Atlas Missile. Nothing worse than workers getting tetanus from handling rusted nuclear missiles. The WD-40 worked like a charm.

The concoction worked so well that several employees at the missile base snuck cans of WD-40 out of the plant in their lunchboxes to use at home. I assume the security was tight enough to prevent them from sneaking the actual missiles out of the plant; so perhaps we can forgive the security breach.

Years later, the Rocket Chemical Company put the chemical into aerosol cans and sold them to homeowners for their home workshops and garages. How right they were. In 1983, the WD-40 Company goes public and is listed on the stock exchange. The stock price increased by 61% on the first day of listing. By the early 1990's the company was named among the Top Ten Most Profitable companies on the NASDAQ exchange.

WD-40 is found to be in 4 out of 5 American households and is used by 81 percent of trade professionals at work. More than one million cans are sold each week in the United States alone.

Before Facebook, Twitter or Instagram, there was the WD-40 Fan Club. Thanks to the Fan Club there is an official list of 2,000 uses for WD-40 (they have refused to list it as a treatment for arthritis, although there is an army of arthritic sufferers who swear that it helps their joints).

PROBLEM SOLVER: WD-40 stands for Water Displacement, 40th formula. One of the problems with stockpiling as many weapons as the U.S. could produce during the Cold War was preventing rust on the surfaces of the Atlas Missile. The WD-40 worked like a charm.



WD-40 is sold in over 170 countries worldwide. WD-40's formula is a trade secret and has not changed over the years.

There is an axiom that is recognized by mechanics around the world, including those responsible for sending rockets and satellites into outer space.

"You need only two tools in life. WD-40 and Duct Tape.

If it doesn't move and should, use WD-40. If it moves and shouldn't, use Duct Tape."



ROCKET SCIENCE: In 1953, the fledgling Rocket Chemical Company set out to create a line of rust-preventers and degreasers for the aerospace industry.

For years Exceptional Parents have encountered a unique type of rust. Daily they are challenged by frozen notions, corroded concepts and eroding prejudices. They seek ways to free up stalled programs, lubricate crumbling ideology, and penetrate pitting stigmatizations. While they turn to WD-40 to lubricate and protect wheelchairs, tricycles, swings, and other devices that allow their children with special needs to feel the rush of fresh air on their faces, they turn to EP Magazine to learn from others on the best ways and best places to squirt some magic juice on reluctant and corroded obstacles.

In 2014, WD-40 was inducted into the International Air & Space Hall of Fame.

In 2019, my Model T Ford got a new bolt in its rear suspension. •

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

DR. MATT HOLDER RECEIVES THE "MOVE TO INCLUDE" AWARD

Ann Costello, Director of the Golisano Foundation presented the Foundation's 2019 Move to Include Award to Dr. Matthew Holder, an international leader in the care of individuals with Intellectual and Developmental Disabilities (IDD).

The Move to Include award was presented at this year's annual American Academy of Developmental Medicine and Dentistry's (AADMD) One Voice Igniting Change Conference, which was held in Rochester, NY.

Since 2015, the award has been given to those who both "believe" and "act" in the purest realm of the essence of "move to include," in the hope that the understanding of "include" can be elevated, promoted, ingrained and demonstrated at the highest levels of human behavior.

In presenting the award Costello said, "Matt is a gifted doctor who epitomizes the characteristics of the Award every day in his work, life and professional associations. Throughout his career he has demonstrated that inclusion is never an afterthought or a "do over" effort in social justice. He understands that true inclusion is not something created through a mission statement, a tagline or a bumper sticker."

ABOUT DR. MATT HOLDER

Dr. Holder began working on what would result in Developmental Medicine becoming a recognized medical expertise soon after

starting his career.

In 2002, he took over the American Academy of Developmental Medicine and Dentistry (AADMD). Since then the AADMD has set the curriculum and standards that guide medical students, residents and fellowship-level physicians to better treat and understand patients with IDD. Medical schools and residency programs around the world have implemented curriculum changes

based on the work done by Dr. Holder and the AADMD.

In 2005 Dr. Holder became Global Medical Advisor for the Special Olympics. He has trained thousands of healthcare providers in addressing the health needs of athletes with IDD. He also assists the American Medical Association and the American Dental Association in developing and passing resolutions that improve the lives and health-



BELIEVE AND ACT: Dr. Matt Holder receives the 2019 Golisano Foundation's Move to Include Award from Ann Costello, Foundation Director.

care of IDD patients.

Dr. Holder, alongside colleague Dr. Henry Hood, designed and developed a unique, interdisciplinary patient care and teaching model that meets the health needs of adults with IDD living in the community – the first of its kind in the nation. Today the Lee Specialty Clinic exists as a testament their shared vision.

Dr. Holder is a graduate of the University of Louisville School of Medicine. He earned a BA and MBA from the University of Louisville. *Learn more about the Golisano Foundation Move to Include Awards by visiting www.golisanofoundation.org*

WHAT'S HAPPENING

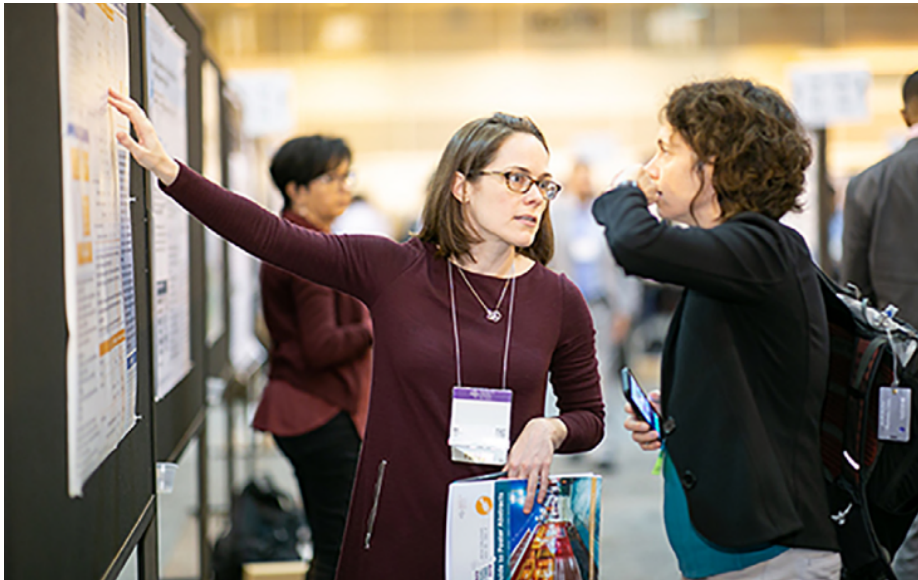
THE AMERICAN EPILEPSY SOCIETY AWARDS 25 EPILEPSY RESEARCH FELLOWSHIPS & GRANTS

Fellowships or grants have been awarded to 25 early career epilepsy scientists, the American Epilepsy Society (AES) announced recently. Included are predoctoral and postdoctoral trainees, junior investigators establishing their independent programs, and clinicians and fellows pursuing additional training for a career in research.

The scientific and medical communities recognize there is a shortage of researchers focused on epilepsy," said Page Pennell, M.D., president of the American Epilepsy Society. "AES is committed to supporting early career investigators, which in turn will produce new discoveries and treatments in the years to come. Supporting junior investigators is vital given that cutbacks in research funding, particularly by government agencies, have made it extremely difficult for new investigators to secure grants needed to launch a research career and subsequently compete for larger, longer-term support from the National Institutes of Health or other sources."

AES is one of the largest non-governmental funders for those starting their careers in epilepsy research, with over 85 percent of its grant dollars targeted to early career researchers working across the spectrum of epilepsy research from basic science through translational and clinical investigations. The program has nearly doubled in its reach from 14 awardees in 2015 to 25 awardees in 2019. The full list of 2019 awardees is available at: aesnet.org/earlycareer.

AES grants are supported by generous philanthropic donations both from the public and from AES members, with additional support in the past year from LivaNova and Upsher-Smith Laboratories, LLC. Ten awards were made possible, in full or in part, by the support of other non-profit organizations, representing a shared commitment to support the future of epilepsy research. Three awards are supported in full by the Epilepsy Foundation and two by the Epilepsy Study Consortium. The Pediatric Epilepsy Research Foundation co-funded one pediatric research fellowship at 50% and two grants were supported in part by the Wishes for Elliott or the Lennox Gastaut Syndrome Foundation.



LOOKING AHEAD: AES has an explicit, long-term commitment to developing talented researchers who will advance the understanding and treatment of epilepsy over the next generation.

The AES is a partner on the Susan Spencer Clinical Research Training Fellowship and congratulates the 2019 recipient, Lisseth Burbano, MD, of the Florey Institute of Neuroscience. The award was established in honor of Susan S. Spencer, MD, a past president of AES, and was created to foster the development of investigators interested in pursuing careers in patient-oriented research. The award is made possible by the American Academy of Neurology with funding from the American Epilepsy Society, the American Brain Foundation, and the Epilepsy Foundation. "It is a pleasure to congratulate this impressive group of talented and committed scientists," said Eileen M. Murray, MM, CAE, executive director of the American Epilepsy Society. "Their work is an important part of our mission of advancing research and education for professionals dedicated to the prevention, treatment and cure of epilepsy."

ABOUT THE AMERICAN EPILEPSY SOCIETY



Founded in 1946, the American Epilepsy Society (AES) is a medical and scientific society whose members are dedicated to advancing research and education for preventing, treating and curing epilepsy. AES is an inclusive global forum where professionals from academia, private practice, not-for-profit, government, and industry can learn, share and grow to eradicate epilepsy and its consequences. For more information, visit AES online at aesnet.org

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WHAT'S HAPPENING

AFTER CONCUSSION, BIOMARKERS IN THE BLOOD MAY HELP PREDICT RECOVERY TIME

A study of high school and college football players suggests that biomarkers in the blood may have potential use in identifying which players are more likely to need a longer recovery time after concussion.

According to a study with so many people sustaining concussions and a sizeable number of them having prolonged symptoms and recovery, any tools we can develop to help determine who would be at greater risk of problems would be very beneficial, so these results are a crucial first step," said Timothy B. Meier, PhD, of the Medical College of Wisconsin in Milwaukee and a member of the American Academy of Neurology, author of the study published in the July 3, 2019, online issue of *Neurology*, the medical journal of the American Academy of Neurology (AAN),



BLOOD, SWEAT AND TEARS: "These results may help us better understand the relationship between injury and inflammation and potentially lead to new treatments."

The study involved 41 high school and college football players who experienced a concussion during the season. None of the players lost consciousness with their concussions. The players were matched with 43 football players of the same level, age and position who did not have a concussion during that season. All of the participants had blood tests at the beginning of the season. Those who had concussions had blood tests within six hours after the injury, then again 24 to 48 hours later and also eight, 15 and 45 days later. Those who did not have concussions had tests at similar times for comparison.

The tests looked at levels of seven biomarkers for inflammation that have been related to more severe brain injury. Of the seven biomarkers, two were elevated for those with concussion at six hours after the injury compared to the athletes with no concussion. The biomarkers interleukin 6 and interleukin 1 receptor antagonist were both elevated at six hours after concussion. For interleukin 6, levels at the beginning of the study were 0.44 picograms per milliliter (pg/mL) for those who later had concussions and 0.40 pg/mL for those who did not have concussions. At six hours after the injury, those with concussions had levels of 1.01 pg/mL, compared to levels of 0.39 at a similar time for those without concussions.

"These results demonstrate a meaningful increase in the levels of interleukin 6 for athletes who sustained a concussion compared to athletes who did not," said Meier.

Athletes with higher levels of interleukin 6 six hours after the injury were also more likely to take longer to recover from their symptoms. Overall, the athletes with concussions had symptoms for an average of 8.9 days. Eight of the 17 athletes with concussion and high interleukin 6 levels at six hours after injury, compared to their levels at the beginning of the season, still had concussion symptoms eight days after the injury.

"Eventually, these results may help us better understand the relationship between injury and inflammation and potentially lead to new treatments," Meier said.

Learn more about concussion at BrainandLife.org, home of the American Academy of Neurology's free patient and caregiver magazine focused on the intersection of neurologic disease and brain health. Follow Brain & Life® on Facebook, Twitter and Instagram. *The American Academy of Neurology is the world's largest association of neurologists and neuroscience professionals, with 36,000 members. The AAN is dedicated to promoting the highest quality patient-centered neurologic care. For more information about the American Academy of Neurology, visit AAN.com.*

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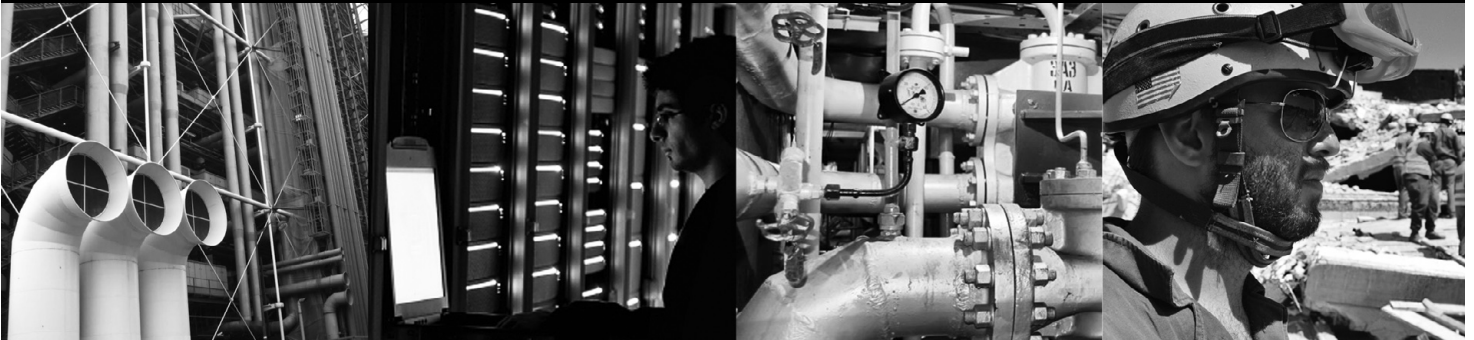
Bring together more than thirty professionals, each a craftsman in his or her former industry, in one organization and no industry, situation, or challenge will be new to us. Not to say that we've seen it all. Technology adds novel challenges daily, making a flexible organization – one willing to grow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

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

The staff forms two teams, each offering comprehensive expertise in one of the company's two main divisions of facility services. The "Electrical Team" and the "HVAC/Mechanical Team" can cope with any situation an client or homeowner might encounter.

Contact: Vice President of Operations
pmaloney@ljselectric.com
201-777-6625

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WHAT'S HAPPENING

U.S. DEPARTMENT OF EDUCATION DELIVERS ON KEY SCHOOL SAFETY REPORT RECOMMENDATION

Acting on the recommendations of the Federal Commission on School Safety, U.S. Secretary of Education Betsy DeVos recently announced the release of the Parent and Educator Guide to School Climate Resources.

This guide, produced jointly by the Department's Office of Elementary and Secondary Education and Office for Special Education and Rehabilitative Services, provides best practices and includes resources school leaders and teachers can utilize as they work to achieve a positive school climate, lower disciplinary issues and enhance school safety.



SAFER SPACES: Education Secretary Betsy DeVos visits with a student soon after the release of the Parent and Educator Guide to School Climate Resources.

“We know that fostering a positive school climate is critical to the well-being, safety and long-term success of all students,” said Secretary DeVos. “In the absence of a safe and positive learning environment, a student may feel disconnected, disregard consequences, and engage in bullying or other destructive behaviors. As teachers and school leaders assess the unique needs of their school communities, we hope this guide helps them make the decisions that are right for their students and also provides parents and guardians with effective tools to support teachers in making those decisions.”

The Q&A document, which is available on the Department of Education's website, provides parents and educators with useful decision-making frameworks and implementation tools, as well as best practices that school leaders can consider as they work to foster positive and inclusive learning environments. Examples from

schools across the country are included to illustrate the various interventions communities are employing to enhance student behavior and achievement. With recent research highlighting the importance of evaluating school climate through a range of indicators, the guide provides diagnostic tools so educators can collect and utilize data to drive their climate improvement strategy.

Additionally, the Parent and Educator Guide to School Climate Resources provides information to teachers and school leaders on how they can receive support from the Department's two technical assistance centers dedicated to promoting safe and supportive schools, including the National Center of Safe and Supportive Learning Environments (<https://safesupportivelearning.ed.gov>), and the Technical Assistance Center on Positive Behavioral Interventions and Supports (www.pbis.org). The guide includes an appendix of additional resources spanning the work of government agencies and private organizations, equipping parents and educators to create positive learning environments for all students.

To view the Parent and Educator Guide to School Climate Resources, click here: <https://www2.ed.gov/policy/elsec/leg/essa/essaguidetoschoolclimate041019.pdf>

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Over-Protection of Children with Disabilities

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

“Lowered expectations and over-protection of the individual with a disability can cause lowered self-esteem which can result in a life time of underachievement and failure to reach their full potential. Both lowered expectations and over-protection are forms of discrimination.”¹

Over-protection and lowered expectations of persons with disabilities may result in several unwanted and unintended consequences which can have lifelong impact. “The prejudicial attitudes of those around a child with a disability often include overt acts of sympathy and pity. This discomfort may cause the person with a disability to be segregated and may exaggerate the sense of inequality.”¹

Adolescents with disabilities may not be prepared to make decisions for themselves because of their subjection to low expectations and because they are micromanaged by parents and educators. This negative feedback keeps the individual in an inferior and dependent position, often giving up on him/her self.³

- Parents unknowingly cause their child to become powerless by failing to allow the child the opportunities to advocate for their self.
- Parents who over-protect their children can deprive them of their independence as they transition into adulthood and inadvertently promote dependence on others.
- Physical disabilities significantly impact development of the child’s personality in that they may lack a sense of belonging.

- Parents who over-protect the child with a disability will continue to over-protect as the child enters adolescence and young adulthood.
- Another consequence of over-protection may be hostility of the child toward the parents.¹

“For all parents...who have a child (with a disability), the diagnosis represents a loss which must be grieved. The loss for which the parent grieves is of the dream that all parents have of how their child and how their life would turn out. Their dream does not include a child with disabilities... (T)he grief engendered by the death of a family member is acute and terminal...The grief experienced by the parent of a child with special needs is chronic. There is usually minimal emotional support carrying a fetus for 9 months and delivering a healthy child. When the child has a disability, the mother feels she has failed in some way...”³

“Grief very often translates into...behavior that is not helpful for the child. Guilt-ridden parents tend to over-protect their child (‘I let something bad happen to you once. I am not going to let that happen again... I am going to make it up to you.’)³



AMERICAN ACADEMY OF DEVELOPMENTAL MEDICINE AND DENTISTRY

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



FRESH ARRANGEMENT: All too often, individuals with disabilities were “hidden” in institutions and in back rooms. Today, they are in public and private schools, many forms of employment, entertainment and just about all settings for everyday activities.

COMMENTARIES AND PERCEPTIONS

Negative effects of over-protection and lowered expectations have far-reaching consequences. All that lack of belief can have an effect on one self. Individuals with disabilities are not expected to do more, so they do not. In some reviews, the responses by over-protected college students included: “I was restricted at home; was prohibited to go on trips; rarely allowed to leave home; I could never go where I wanted; they balked against my independence.”⁴

A consequence of lowered expectations can lead the individual to believe that the disability is the root cause of all his/her futility and uselessness. The over-protected child with a disability is often not challenged to strive for excellence; they are allowed to settle for less.⁵

Children with disabilities may have developmental delays or physical limitations which could have an impact on the individual and how they are perceived by others. These differences may cause the child to develop perceptions about him/herself which may be based on actual functional limitations. “Parents must be aware of the child’s perceptions concerning (her/) himself so that child’s perceptions of the disability does not negatively affect the child’s ability to reach their full potential.”⁵

One of the tasks of effective parenting is to teach their child appropriate behavior. Society and culture have different expectations about persons with disabilities, which may influence the parent’s role as a parent of child with disabilities.⁶ This task can become even more essential and complicated. In the past, all too often, individuals with disabilities were “hidden” in institutions and in backrooms of homes. In today’s world, youngsters with disabilities are in public and private schools (not segregated in classrooms for individuals with special needs); as adults, they are involved in all forms of employment, entertainment and just about all settings for everyday activities.

PSYCHOLOGICAL ISSUES FACED BY ADOLESCENT AND YOUNG ADULTS WITH DISABILITIES

Adolescence is a period of complex biological, social and emotional changes with four major developmental tasks for the teenager to achieve:

- *To consolidate his or her identity.*
- *To achieve independence from parents.*
- *To establish new love objects outside of the family.*
- *To find a vocation.*

When the adolescent has a disability, there are particular reasons why this period is almost always prolonged.

- *The individual with a disability has been over-protected and sheltered.*
- *The growth of individuals with a disability occurs within the nucleus of the extended family. As a result, there is limited experience with peers.*
- *The individual with a disability may have an identity crisis that is even more profound because of a dearth of appropriate role models.*⁷

FIRST, AVOID OVER-PROTECTION

- **Understand the difference between risk and risky:** Most parents with over-protective tendencies have the best intentions to keep their child safe. By example: Every time your child rides a bike, he/she risks falling and getting hurt. But riding at night with no reflectors or a helmet is risky.
- **Practice safety:** If you’re worried your child will make decisions that stand in the way of their safety, try practicing safety skills before letting them try things on their own.
- **Take a deep breath:** Usually, it’s the parents who are more nervous than their kids. Try a simple exercise to calm your nerves by taking a deep breath.
- **Provide the children with life skills:** Letting children have independence teaches them competence.
- **Let them be fun-finders:** Children should be made to find their own fun with their own imagination.
- **Stop obsessing:** Constant anxiety isn’t helping your child or yourself.
- **Be honest about fear:** When children see parents struggle, it will help them to see that all people have fears to deal with life.
- **Introduce dangers:** Learning to control these things (using proper safety measures) kids will learn in a more meaningful way.
- **Teach problem solving:** Teaching children problem-solving skills encourages them to be independent.
- **Avoid peer pressure:** Avoid spending time with other parents who are over-protective.
- **Surround yourself with like-minded people:** Avoid other “helicopter” or “snow plow parents”. Surround yourself with other parents who could promote autonomy and independence.⁸ (Note: A snow plow parent is a person who constantly forces obstacles out of their child’s path.)

ON THE OTHER HAND

Comments from a “helicopter parent”: “By definition, a helicopter parent is ‘a parent who takes an over-protective or excessive interest in the life of their child or children.’ As a parent to two chil-



dren with special needs, I don't see being over-protective as a bad thing. Having an excessive interest in their life seems perfectly fine and helpful in many ways. (sic)

Parents of children with special needs follow their own sets of rules. Instead of focusing on the helicopter parent as some-

one with unnecessary fears who gives their child instant gratification and solves every problem for their child, let's look at the characteristics of an actual helicopter pilot and see how these top qualities are an asset in parents of children with and without special needs." ⁹

HOVER-CRAFT : WHAT IT TAKES TO PARENT A SPECIAL NEEDS CHILD

The top six qualities of a great helicopter pilot (and parent) include:

- 1. Has Strong Communication Skills:** A special needs parent needs excellent communication skills with doctors, school system staff, insurance companies, therapists, and even complete strangers. Special needs parents also require strong communication skills for connecting with their child.
- 2. Is Able to Handle Pressure:** A special needs parent must handle the pressure of difficult decisions, stay calm during a time of crisis, and be able to survive stressful situations. Pressure for a special needs parent can come from dealing with finances, lack of services, sleep deprivation, and the desire to provide what is best for your child. Pressure can also come from managing relationships with a spouse/partner, family, and co-workers.
- 3. Uses Good Judgment:** Confident in their decisiveness, a special needs parent must have good decision-making skills to analyze a situation and proceed in the direction that is best for everyone involved. Special needs parents often have to make decisions about how much freedom to give their child, when to step in, and when to step aside. When a special needs child becomes an adult, decision-making and good judgment skills may be needed more than ever.
- 4. Exercises Patience:** A special needs parent's patience is necessary when working with teachers, special services, and therapists. Patience is especially needed for test results and when dealing with doctors.
- 5. Believes in Teamwork:** Teamwork is essential to achieve the best results for the child. When the school, special services support team, and family work together, everyone benefits. When therapists, doctors, and the family can all be on the same page, great things can happen.
- 6. Has a Good Temperament:** A special needs parent must have an even temperament and be able to manage stress well. A special needs parent often works in high-stress situations on a daily basis. Having flexibility and adaptability when dealing with frustrating situations is an amazing characteristic of a special needs parent.

So, while many may ridicule the helicopter parent, I say be proud and fly high! ⁹



QUESTION: HOW DOES ONE BALANCE?

- Against over-protection
- Determined and understanding parents
- A child's perspective: "Over-protective parents can hinder my life! The best thing I can learn is how to gain my liberty." ¹⁰ •

ABOUT THE AUTHORS:

H. Barry Waldman, DDS, MPH, PhD is a SUNY Distinguished Teaching Professor, Department of General Dentistry, Stony Brook University, NY.

E-mail: h.waldman@stonybrook.edu

Jeffrey Seiver, DDS is a Clinical Assistant Professor, Department of General Dentistry, Stony Brook University, NY.

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

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Let's Talk About Breathing

If you practice diaphragmatic breathing, you will develop an ability to choose this relaxation response when you start to feel that stress response. This can lower anxiety, it can lessen pain, and it may decrease the risk of stress-related conditions.

Breathing is something we do all day, every day, but I am sure you rarely give it much thought. But how we breathe is related to many of our body's functions. One way of breathing is more of a chest breathing. This is the way we naturally breathe when we are upright and walking – the shoulders rise, and the chest expands.

Now think about how you breathe when you are stressed or anxious. You may be running late, or you cannot figure out why your child is screaming, or maybe your child is sick. This is also how we breathe when we are in pain. What is your breathing like? It is shallow and faster, right? You may even be holding your breath at times

without realizing it. This allows for less oxygen to enter the lungs, and therefore the blood. It also increases the amount of carbon dioxide in our blood, which actually increases our anxiety! So, it is a spiral. Our heart rate increases, and our muscles tense. This can exacerbate any pain that we are already in, and any stress we feel.

Can you see why it may be beneficial to pay more attention to our breathing? We may be triggering an overactive sympathetic nervous system, and keeping our bodies in a “fight or flight response.”

To get out of this, even if only for a few



minutes, we want to focus on diaphragmatic breathing. Diaphragmatic breathing is intended to help you use the diaphragm correctly while breathing to:

- **Strengthen the diaphragm.**
- **Decrease the work of breathing by slowing your**

breathing rate.

- **Decrease oxygen demand.**
- **Use less effort and energy to breathe.**

The diaphragm sits as a dome into your rib cage, and contracts by flattening out. This makes more room available in the lungs for air to flow in. This movement of

the diaphragm massages our parasympathetic system, turning on our “rest and digest” system. This calms down that overactive sympathetic system. This slows our heart rate and helps us digest food more efficiently.

If you practice diaphragmatic breathing, you will develop an ability to choose this relaxation response when you start to feel that stress response. This can lower anxiety, it can lessen pain, and it may decrease the risk of stress-related conditions. Increased stress leads to heart disease, digestive disorders, sleep disorders, depression, and pain syndromes.

When the body is in this stress response frequently, it can divert blood from the gut.

This is because the brain is telling the body to get ready to fight, and the muscles need the blood. Taking this blood from the gut can cause various digestion issues.

Our breath is also closely related to our pelvic floor musculature. This can get more complicated, but the pressure created in our bellies by the diaphragm is balanced by our pelvic floor muscles. If you are not provided sufficient pressure on your organs with your diaphragm, your body may increase the tension held in your

pelvic floor muscles. This can lead to pelvic pain and/or weakness. Pain can be vague in location and inconsistent. It is often difficult to diagnose.

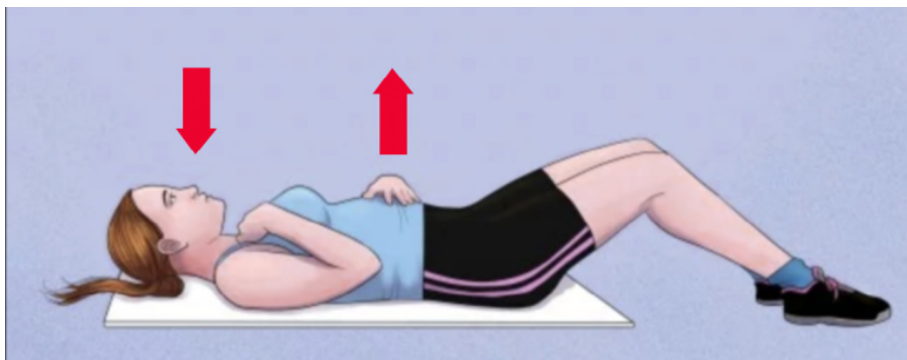
Weakness can cause some difficulty in holding urine. All because we did not take time to think about our breathing. If any of this sounds familiar,

“At first, you may get tired, but keep at it. Diaphragmatic breathing will become easy and automatic with practice.”

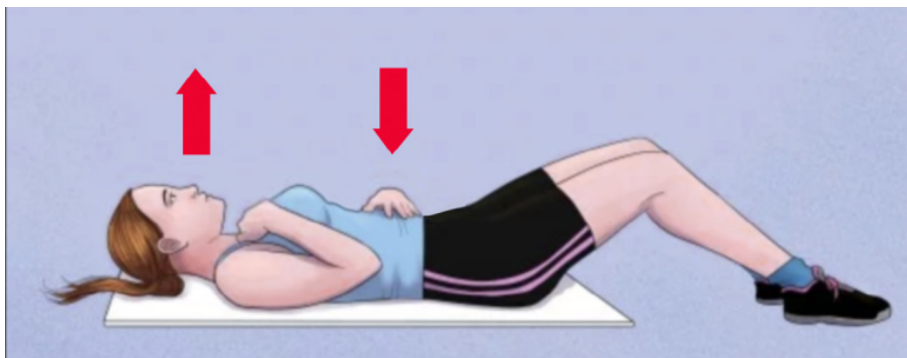
there are physical therapists who specialize in pelvic health. You can find one near you by visiting: <https://pelvicrehab.com/>

You may notice an increased effort will be needed to use the diaphragm correctly. At first, you may get tired while doing this exercise. But keep at it, because with continued practice, diaphragmatic breathing will become easy and automatic. Practice this exercise 5-10 minutes. Gradually increase the amount of time you spend doing this exercise, and once you feel more comfortable, perhaps even start incorporating this breathing technique into everyday settings. Maybe when you are still in your car before going inside the house, before bedtime after the kids are asleep, or in the morning when you first wake up. You may find that you are able to find a place of a little less stress. Hopefully, it will help ease digestion issues. And maybe you can lower your level of anxiety. •

LIVE AND BREATHE : DIAPHRAGMATIC BREATHING EXERCISE



- Lie on your back on a flat surface or in bed, with your knees bent and your head supported. You can use a pillow under your knees to support your legs. Place one hand on your upper chest and the other just below your rib cage. This will allow you to feel your diaphragm move as you breathe.



- Breathe in slowly through your nose so that your stomach moves out against your hand. The hand on your chest should remain still. Then let the air out in a long, slow exhale and feel the belly deflate like a balloon.
- When you first learn the diaphragmatic breathing technique, it may be easier for you to follow the instructions lying down. As you gain more practice, you can try the diaphragmatic breathing technique while sitting in a chair.

THE FITNESS PRIORITY

Kristin McNealus, PT, DPT, ATP received her Masters in Physical Therapy from Boston University then went on to earn her Doctorate in Physical Therapy from MGH Institute of Health Professions. She has been a staff physical therapist on inpatient rehabilitation for people with spinal cord injuries at a number of hospitals in Southern California, as well as Director of a community adaptive gym for people with neurological injuries. She is a member of the International Network Spinal Cord Injury Physiotherapists, and has contributed to the APTA Guidelines for Exercising with a SCI. She has completed 3 marathons, and 25 triathlons, including the Ironman! SCI Total Fitness is designed to promote health and wellness for people with physical disabilities.

The Efficient Homemaker with Vision Loss

Most houses of visually-impaired people may be a lot cleaner and more organized than others' homes. This is not because we're more diligent at cleaning or organizing. It's because people with visual impairment want to enhance functionality and efficiency by keeping tidy, well-organized homes where there are no obstructions, confusion, or clutter.

Imagine a dingy house with shoes, socks, clothes, an assortment of boxes, empty containers of food and whatnots strewn all over the living room. While you may be thinking that I'm describing the average college student's dorm room, what I'm portraying here is a common misperception of a visually-impaired person's home.

As soon as well-meaning friends and family walk into our home, they speculate my part in maintaining our household, tossing questions like: "How do you clean?" – to which I reply with a grin, "with a vacuum cleaner." Or, "How do you know what you're cooking?" – to which I banter, "I sniff it." I never fail to tell my funny stories to dinner guests, such as how I mistakenly put wet dog food instead of tuna on my vegetable salad because I was absorbed with my audiobook and not paying close attention to the dish I was preparing.



ACCESSIBLE HOMES

Contrary to popular misperceptions, people with special needs can be efficient homemakers if they set up their homes to be accessible and orderly according to their requirements. Most houses of visually-impaired people may be a lot cleaner and more organized than others' homes. This is not because we're more diligent at cleaning or organizing. It's because people with visual impairment want to enhance



functionality and efficiency by keeping tidy, well-organized homes where there are no obstructions, confusion, or clutter.

To illustrate this point, take the wallet. Sighted people randomly throw in receipts with their credit cards, ID's, cash, but can easily fish out precisely what they need.

On the other hand, a visually-impaired person whose wallet isn't adaptively organized may hand a cabbie a \$100 bill instead of \$20. Learning this expensive lesson was a wake-up call to get my stuff in order on all aspects of my life, including managing an accessible home. After all,

maximizing efficiency is vital in daily living.

Accessibility and organization techniques apply to the house layout, furniture, appliances, the pantry, closets, cupboards, shoe and wine racks, freezers, dressers, bathrooms and everything that involves an assortment of items.

HOUSE LAYOUT

First, allow me to describe some issues I have in getting around. I have orientation problems so bad that I can get disoriented in a tiny shed. Sometimes, my husband wonders if I have memory loss on top of my visual impairment. I also cannot walk a straight track even when using a cane. One old school orientation and mobility instructor alleged I might have problems with my “hypothalamus” (a part of the autonomic nervous system) because I tend to walk diagonally. Considering these mobility issues, layout considerations are central in choosing a home.

In an earlier house that my husband, Silver, and I built in the Philippines, I detailed specifications that I needed – multiple entrances, a wrap-around balcony, orthogonal and well-defined living, dining, and foyer areas. All these facilitated my ease of navigation since I don’t want to use a cane in my own home. The multiple entrances provided ease of access. The wrap-around balcony was where I could jog or take a brisk walk in times when I felt the treadmill was boring. The symmetrically-shaped rooms served as a safety net in case I lost my memory while navigating.

We don’t enjoy the same luxury in our current home – but it’s a good-sized, ranch style, high-ceiling structure. There’s space between furniture and fixtures enough for me to be able to dash out from the bedroom to the kitchen if I need to, like when I hear the oven beeping when it’s done baking.

There are some rules I’ve laid out regarding the furniture. Rule Number 1: “Visually-impaired family members should be notified before furniture is rearranged.” Then there’s Rule Number 2, which is “Don’t break rule number 1.” Oh, and I’d be remiss if I didn’t mention that overhangs are banned! I don’t care how pretty they look – overhangs are a death threat to visually-impaired persons, especially to me, because I walk recklessly fast.

CLEANING

A house simply laid out is easy to clean. First, I run the vacuum cleaner over the whole floor area. I need to make sure I cover the

entire floor surface. Spot-cleaning got me in trouble so many times since I could never guess which spot was dirty, so I dropped this option. After vacuuming, I apply a wood floor polishing solution over the whole surface. I spray the solution on a microfiber rag, get down on all fours and wipe down the floor with the solution, using my hands to manipulate the cloth. I have the option to use a mop, but my method, though much more laborious, assures me that I don’t miss a spot. In the absence of sight, I use my hands

MONEY MATTERS

Lessons from a Visually-Impaired Person’s Wallet

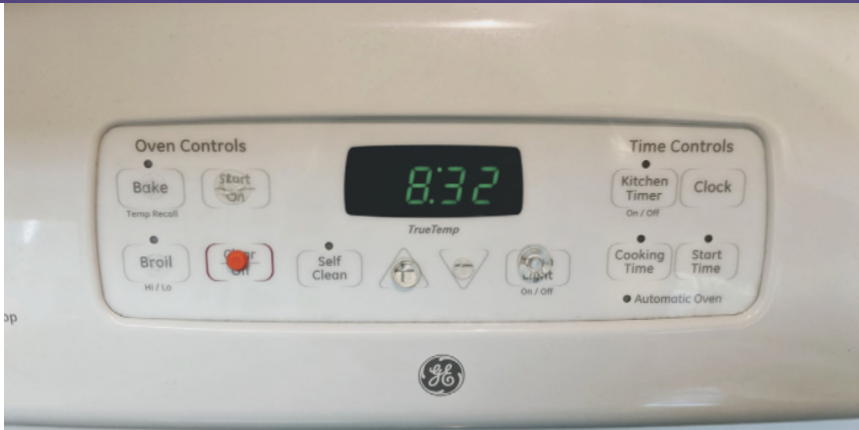
The orderly arrangement of the contents of a visually-impaired person’s wallet is a perfect illustration of adaptive organization. The same principles are useful in identifying household items of numerous assortments.

My wallet is purple with an ID holder on the front side. It zips open into 12 partitions. The first section inside, closest to the front of the wallet is where I store other identification cards such as my passport card and minister’s license. Next to this section are my credit cards, arranged from the most frequently-used to the least, each card tucked into a separate division.

I carry cash of different denominations. I identify each bill with a money reader app. I fold bills of the same denomination together, e.g., all the \$1 bills are folded once, \$5 bills twice etc. The idea behind this is bills of every denomination are folded differently, or are dog-eared for easy recognition. This system is efficient for me, although it may not be for other people. A visually-impaired person may use whatever she thinks works best.



Creativity in devising methods for identifying an item out of an assortment adds leverage. For example, in the kitchen, we have several packets of food flavorings, all of the same size. The KNFB reader (an app for reading documents which converts text to speech) helps me identify flavors. I group together packets of similar flavors and put distinguishing marks on them, like folding the top side of the sachet.



ON THE DOT: The kitchen could well be a battleground, but a person with visual impairment need not hastily raise a white flag in defeat. They can win the battle by making the kitchen accessible and systematically organized. I have bump dots on the microwave oven, the dishwasher, the oven toaster, and the dryer.

to scan the floor. I practice the “Z pattern” of wiping, a method I have learned over time. It’s wiping across a linear area from left to right and moving down the next line from right to left, and so on. I use this same method in wiping down counters, bathtubs, and other surfaces in the house. Recently, I acquired Roomba, my robot vacuum cleaner and best friend that I can simply program to clean my home.

A “SMART” HOME

Most electronics have earned the label “smart” for saving people time, labor, and brain-use, sometimes to the point of encouraging laziness. But for people with special needs, smart devices are the breakthrough that empowers them to be productive and independent. Currently, adaptive technology in the homes for blind and visually-impaired persons include those that are controlled by voice, or through smartphones with accessibility features,

i.e., voiceover or magnification.

Take lights, for example. People like me who are blind do not need lights. But since I’ve given up all hope of training my sight-

Alexa can, among other things, control the security system, the TV and lights, adjust the house temperature, do online shopping, even play music as you tell it to.”

ed and partially-sighted family members to function in the dark, we set up proper lighting in our house. Lights do not affect me in any way except for times when I’m the last to go to bed, or when alone in the house and, like any responsible homeowner,

need to close down the house, lock all doors, turn on the security systems, and switch off all the lights and most appliances. If every light in our house were controlled by only one switch, turning them on or off should not be a problem. However, most of our lights have multiple switches, and I can never tell if they’re off by flicking the switches up or down. Thanks to my “Alexa”, smart lightbulbs, and all connected devices, this problem is solved. Alexa is a digital assistant who can control smart devices by means of voice commands, or through the phone. Alexa can, among other things, control the security system, the TV and lights, adjust the house temperature, do online shopping, even play music as you tell it to.

THE KITCHEN

For a visually-impaired person, the kitchen could well be a battleground with fire-breathing stoves, sword-like knives,

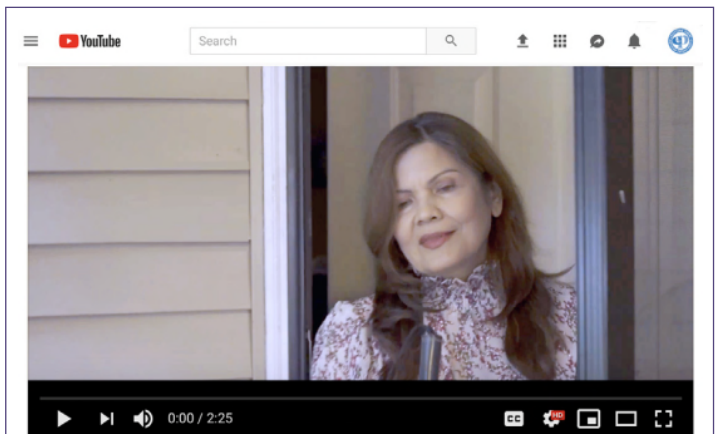


ALL SYSTEMS GO: Contrary to popular misperceptions, people with special needs can be efficient homemakers if they set up their homes to be accessible and orderly according to their requirements; Bump dots are the cheapest and best aids that can turn kitchen appliances blind-friendly

breakable porcelain traps, and slippery floors. But wait, a person with visual impairment need not hastily raise a white flag in defeat. One can win the battle by making the kitchen accessible and systematically organized.

Consider the stove, which has been modernized from having steel burners with elevated spokes where pots and pans could be precisely landed, to today's flat, conductive stove tops where cookware are set within white circles undistinguishable to persons with visual impairment. I initially thought this was a poor innovation that could end any visually-impaired person's cooking dreams – until I figured out a workaround. One only has to remember the sizes of the white circle drawings that match the diameter of the cookware, and the corresponding knobs that control each burner. Set the pan or pot on the similar circle, turn on the knob for that particular burner, and hover your hand over the area to feel from the heat emitted if the cookware is centered. Move the cookware to the middle accordingly. Then one can cook as usual.

People who are blind like me can prepare cooking ingredients “with our eyes closed.” When cutting, however, we need to be careful and attentive to what we're chopping or mixing into the pot. Ingredients, condiments, and seasonings that come in similar containers are labeled for identification.



July 2019 EP-Magazine Cover Story - Accessible Homes

EP Magazine's July 2019 issue cover girl is our monthly columnist Christina Llanes Mabalot. She demonstrates how a person who is visually impaired can make his or her home organized and efficiently-run with her article, “The Efficient Homemaker with Vision Loss.”

You can view this creative and informative video on EP Magazine's Youtube Channel: www.youtube.com/watch?v=gh18ZRY2-IQ



SMART IS AS SMART DOES: For people with special needs, smart devices are the breakthrough that empowers them to be productive and independent. The Reizen Talking Label Wand is a battery-operated, voice-output labeling system designed to help individuals have low vision identify household items, such as cans and jars, medicine bottles, toiletries and more.

I also utilize digital cookware that can be programmed by pressing buttons that beep, such as electric roasters, skillets and pots, as well as infrared ovens. These are usually high-end products and, thus, also come at a high price – but they are a good investment for persons with special needs and their families who love to eat.

Bump dots are the cheapest and best aids that can turn kitchen appliances blind-friendly. I have them on the microwave oven, the dishwasher, the oven toaster, and the dryer. The digital surface of

our microwave oven is pimped with bump dots. I have labeled the number 5 (which is usually the center of most keypads), and the cancel button to reset time – and lastly, the 30-seconds button, which I often use. On the dishwasher, the start and stop buttons are marked with bump dots. On the oven toaster, I tagged the “toast” button and the 250-degrees time, which is midway of the heat meter.

The clothes dryer has one knob that I’ve accentuated with bump

FLASHBACK : EMPOWERING TECHNOLOGY AND “EXTREME MAKEOVER HOME EDITION”

In July 2006, the Llanes family was living like the Jetsons (the family in the Sixties’ animated futuristic show). They were a household of six where all but one was born with special needs. My brother, Vic Llanes, the head of the family, and our mother when she was living, were totally blind from a rare congenital condition, aniridia. Two of Vic’s children, Guenivir and Carrie, have the same genetic special needs as their father and grandmother.

Meanwhile, Vic’s son, Zeb, is profoundly hearing impaired because his mother contracted German measles during pregnancy. Vic’s wife, Maria, was fighting thyroid cancer in 2006. Their house was one of the most advanced and high-tech home in the country that year, specially designed to empower the family to live accessibly. The Llanes family was chosen out of thousands of applicants for the “Extreme Makeover Home Edition” reality TV show that provides home improvement for less-fortunate families. The family was consulted by the Extreme Makeover team about their needs, difficulties, and desires as people with special needs. The original house was a 50-year-old, split-level unit furnished with steps in the most unlikely areas, cramped, dark, and with eaves in every side and corner.

Dr. Ronald Siwoff, an internationally-known leader in the low-vision field with over 25 years of practice helping people who have severe visual impairments, was asked to volunteer as a consultant to the Extreme Makeover design team. He explained how people suffering from aniridia have specific visual needs that may be different from those with other types of visual impairment resulting from the absence of irises. The iris, the doctor

explained, is the colored part of the eyeball surrounding the lens that is necessary for controlling the amount of light that gets into the eye. Dr. Siwoff inspired the team to build a haven of empowerment that would transform the lives of the Llanes family. He simulated the challenges of people with aniridia for the design team. As a result, extra care was taken to render the special lighting and textures within the home for the visually-impaired residents to navigate smoothly. A number of lights were installed for the family members to function maximally, and additional attention was devoted to regulating the glare from the exceedingly bright lights, which can be very painful and may worsen vision for aniridia sufferers. It was touching how Dr. Siwoff brought the experience of transforming the Llanes house to the hearts of the team.

About 3,000 workers, including the production team, were contracted for the Llanes house’s extreme makeover. After a week of construction, the Llanes’ residence was transformed from a “disabled house” to a “smart” one. Dubbed as the “Z home,” the Llanes residence had intelligent devices and gadgets from A-Z. Central to the transformation was the Home

dots, and that is the timer. One marker sits on the timer pointer. Two bump dots are fixed on the 0 and the 70-minute indicators, so I can set the time needed for drying the clothes. The other knobs click as you turn them, and all the visually-impaired person has to do is count the clicks to set the machine accordingly.

Our washing machine also is blind-friendly. The buttons are tactile and they beep with every push. If a person like me with memory loss manages to remember these buttons, usage should come easily to anyone. Just don't forget that you have clothes sitting in the machine.

HEALTH AND GROOMING

People with visual limitations are usually less mobile than their sighted peers, so there needs to be a conscious effort to stay active for health and wellness maintenance. I am able to watch my weight, or, better yet, listen to it with a talking weighing scale. (Unfortunately, I end up harming this device whenever it announces my weight within other people's hearing

range.) Exercising per se is annoying, but I feel exhilarated running on the treadmill since it allows me to listen to my audiobooks. My digital treadmill is well decorated with bump dots that indicate the speed, incline, and program levels. For measuring my blood pressure, I use a talking sphygmomanometer.

Ever since my husband caught me using his body wash for my hair, I've marked my toiletries with waterproof materials like rubber bands of different sizes to differentiate bottles. I don't rely on my husband to pick my clothes since I don't want to look like a cloistered nun, so I set up my closet according to my fancy. Occasionally, I end up wearing uncoordinated clothes, or shoes of different colors; nevertheless, I feel I can rock my brand of fashion just by looking confident.

Recently, my husband attempted to do his laundry and he announced that we were out of fabric softener. I told him we weren't, then directed him to move his hand to the sixth container to the right, and guess what? He found it – concrete

proof that systematic organization of one's home aids can greatly help one deal with visual limitations (as well as memory loss).•

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.

Automated Living system (HAL), that enabled the Llanes family to program lighting, heating and security systems via microphones, telephones, the TV, or the web.

Other smart devices included talking thermostats, smoke sensors that give spoken warnings, a Braille printer that was controlled wirelessly by computers throughout the house, a currency reader, a color identifier, a GPS system, and all sorts of Kurzweil products (a company that provides solutions for persons with disabilities) integrated into a computerized home-integration system. To top it all was the specialized communications gear, the system that depicts how technology contributed to connecting the hearts of every Llanes family members. This system converted the visually-impaired family members' speech into text and sign languages video clips that Zeb (the sibling with hearing impairment) could



EXTREMELY SMART: The Llanes family, Maria, Vic, Carrie, Isabel and Gwen, gathered outside of their New Jersey home for the reveal of their extensively remodeled home. After a week of construction, the family residence was transformed from a "disabled house" to a "smart" one.

see. In reverse, it converted Zeb's typing into speech, which his blind father and visually-impaired siblings were able to listen to. This miracle of technology established secure communication between Zeb and the rest of the family, thus preventing a feeling of isolation due to his dissimilar impairment.

The Llanes episode was the summer special of that year's Extreme Makeover Home Edition. The production team hired Academy Award-winning actress Marlee Matlin, who is profoundly hearing impaired (and an Oscar winner for *Children of a Lesser God*) to host this moving episode which attracted a number of viewers

and raised funds needed for the production.

To learn more about the television show's production and airing, visit: <http://derok.net/randomness/derok/extreme-makeover-home-edition.html>

HOME MODIFICATIONS

THINKING

OUTSIDE

THE

Children and people with disabilities may need modifications to their family home.

Beyond the usual ramps and lifts, there are other considerations for home modification.

BOX

BY LAUREN AGORATUS, M.A.



ACCESSIBILITY Physical access is essential for caring for children with special health care needs at home. Even if a child doesn't use a wheelchair, some children may have motor skills issues that make it difficult for them to get around at home. Other children may come home weakened from multiple hospitalizations and can't do what they used to do. Accessibility using universal design may benefit both the child and family. For example, a child who can't get into a tub for whatever reason could benefit from a walk-in shower. Adjustable showerheads, non-skid tub floors, and grab bars can make bathing easier. Shower chairs can help with personal care and some showers now come with built-in benches.

HEALTH Medically-fragile children could benefit from items that reduce the risk of infection. For example, a whole house humidifier could help in the winter months. There are also whole house air filters, which provide the home with hospital quality air. Many children with disabilities have medical equipment on which they rely. Other children may have to be in climate-controlled conditions. Some children have special medications that need to be refrigerated. Stand-by or whole house generators will provide electricity for

medical equipment, heat/air conditioning, and refrigeration in the event of a power outage. Please note that some utility companies prioritize power restoration if the family makes them aware of their circumstances, i.e., having a child or family member that is critically reliant on electrical power, prior to power being out.

SAFETY Some children with developmental disabilities, such as autism, may wander away from the home. Special window/door locks, alarms, and tracking devices may help prevent this. Families may want to consider a fenced-in yard.

Other children may be on restricted diets, or suffer from Prader-Willi Syndrome, and constantly seek food, while others may have pica and eat unsafe nonedible items. There are cabinet, stove, and refrigerator locks for this purpose.

Children with special needs with poor muscle tone may be at risk of falls. Checking the home for fall hazards is essential in this case. Bare floors or wall-to-wall carpeting are better than area rugs. Homes on one level are safer than those with stairs, which could be blocked off with baby gates if needed, or basement doors locked. There are now even kitchen draws and cabinets that cannot be slammed which self-close and have a rubber stopper preventing injuries. There are portable bed rails for children who fall out of bed. Parents can use baby monitors for children who have seizures. It is beyond the scope of this article, but families should have emergency preparedness plans in place for their children with disabilities.

WHERE WILL MY CHILD LIVE IN THE FUTURE? With supportive housing, many children with disabilities can live independently as adults. Families of children who may need lifelong care may want to consider home modification for their child to have a roommate or live-in aide. Some families have used an extra bedroom or even added a room to their home for this reason. Others have pooled funds with other families to create a group living situation. For young adults with disabilities remaining at home, families should consider privacy needs and solutions such as intercoms, if needed.

AGING IN PLACE FOR BOTH THE CHILD AND FAMILY Some types of disabilities have similarities with aging or even result in earlier aging, such as dementia. Home modification can help both the child and parents remain in their home as they age. Accessibility features, falls prevention, and other safety devices such as personal emergency response systems (PERS) can allow people with disabilities and their families to remain in their homes and communities. PERS now have fall detection, are waterproof for bathing, and the individual doesn't even have to make a call as it is automatic.

There are many considerations for home modifications beyond the typical accessibility features. By thinking beyond the usual items that come to mind for people with disabilities, children with special needs and their families can benefit from modifications that improve their health, safety, and future living needs.

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

MAKING A HOUSE A HOME : ACCESSIBILITY RESOURCES

DESIGN RESOURCES



**CENTER FOR INCLUSIVE DESIGN
AND ENVIRONMENTAL ACCESS**
The Principles of Universal Design
<http://idea.ap.buffalo.edu/udny/Section3.htm>

POSSIBLE FUNDING SOURCES

- **STATE/COUNTY OFFICE ON DISABILITY**
- **DEVELOPMENTAL DISABILITY COUNCILS**
<https://nacdd.org/councils>
- **CATASTROPHIC ILLNESS FUNDS**

Click on Title V in your state at bottom of page
<https://mchb.hrsa.gov/maternal-child-health-initiatives/title-v-maternal-and-child-health-services-block-grant-program>

- **CIVIC GROUPS: KIWANIS, ELKS, JAYCEES**





More than half the battle for parents is first to see the components and the phases of housing as a loved one with a psychiatric disability might experience it.

Vanquishing the Vexation of Housing for Loved Ones with Psychiatric Disabilities

BY TOM PYLE, MBA, MS, CPRP

A great vexation of families navigating mental illness is housing. Once a loved one's psychiatric situations is sufficiently reliable, a family's thoughts inexorably turn to the quest for a suitable abode for the loved one. Because loved ones with mental illness tend to be both disabled and poor, their housing need is acute, but their financial capacity abject.



A Quagmire of Questions

Many loved ones with psychiatric disabilities continue to live with parents. This is usually a good thing; the family can give social, financial, and moral support – provided that the family and loved one can overcome the challenges a loved one's illness can pose. Assuming the best, then a gigantic worry eventually arises: what to do for the loved one's housing after the parents pass on? Assuming the worst, where loved ones abandon or are abandoned by their families, loved ones often must default to substandard boarding homes and shelters. This often leads parents to incessant worry or insufferable guilt. Worse still, not a few ill loved ones may live in their cars, if they have them, or in railway stations, under

bridges, and on the streets, the nadir of all possible living situations, especially for one with a psychiatric disability.

The vexation for families comes when confronting the critical questions about housing for their disabled loved ones... Where to find it? How to afford it? What to expect of supports along with it? How long can one keep it? Who has priority for it? How to qualify for it? Who else is competing to get it? The ways and means to get appropriate housing are complex, confusing, and sometimes contradictory. Where do parents even begin?

Housing's Three Key Components

Perhaps the best start is to break down the housing conundrum into components.

There are three aspects of housing: *stock*, *subsidies*, and *supports*. *Stock* refers to the actual number of units in any particular market. Tragically, housing stock in many states is in short supply. Housing prices and rentals in many locations thus rise beyond reach even for the middle class, but especially for the poor. Programs to increase housing stock include special government grants and loans and tax credits for builders of new housing stock, especially when intended to provide for the poor of disabled.

Second are *subsidies* that can reduce to cost of renting or buying an abode. Market rental rates often far exceed a poor person's ability to pay. A real estate rule-of-thumb says that a person's rent should total no more than 30% of one's disposable income.

Yet market rents even for modest one-bedroom and efficiencies can eat up even 80% or more of one's disposable income.

Programs providing rental subsidies include Federal and state programs. The best known Federal rental subsidy is the "Housing Choice Voucher" (formerly "Section 8 vouchers") provided by the U.S. Department of Housing and Urban Development and generally passed through state entities.

Third are *supports*, critical for many loved ones with psychiatric disabilities. These include intensive full live-in supervision and care staff among the residents in "group homes". They also include moderate supports like visits by a social worker, employment counselor, education consultant, direct support staff, psychologist, and even psychiatrist, all to assist the loved one manage daily life. They can also be only very light supports, perhaps only a weekly visit by a social worker, or a collective food shopping outing.

Housing's Seven Phases

Another way to think about housing is temporally, by the stage or phase in time of a loved one's potential housing odyssey. For a disabled loved one, there are seven (7) stages, ranging from most dependent to independent. The first phase might be considered the simplest and surest: *familial housing*. A loved one living with parents, at least theoretically, can enjoy housing that is lowest cost (e.g., free), supportive, and secure. While the true service level from the family is usually high, use of outside services in this phase is usually very low. Of course, familial housing presupposes an intact family that is financially capable. Often the opposite is true, if the mental illness breaks the family apart.

Family break-ups can lead to the second phase of a housing odyssey: *emergency housing*. When a mental illness skews symptoms and behaviors, bad things can quickly befall a loved one's health. Thus, the most emergent form of housing is a hospital emergency room. Another emergent form of housing are emergency shelters, where a loved one without a place to stay might find housing only a few nights.

But far too often, shelters are few and their beds scarce and hard to access, not to mention unsanitary and unsafe.

The third phase is usually *transitional housing*. Except for very severely psychotic loved ones unable to live in the community, hospital inpatient commitments can be considered transitional. Their ultimate goal is almost always community placement upon discharge after a shortest possible stay. Other transitional housing entities can house loved ones for only a limited period



"For a disabled loved one, there are seven stages of housing, ranging from most dependent to independent."

of time, such as six weeks, as a bridge from homeless or emergency housing to more permanent solutions. These assume that a loved one can find, or the market provide, such an abode in such time.

The fourth phase is *supportive housing*. "Supportive housing" is a term of art in professional communities that serve the disabled. It is a combination of housing and services intended as a cost-effective way to help those with the most complex challenges live more stable, productive, integrated lives. The level of supportive housing services ranges from high, as in group homes, to low, as in so-called scattered site housing. Families of loved ones with psychiatric disabilities often view supportive housing as an ultimate goal, anxious about a loved one's abilities to live truly independently. A goal of supportive housing is eventually for a loved one to recover sufficiently to be ultimately capable of independent living. An expensive kind of housing for governments, the availability of supportive housing is usually very constrained.

The fifth phase, *subsidized housing*, is housing generally offered at below market rates to for the indigent. Federally funded public housing authorities or projects can be considered as subsidized housing, receiving their subsidies for their buildings directly from the government. Private landlords participating in subsidized rental voucher programs such as "Housing Choice" (Section 8) vouchers are also part of this phase, although their subsidies are linked not to their buildings but to individual tenants who present rental subsidy vouchers.

The penultimate phase is *"affordable" housing*. The definition of affordable hous-

ing will vary from state to state. In New Jersey as one example, affordable housing is a kind of privately-developed housing derived in new building projects. Typically, developers must dedicate 20% of units in a new housing project to the affordable housing category. Renters or buyers of such units are typically designated by income category, such as "moderate", "low", and "very low". Each category is defined by a family income range set by the government and depending on family size. Typically, there are no subsidies in affordable housing. To bolster the lower revenue flows from affordable housing rentals, project developers adjust their market rates for the rest of their units accordingly. The economic benefit of an affordable housing unit to a loved one qualified as a very low income renter can be substantial. A very low income unit rental can be four or five times below the rental for a comparably sized unit on the regular market. A very low income purchase price for an affordable unit can be half the market price.

Finally, the seventh phase, with the most plentiful supply, but too often for those with disabilities with the least attainable prices, is of course *regular market housing*.

Understanding the First Step to Planning

For families navigating the maelstrom of mental illness, the housing challenge is vexing. More than half the battle for parents is first to see the components and the phases of housing as a loved one with a psychiatric disability might experience it. Understanding its three aspects (stock, subsidies, and supports) and its seven phases (familial, emergent, transitional, supportive, subsidized, affordable, and market) is half the battle. It can be a great help both to reduce undue parental anxiety and to begin charting a long-term strategy for navigating the treacherous shoals of housing for loved ones with psychiatric disabilities.

ABOUT THE AUTHOR:

Tom Pyle is father to a loved one with a psychiatric disability. Previously a banker and education foundation executive, Tom returned to school for a master's degree in psychiatric rehabilitation. A member of the New Jersey Behavioral Health Planning Council and board member of NAMI Mercer in Lawrenceville, NJ, Tom serves families and agencies navigating the maelstrom of mental illness. Contact him through:

www.psychodyssey.net

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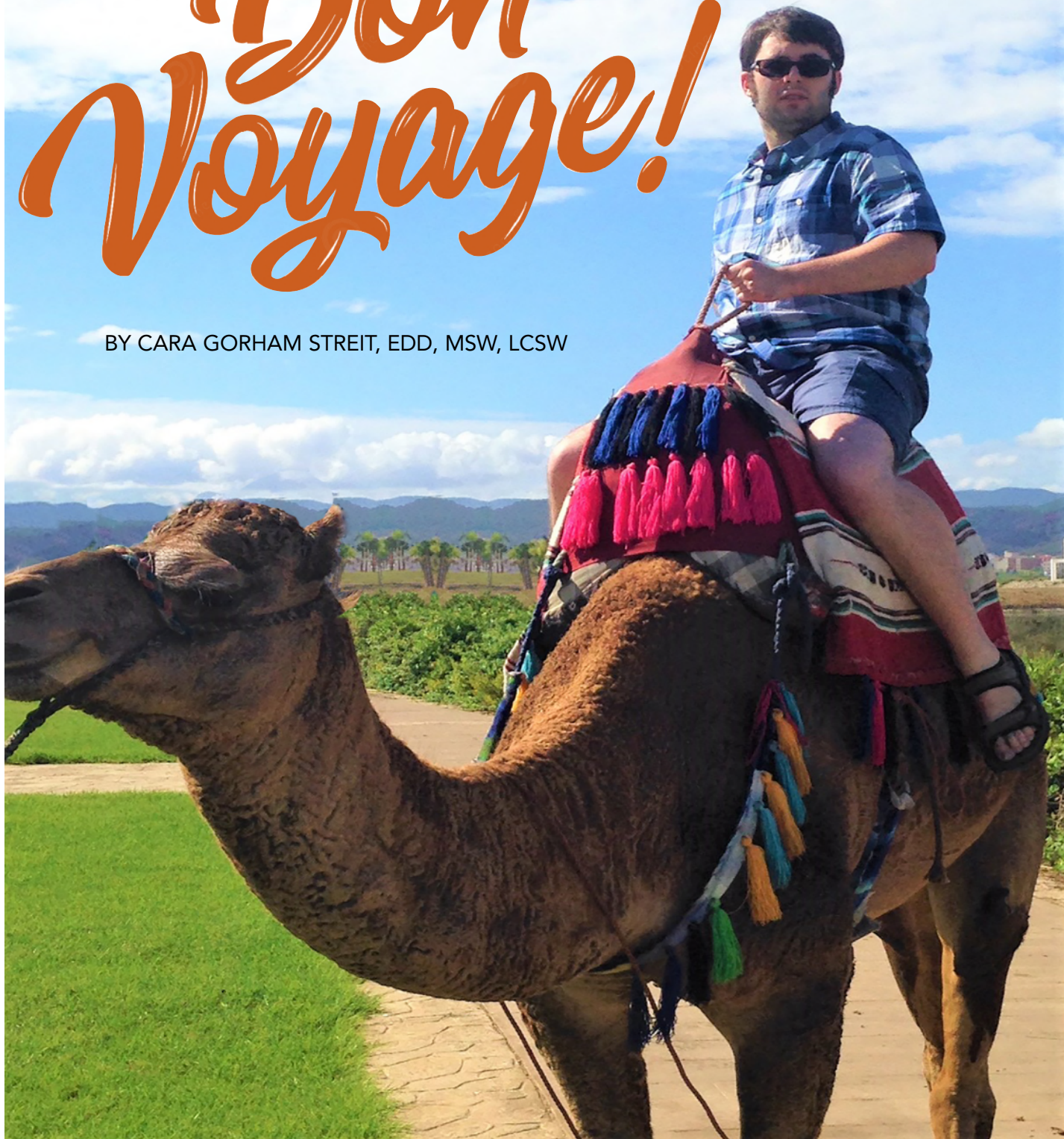
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EP MAGAZINE: THE JOURNAL FOR SPECIAL NEEDS FAMILIES AND PROFESSIONALS

Bon Voyage!

BY CARA GORHAM STREIT, EDD, MSW, LCSW



Accessible and inclusive international trips are becoming widely available through middle and high schools, colleges, non-profits, and for-profit travel agencies, and the benefits of these experiences are deep and long-lasting.

“What are your plans for the summer?” How many times are we asked that question at the end of a school year? Any one of us would be thrilled to be able to answer “Oh, I’m going on a cruise around the Greek islands,” or “I’m spending a couple weeks in Germany and the Swiss Alps.” More than ever before, adolescents and adults with diverse disabilities have opportunities to engage in these exciting conversations.

Accessible and inclusive international trips are becoming widely available through middle and high schools, colleges, non-profits, and for-profit travel agencies, and the benefits of these experiences are deep and long-lasting.

Whether you are a self-advocate, a parent of a child or adult with a disability, or a professional, read on to find out how inclusive travel changes lives. As your tour guide may say while you’re gallivanting through Paris or Madrid, *allons-y, vamos, or let’s go!*

WHY TRAVEL?

“All journeys have secret destinations of which the traveler is unaware.” – Martin Buber

- **Learning about other cultures**, people, landscapes, food, types of art, and ways of being in the world expands our perspective and helps us to understand that we are one small part

of a much larger world. This understanding builds awareness, tolerance, acceptance, and empathy for others.

- **Travel challenges us by taking us out of our comfort zones** and giving us new experiences we never could have anticipated. It teaches us flexibility and increases our tolerance for change and uncertainty in a way that feels exciting and adventurous, even when it’s also a little scary!
- **When we travel, we get chances to practice our skills for independence** in a setting that is highly motivating. Don’t want to miss the guided tour of the Colosseum? Gotta get out of bed and get down to the lobby ready to go!
- **Inclusive travel opportunities are often group-based**, and social engagement is an inherent part of the experience. Generally, group leaders for inclusive tours will intentionally and skillfully facilitate connections between travelers. Staffed small group outings, buddy systems, roommate pairings, and rows of seating on coach buses, planes, and trains create natural opportunities for travelers to have shared experiences, an excellent foundation for new friendships.
- **Not only does traveling with a group promote the development of new connections** on tour, it also helps us connect with others when we get back home. Having an adventure gives us something interesting to talk about with other people! This is especially powerful for travelers who may face barriers to developing strong social connections or making small talk. Stories about adaptive zip lining in Costa Rica, buying spices in a market in Morocco, or that time your group leader didn’t get off



AMAZING VIEWS: (*Opposite page*) Patrick experiences exotic Tetouan, Morocco; (*Below*) Tourists marvel at the Colosseum in Rome; Italy



What should I consider, and how do I prepare?

Whether travelers are self-advocating for their needs, or have a caretaker or staff person advocating with/for them, it's important to consider the ways in which life abroad, even for short stretches, will be different than life at home. Planning ahead for these differences will minimize their impact and maximize the traveler's enjoyment!

• **Physical accessibility:** Every country has its own unique laws about physical accessibility to public transportation, monuments, landmarks, hotels, restaurants, etc. It's important to do research and make your needs known in advance. When traveling with a group, make sure the group leader or travel coordinator understands any accessibility features you need. Make sure to think about air-plane, bus, boat, public transportation, and other methods of transit that could be involved, as well as overnight accommodations and major tourist sites.

• **Food sensitivities and allergies:** It's not always easy to get allergy-sensitive meals in other countries, especially if you don't speak the language. If you have a serious allergy or sensitivity, in addition to the usual precautions you would take at home, make sure to carry a note card with you that explains your allergy in English and in the local language of the place you are going so you can show it to food service workers. Have an EpiPen with you, if you use one, and make sure fellow travelers, especially group leaders, are aware of your allergy.

• **Other health conditions:** Just like with allergies, it's important that group leaders are aware if you have a medical condition that could need treatment while abroad. Talk to your doctors about upcoming travel plans to find out if there are any additional vaccines or other precautions needed, and if you take prescription medications, consult with your provider on how to adjust the time you take them for any time change you'll experience. Bring extra medications with you, and carry your meds in your carry-on luggage if possible, to avoid them getting lost in transit. Bring a wallet card that explains your medical conditions and lists your medications and dosages in

English and in the national language of your destination. For ease at airport security, bring the original prescription bottles, even if you also have your medications counted out in day-of-the-week containers.

• **Changes in routine:** The excitement of traveling is as much about the experiences you never could have predicted as about the ones you've carefully planned out. If that thought gives you some anxiety, fear not. Yes, routines are an important part of life for many people, with and without disabilities, and there is no question that traveling disrupts those routines rather dramatically. Some of the anxiety this could cause can be managed by taking time to preview the idea that disruption is going to happen. For example: "The schedule for the day will be different than it is at home." "The food is going to be different than what you usually have." "It will be hotter there than it is here." Knowing some of the changes in advance, even without being able to predict exactly what the experience will be like, helps make the changes feel more manageable. At the same time, some things can stay consistent and give the traveler some grounding, so go over the things that will stay the same. "You'll still take your medications at the same time." "You'll still have your headphones and your music with you when you need them."

• **Money:** For many people, money management is a challenge, and when you're using a different currency than the one you're used to, it gets even more complicated. Downloading a currency exchange app on your phone/tablet that works both on and offline can help you understand what you're spending. Need to know what this 2,50 soda costs from euros to US dollars?

Pop it in the app and find out (and yes, the comma in 2,50 is correct; that's another interesting difference you'll learn about when you travel!). Make sure to put a travel flag on your account for any debit or credit card you will bring so your banks don't think your card was stolen and shut it off. This can be done over the phone using the customer service number on the back of the card, and sometimes online. Finally, buy a little bit of the currency you need from your bank at home before you leave.

• **Packing:** Consult with the leader of the group on what to pack and how to pack it. They should have suggestions and will know the luggage allowances given the modes of transportation involved in your tour. Pack light, but do bring things that make you comfortable or would be difficult to get abroad. Toiletries and personal hygiene products may be very different in other countries, so bring the items you like with you from home. I also prefer bringing enough clothing so that I don't have to wash anything while traveling and I can spend my time enjoying the sites. Your preference may be different, and your group leader will know if it will be possible to do laundry while on tour. Understanding your daily itinerary and the weather will help you to pack appropriately.

Make sure to leave room in your suitcase to bring back souvenirs!

• **Get excited:** Most important of all, think about where you want to go and what you want to see! International travel is a big commitment of time and resources, so make sure you're headed for a destination you're really excited about and with a group/organization that you think you will vibe well with. Learn about the place you're going so you can understand and appreciate what you see.



the Tube in London before the doors closed and she ended up at Piccadilly Circus – these are topics that almost anyone will find interesting in conversation. P.S... Did that last part happen to this author? She'll never tell!

• **Finally, you won't really know why you should travel until you do it!**

There are plenty of reasons to book a trip, but you can't appreciate the real impact of travel until you've tried it. Your fondest memories will be of things nobody told you would happen. My favorite example of this happened in 2018 on a trip to Greece. Because of significant flight delays, our group was re-booked on one of the nicest airlines in the world, and three members of our group were upgraded to first class for free. On a 12-hour flight! Upon sitting down in their fully reclining, semi-private luxury cabins, they were offered pajamas and a pair of slippers. They sure couldn't have predicted that, but they'll never forget it!

Not convinced yet? These seasoned travelers are happy to tell you what they love about exploring the world:

"I feel like I'm living an adventurous life when I travel!" - Leslie, age 40

"I travel because I love to learn about the cultures of other countries. I feel independent and enjoy meeting new people. Traveling in a group makes me feel safe and secure." - Brandon, age 28

"The reason I love traveling is because it is a wonderful experience for new adventures and seeking new experiences." - Olivia, age 27

"The reason why I love to travel and loved traveling to Greece is that I love meeting new friends and eating new food and experiencing the culture!" - Chelsea, age 33

HOW DO I FIND A GROUP TO TRAVEL WITH?

For school-aged students and college students with disabilities, school-sponsored trips can be an excellent option. Typically highly organized, structured, and supervised, these trips offer all or most-expenses paid options, usually have travel insurance, minimize the dreaded "free time," and generally have extensive emergency preparedness plans. As a bonus, they are often led by teachers or other school staff who are accustomed to working with students from a wide range of backgrounds and experi-



EXPANDING HORIZONS: Travelers Hunter and Jessie explore the sites in Mykonos, Greece; Understanding that we are one small part of a much larger world builds awareness, tolerance, acceptance, and empathy for others.

ences. Scholarships and structured fundraising opportunities may be built into these trips, making them more affordable than traveling on your own.

Adults can find travel opportunities through for and not-for profit organizations that specialize in inclusive travel. In the case of non-profits, subsidized spots may be available for travelers with financial need. Many travelers with disabilities can also travel through agencies and organizations that design individual and group travel experiences for all adults, with or without disabilities.

For more information on accessible and inclusive travel, try internet search terms like "travel agencies for people with disabili-

ties," "accessible tourism," "international travel and autism," and related terms that fit your interests and background.

Bon voyage, and enjoy your next adventure! •

ABOUT THE AUTHOR:

Cara Gorham Streit, EdD, MSW, LCSW is the Associate Director and Director of Academics, Innovation & Inclusion of the Lesley University Threshold Program in Cambridge, MA, a comprehensive, college-based postsecondary program for young adults with a range of intellectual, learning, and developmental disabilities. Dr. Streit has organized and led international and domestic trips with Threshold Program alumni and EF College Study Tours to a number of destinations including Greece, Spain, Italy, France, England, and Germany.

A DAY IN THE LIFE



OF A MOTHER WITH A HIGH FUNCTIONING ADULT SON WITH AUTISM

BY SARAH KENNEY

I wrote this for parents who may share some of their frustrations experienced with their special needs child when taking them on a vacation. I felt as though it was such a rough, long day and that it is important to share it with other parents so they feel they have company in their strife.

One day in my life... The following is a text I had written in July 2017, re-sent to me by my niece:

OMG I just got to the vacation destination with Patrick at 9:00 PM (distance from his apartment 2.5 hours)

I left my place at 7:30 AM – A very loooong day for sure... I drove an hour to “himself” and his dog and I got to his apartment door...

(Yes, HIS apartment and I thank you, National Louis University, The PACE Program in Evanston, Illinois, he is living in his own

**AND SO, OPTIMISM
IT IS, AND THIS MOM
WILL CALM DOWN
AS SHE HAS NO
CHOICE IN HER
MIND SO...**

**TO MIMIC A LITTLE
LESLEY GORE CIRCA
1963...**

**SUNSHINE,
LOLLIPOPS AND
RAINBOWS...**



A MOTHER WONDERS: "One day at a time," my mother used to say, and, "Tomorrow is another day." Where was my mother when I needed her? I wonder how different my life would be today if she had not gone into the deepest depths of depression. Maybe my overall life choices would be different or better or, at the very least, happier.

apartment. Although, I will never forget his voice as he called me crying for weeks from "college." The only way we were able to get him to go was to tell him he would be homeless otherwise. In order for him to stay there, we bribed him with a dog from the pet store where he was "working" through the PACE program. Eventually, he didn't want to come home on the week-ends.)

He isn't answering the door while I

pound on it and call his phone.

Finally, after 30 minutes, he comes out with his dog...

I said, "Why didn't you answer the door?"

Then I noticed he had earphones on... Seriously, that was the start of the vacation...

"Paddy me boy," proceeds to tell me he can't go on the trip we planned for nine months...and he angrily replies, "It's because mom, you said we might change the day that we leave." (It was a big mistake to think out loud on my part).

I answered, "That was two weeks ago, but I texted you and talked to you and said I am coming today and you didn't tell me that on the phone..."

Ugh so... he took a shower and I packed his suitcase: clothes, meds, toothbrush and fishing stuff and dog, of course...

Then I dropped off Kringle pastry at the dentist's office because I promised him and he gives us discounts...

Then I took Patrick to Joseph Banks Men's Store to get pants and a shirt...

Of course, they don't carry his size (19" neck & 33" sleeve)

Then I took Patrick's pants to the tailor to get pants shortened...

Then I took him to Walgreens for his meds because he needed some refills.

Oh, and let me add that he forgot to refill and bring his Metformin (for Type 2 diabetes) medication... Then the pharmacist stated that he has not filled it since(last) October (now July), and we had to transfer the prescription to a different Walgreens en route because we couldn't wait for it in Milwaukee.

I said, "Patrick you can't not take your medicine and that's why you gained all that weight... ugh."

"But my numbers are good," he then exclaimed that he doesn't like the medication because it gives him "the" diarrhea... UGH!

Then we took his dog to the vet for a shot so he can go to the dog kennel,

Then I dropped off a check at a gal's house for a wedding gift,

Then lunch – with a glass of red wine...

Then a new doctor for my thyroid issues, en route to our destination...

Then we walked into a place on the road

to get Patrick's beard, mustache, hair trimmed because he looked like Grizzly Adams!

Good Lord, this mom tried to calm down...

Then dinner – a glass of red wine... at the restaurant where he orders the most expensive thing on the menu...

Finally, we take the dog to the kennel.

I just sat down at 10:00 pm.

"Pooped," as dad used to say.

"One day at a time," my mother used to say, and, "Tomorrow is another day."

Where was my mother when I needed her? Since 1963, she chose to sleep in a grave at Arlington National Cemetery... suicide... I'm not sure of the reason, but there are speculations...I wonder how different my life would be today if she had not gone into the deepest depths of depression... Maybe she would have been at the hospital for that horrific labor and delivery of my first child, so he might have been spared his brain damage from lack of oxygen and be able to pay taxes and have a wife and child of his own. Maybe my overall life choices would be different or better or, at the very least, happier.

Luck and fate and destiny...

So I was raised to be an optimist by my father who grew up in the Depression in an abandoned circus wagon until he was taken away and given to the nuns then joined the Marines to have his first pair of shoes without holes...

And so, optimism it is, and this mom will calm down as she has no choice in her mind so... to mimic a little Lesley Gore circa 1963... Sunshine, lollipops and rainbows... just like the double rainbow I discovered while traveling in Dingle, Ireland... and the good luck that those rainbows are supposed to deliver as I sit on hold with Social Security Medicaid and Medicare and try to sort out the government's mess with my son's special needs status.

But the good news is that my boy is happy in his own little world.

ABOUT THE AUTHOR:

Sarah Kenney Is a retired speech-language pathologist (35 years in a school district) and a mother of an adult son with special needs.

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YOUR POWER OF CHOICE

BY ELLEN NOTBOHM

- A. “Overwhelmed.”
- B. “Paralyzed.”
- C. “Crushed.”
- D. “Scared.”

All of the above. These evocative words embody some of the first emotions to erupt in many parents of children newly diagnosed with autism. And no wonder, as we confront the sheer volume and weight of the decisions we now face and the bewildering range of choices within each decision, on subjects unfamiliar and unnerving. As time goes on, we find that the demands of having to make such choices never ends. Our child travels his or her developmental timeline, matures, outgrows choices and solutions that once worked, faces new challenges requiring us to search out or create new alternatives.

Do we find those choices empowering—or overpowering? Rare is the parent of a child with autism who hasn’t at least once felt strapped to a pendulum reaching one of its polar apexes of too many choices, or no choices. This uncomfortable dichotomy leads to the same need—a way to make choices in which we can feel confident. Although we know intellectually that there are no perfect parents, and that mistakes and missteps are inevitable, we may also feel that we simply can’t make mistakes, that there is too much at risk. We fear making the wrong choices.

We need strategies for making the best possible decisions, whether from a slate of inferior options or viable ones.

It’s like a never-ending multiple-choice test. Fight or flight? Some parents facing (or fleeing) this avalanche of choice will search for the nearest escape route, and they’ll easily find it. They can choose to allow others to make the many decisions

necessary about their child’s education and health. Absent parent input, school personnel will make decisions about a child based on many factors, some with heartfelt effort to act in the best interests of the child, some with expediency or cost-efficiency as the primary motivation. Parents can make the choice to accept without question the recommendations of therapists and clinicians, regardless of whether the advice is acutely individual to the child’s needs, or generalized treatments and practices (“this is how we do it for all autistic kids”).

But most parents and guardians I’ve encountered choose fight over flight. They step up to take the responsibility and the lead in making these choices. They recognize that in the ever-changing array of professionals in their child’s life, parent/guardian stands as the constant. Teachers turn over annually, doctors and therapists change, caregivers, counselors and coaches come and go. It falls to the parent/guardian act as Information Central, to ensure that the aggregate knowledge and wisdom, the sum of the choices we’ve made for and about our child, passes

firmly into the hands of those who will play roles in the next chapter of his life and who will shape the next round of choices we must make.

But choice, that weight swinging from the pivot point of the pendulum, can arc to the converse side of feeling overcome by endless, numberless choices. Sometimes we can’t see the forest or the trees. “I had no choice.”



Title: **Ten Things Every Child With Autism Wishes You Knew 3rd Edition, Revised and Updated**

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When I hear this declaration from parents, it's usually tinged with dejection, often fueled by melancholy, fear, anger. I just did an internet search for the phrase and got 23 million results. That's a lot of anguish, desperation, bleakness. It can swamp us when we reach junctures where we feel we have no choice but to take action against our schools, leave spouses/partners, cut off family members, resort to medication. Or we simply take no action because we feel we have no choices. (Doing nothing is a choice. Sometimes it may even be a sound choice.)

When we say we have no choice, we most often mean we have no palatable choices. No attractive or appealing choices. No acceptable or practical choices. Or that we've exhausted all the choices we've been able to identify.

But crummy choices are choices nonetheless. Here's an example. A common no-choice conundrum for parents of autistic children is the family member or members who do not—choose not to—understand autism's effect on the child. They often voice strident criticism of behaviors, impatience with sensory challenges, refusal to modify methods of communication or to otherwise accommodate and respect the child's needs. "We have a few family members who crush my son's self-esteem every

time they are around him," a parent will tell me. "My only choice is to ease them out of our lives, quietly."

This parent's choice is understandable, justifiable and even logical, but it was by far not the only choice. S/he could also have chosen to:

- *Confront family members aggressively. "Your refusal to accept how Ben's autism affects him is damaging him, therefore we will allow you no further contact with him."*
- *Confront family members firmly but evenly. "I am sure you love Ben, but I don't think you realize how much your constant criticism hurts him. Until you can respect how Ben's autism affects him, it's in his best interest that he not be around you."*
- *Continue to attend family gatherings and confront each instance separately. "That's the second time in fifteen minutes you've criticized Ben for something he can't control. If you do it again, we will leave immediately."*
- *Take the passive-aggressive approach, cutting off contact with no explanation or communication.*
- *Ask a sympathetic family member to intervene with the offending members.*

- *Ask family members to attend family counseling.*
- *Ask family members to accept information about Ben's autism from a professional, such as his doctor, teacher or therapist.*
- *Ask the offending family members to propose a solution. "I can't allow your continued put-downs of Ben. What actions are you willing to take to change things?"*

With a little brainstorming, the "only choice" becomes "many choices."

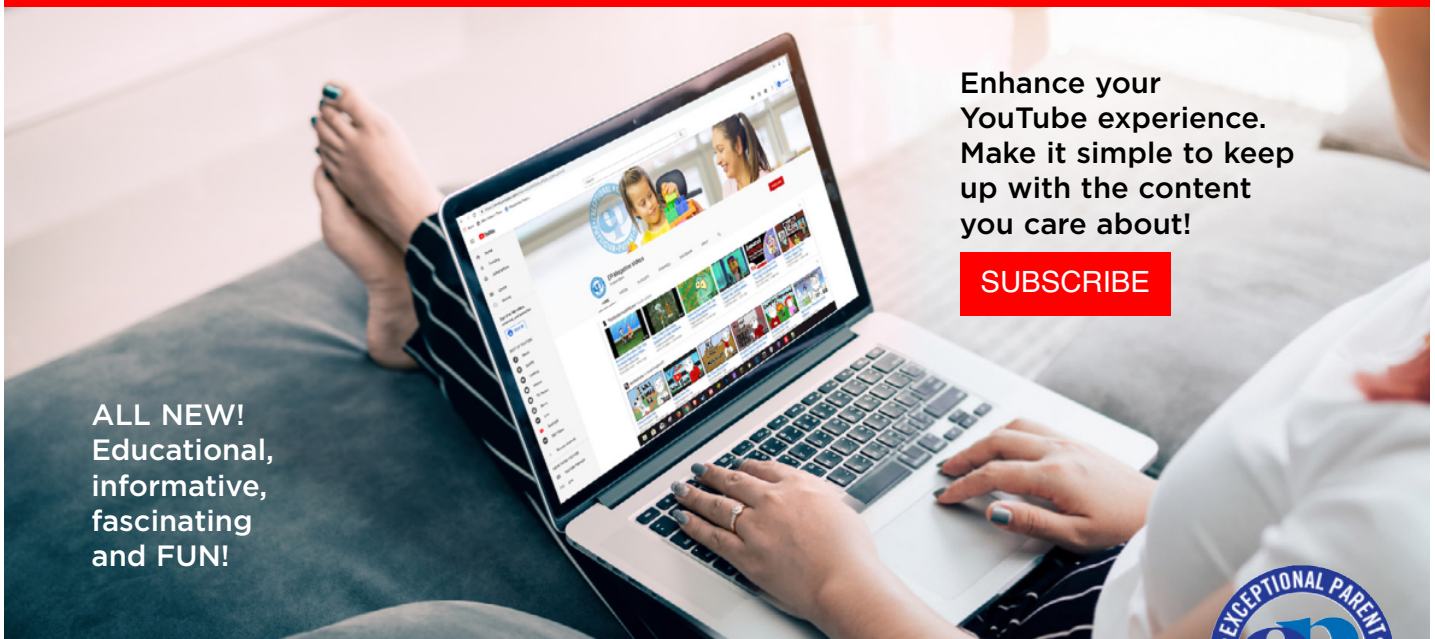
When we explore the expansiveness of choice, we mine the value of summoning the patience and fortitude to consider the widest range of choices we can muster, individually and comparatively. Because seldom is the instance in which we truly have no choices... •

ABOUT THE AUTHOR:



An internationally renowned author and gold medalist in both nonfiction and fiction, Ellen Notbohm's work has informed, inspired, delighted, and guided millions in more than 20 languages. Connect with her at ellennotbohm.com and on Facebook, Instagram, Twitter, LinkedIn and Pinterest.

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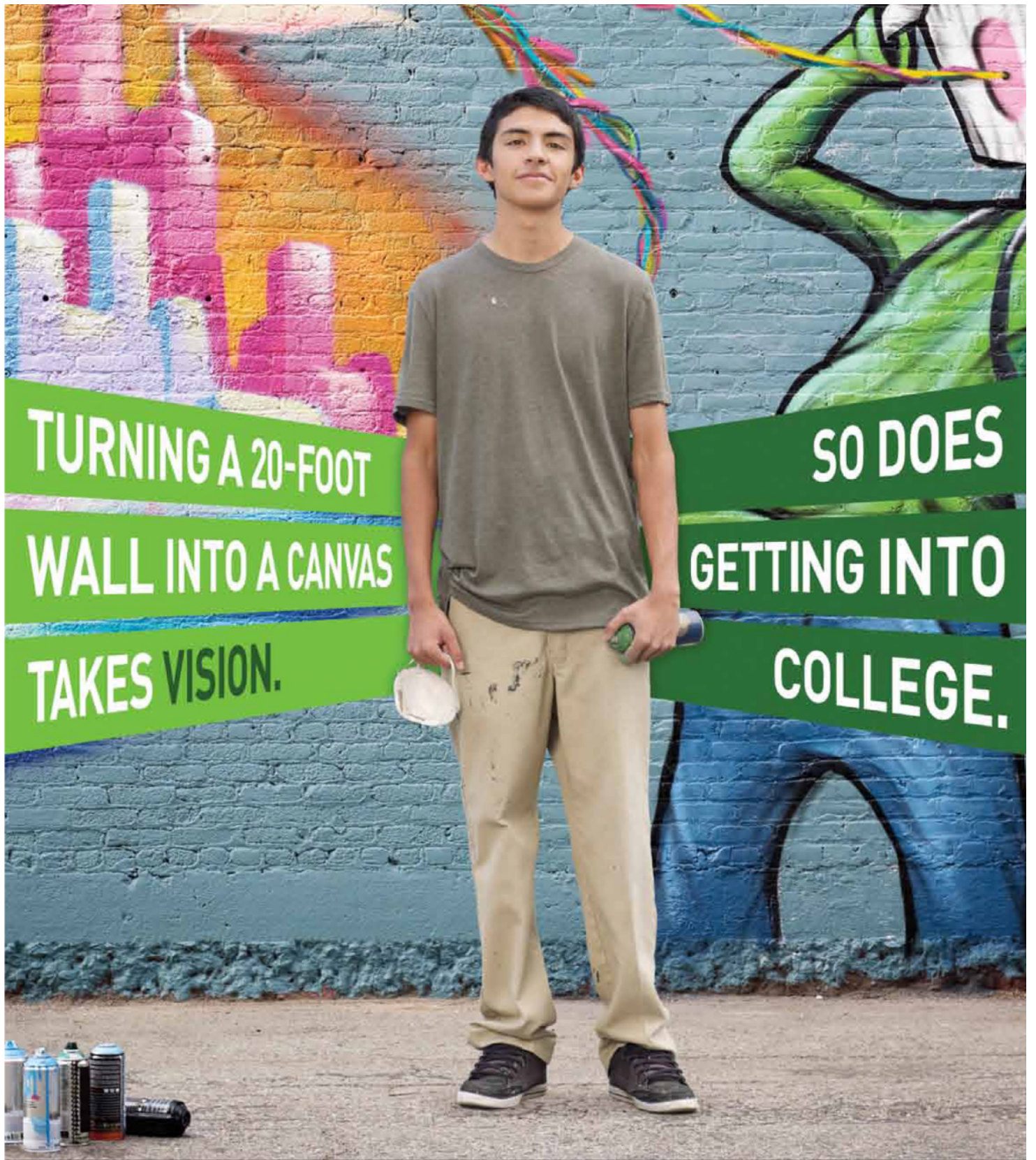
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For every weather event and new lesson learned, it is easy for me to say, "I didn't think of that!" What follows are some of the new things I learned over the past decade that might be helpful with when planning for your family's safety for the next hurricane season.

THINGS WE DON'T THINK OF WHEN CREATING OUR EMERGENCY PREPAREDNESS PLANS

BY LAURA GEORGE

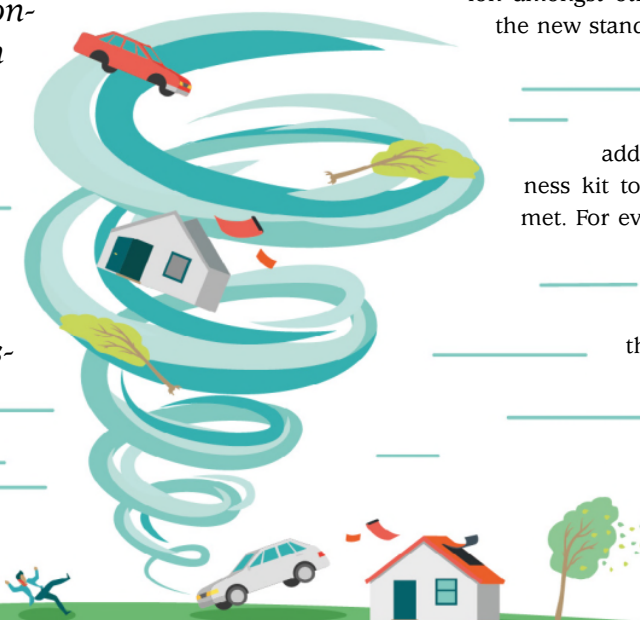
Many of us remember watching the news and learning of Hurricane Michael's arrival and destructive departure. Sadly, many Floridians (including some of my friends) are still trying to pick up the pieces six months later. Despite all the aftermath seen, what strikes me most about the event is how many people are still unprepared for hurricanes and other types of disasters. According to a press release in 2015 on FEMA's website:

"Only 39 percent of respondents have developed an emergency plan and discussed it with their household. This is despite the fact that 80 percent of Americans live in counties that have been hit with a weather related disaster since 2007, as reported by the Washington Post." (USDHS 2018).

When my husband and I first came down to Florida, we did not know anything about hurricanes. We were familiar with blizzards. Food, water, flashlights, blankets, and can openers were pulled out along with fun activities to keep busy with and then we hunkered down for a few days. Our learning curve with Hurricane Andrew when we moved to Florida was high and fast. We continued to add more to our preparedness plan and supplies. It was not until all utilities were lost during Hurricane Wilma, that we figured out it was possible to plug in a non-battery phone into the external house phone box, and that the phone lines would still work.

Later, when my husband acquired paralysis, a whole new list of things were added to our emergency preparedness kit. Catheters, wound supplies and an air pump for his power wheelchair cushion amongst other specific items became part of the new standard set of items to have in the kit.

Now that my daughter has an autoimmune disorder with a list of allergies, I am still adding unique items to my preparedness kit to make sure her health needs are met. For every weather event and new lesson learned, it is easy for me to say, "I didn't think of that!" What follows are some of the new things I learned over the past decade that might be helpful with when planning for your family's safety for the next hurricane season.



EMERGENCY PREPAREDNESS MEANS NEVER HAVING TO SAY “I DIDN’T THINK OF THAT!”

SHELTER

To begin with, plan on your plan to fail. A simple example is planning to stay in a mobile home during a hurricane will mean certain doom. Instead, have several options to choose from when



addressing where a safe haven would be best. It is important to consider having at least three places to stay during bad weather. The first is your

current location. For most of us, this would be our home. But if a tree fell upon the center of it, we might then go a friend’s house to stay. Upon arrival, there might be an issue with entrance into the home if there is no ramp for a wheelchair to access the front door. Not having thought of that, a drive to the nearest hotel might be considered. However, in a disaster, it is quite possible that all your neighbors might have the same idea. Will you be able to continue the journey to a safe haven that would accommodate your child? All of this should be discussed with your support system and researched beforehand instead of addressing the last-minute stress of not planning properly. If staying at home is the best option, make sure the hurricane shutters are put up. In Miami, Florida there is a Residential Shuttering Program (www8.miamidade.gov/global/emergency/hurricane/paint-and-shuttering-program.page) that, if one qualifies will help people with disabilities, and the elderly put up their shutters if a hurricane comes.

MEDICINE

It is not enough to just to bring your medication.

It is important to pack a week’s worth of medication (in its original packaging), in a



container that will keep it safe at the correct temperature. Setting aside a week’s worth of medication is possible if you contact your medical provider or health insurance company and ask them to fill an extra dose of the prescription to put into the emergency preparedness kit. The prescription could be only for a few days, a week, or maybe a month depending on what the purpose of the medication is for and how your insurance company or doctor will allow it to happen. Once filled it is generally on the premise that it will only be used once in the year. Again, depending on the medication’s purpose, the insurance company and doctor, your mileage may vary. Some states have policies on this:

“Emergency prescription laws vary by state and have been passed in the following states: Ohio, Florida, Arkansas, Arizona, Wisconsin, Washington, Illinois, Idaho, Michigan, and Pennsylvania. Utah, Oregon and Connecticut are pursuing similar legislation.” (*Healy 2018*)

To see how other states address this, enter the topic, “Emergency Prescription Law” and the particular state on the same line.

ELECTRIC POWER

Power outages always occur with hurricanes. Some life-saving medications require refrigeration which relies on power. If you have a small refrigerator, you can plug it into a UPS battery backup which is used to give extended power time to computers when there is power loss. Make sure that voltage needed by the refrigerator can work with the voltage on the battery backup. Make sure to pre-identify the number of hours the battery backup can itself work without power coming in to measure temperature reliability.



If keeping the medication cold without using power at all is of interest, then look

into a cooling case that is water-activated and reusable, such as the one by Frio (www.frioinsulincoolingcase.com/how-the-frio-insulin-cooling-case-works.html) which works with more than just diabetic supplies. Other technical life-saving needs might be technology that the child depends upon to breathe, eat, communicate or rely on to keep calm.

The UPS battery backup can also help with this situation, or purchasing a portable hand-held battery charger can help with this situation. Remember to note how many hours they will last for, that the correct cords are kept with it, and they are always kept charged, ready to use at a moment’s notice. My suggestion would be to purchase one at least the size of your hand that costs about \$30 and can last anywhere from about 10 to 20 hours. Purchasing them with two USB ports is even better. Just remember, the power will drain down faster. By contacting the local community addressing the child’s diagnosis or local Center for Independent Living (www.NCIL.org), you might learn of reimbursement programs or scholarships to help pay for supplies to keep safe in a disaster. It would be good to pursue this for oxygen concentrators or power chair batteries. (Side note: Include the model and serial numbers to all equipment, including power chairs, to enable replacement time to be more efficient and faster due to the details those numbers hold.)

IMPORTANT DOCUMENTS/ INFORMATION

In addition to hurricanes, for any disaster, it is good to plan in terms of the scenario of the child not being able to speak for themselves and the parent not being around to help them.



Putting together any documentation that minimally describes the diagnosis, doctors, and medication is a good start. If you are not sure what type and how much medical information would be helpful to notate for others, you can check out my book, *Emergency Preparedness Plan: A Workbook for Caregivers, People with Disabilities, the Elderly and Others* (www.amazon.com/dp/1795865679). Do not forget to include cultural or family concerns that would be specific to the family that are important for first responders to know. If a child senses familiarity with a topic from a first responder, then that will help set them at ease.

Besides writing down important information on a sheet of paper, or entering it on the computer, it could also be scanned and added onto a thumb drive placed onto a key chain. Another option that I read on the Internet recently, was to take a business card, put instructions on it (such as how to handle seizures) and laminate it. A caregiver friend of mine took their mother's health records and placed them onto a business card via

a QR code (Free site: www.the-qrcode-generator.com) to hand out to paramedics. Another option is wearing medical jewelry where the diagnosis and additional information can be seen easily in an emergency. Choices can be from basic identification to beautiful or a technological option which embeds information into the jewelry that is accessed via a USB connection. Lauren's Hope (www.laurenshope.com) will gladly help with unique wording if needed. No matter how this information is gathered, make sure to put it somewhere safe and memorable, protected from wind or water, with a copy with a copy given to a trusted person outside the state.

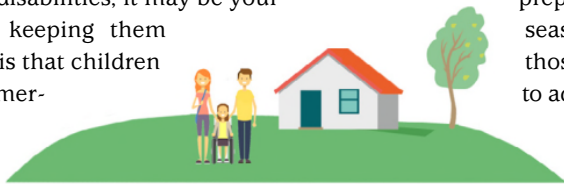
REMAIN CALM

A calm demeanor in preparation for the hurricane season will set a calm example for your child. Many children enjoy taking on the responsibility of packing things for them-



elves. This will give them high self-worth and enable them to feel important because of their participation in the family project of preparedness. Let them help decide what the family pet would need to be happy. Encourage them to pick out snacks, toys, flashlight (Remember batteries!), and clothing (a week's worth) that they would find comfort in when in a disaster. If they are capable, let them help you pack the medical tubing, medication, equipment and other things, to help encourage their confidence, and understanding of the importance of emergency preparedness. Let them learn about it in a fun way by visiting the "Kid's Game" section on www.ready.gov/kids/games. They are educational and fun! Reach out to the local emergency management office (sometimes located through the fire department) and ask when their hurricane preparedness fair will be. There are always items handed out that are great to add to the emergency preparedness kit and lots of fun activities for the kids to participate in.

Did you pause to think on some of the non-standard items I mentioned above? The most helpful emergency preparedness kits in a disaster have the items that most planning tools fail to mention. It is to this point that a good, helpful emergency preparedness kit must be built. One should never plan to put the entire kit together at one time and walk away. Understand that the kit is a living, breathing item in your home. For your child with disabilities, it may be your sole source of keeping them alive. The catch is that children grow up. The emergency preparedness kit you created



should be constantly updated to keep up with their needs. This might mean that the listed shelter location changes, their medication needs have changed, their electrical power needs may be different, and the doctors or medicines used may need to be updated. The examples you establish when preparing the kit may help

them live independently and prepare on their own for future disasters, whatever they may be.

What did I not think of when I first entered this field about 13 years ago? I never thought emergency preparedness could be so encompassing, easy to do, and extremely important to my family members who have disabilities. There were never any thoughts as to how much more families with disabilities have to gather to prepare for hurricane season, compared to those who do not have to address those issues.

Most of all, I never thought I would collect volumes of stories to be shared with others, that are so deeply held in my heart about persons with disabilities who overcame and survived disasters. Yes, I didn't think of that!

Take it from me: "Life isn't about the challenges you face: it's about the actions you perform after meeting those challenges."•

ABOUT THE AUTHOR:

Laura George is Emergency Management Disability Liaison, National Center for Independent Living - Emergency Preparedness (NCIL-EP) Committee, Florida Statewide Independent Living Council / FB: Hurricane Michael Resources - ILC; Miracle Relief Collaboration League - Disaster Assistance. She is an author, presenter, caregiver.

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Autism politics are at it again.
Will the latest episode lose steam, or is the fight over a
British stage puppet a sign of things to come?

WHEN WE ARE OVERWHELMED II

BY MICHAEL JOHN CARLEY

AUTHOR'S NOTE: The following is an updated version of a column written for the *Huffington Post* in 2015.

Over the last few years, all's been relatively quiet on the front of autism politics. But a recent controversy in Great Britain shows signs that we're perhaps ready for another round. The source of the drama (no pun intended) is a play.

All in a Row, written by Alex Oates, was produced earlier this year at London's Southwark Playhouse. The play concerns a married couple about to send their autistic, 11-year-old boy off to a residential center because they either cannot cope, or feel they cannot cope with Laurence. The child displays behaviors of one who has significant challenges such as biting and hitting. I can't speak to the writing of the play but the source of the real uproar was more about the character of the child having been portrayed – not by an actor, or a spectrum actor, but – by a puppet. People on my side of the autism spectrum were livid.^{1,2,3,4}

To be fair, there's the controversy over using a puppet, and there's the controversy over "what does the puppet look like?" as well as how the character/puppet is referred to. As to the first controversy, puppets have been used in theatre for centuries, most notably as foils (a la Punch and Judy) and in traditional forms of

Asian theatre. Their modern usage parallels the manner in which we've tackled deeper philosophical issues through the medium of science fiction. The first *Star Trek* series on television, or books by Ray Bradbury are great examples wherein we often feel more comfortable exploring tougher themes through distance. Movies such as *Get Out* now examine big topics through the genre of horror. What we used to call "kitchen sink realism" doesn't sometimes cut it as a vehicle to discuss painful stuff. So, with the (albeit real) disappointment that another casting opportunity for a spectrum actor has been lost, I give this controversy a dispassionate "pass."

However, the production's response to "#puppetgate"? Not so good.

Does (lead actress, Charlie Brooks) think the creative team had any choice but to represent Laurence the way they have? "No," she says firmly. "Unless you were to cast an adult, but Laurence would have to be an adult, and that would be a different play."

– All in a Row actress Charlie Brooks on autism row:

"We were told to expect a reaction, but we never expected such a backlash."

– Clare Allfree, *The Evening Standard* (UK), February 19, 2019.

Ms. Brooks is wrong. Child actors have been cast in material that is dark, or adult-themed, for quite some time. While I don't want casting to return to the days of an 11-year-old Brooke Shields portraying a sex worker's daughter in 1978's *Pretty Baby*, or a 13-year-old Jodie Foster portraying a real sex worker in 1976's *Taxi Driver*...given the right care it is by no means unheard of when child actors are healthfully eased into the adult content they may be exposed to.

But regarding the second controversy, it's a no-brainer: what the puppet looks like isn't pretty.



GRAY AREA: The play ignores everything we've learned surrounding not only the humanity of potentially-ostracizing behaviors, but also what constitutes healthy parenting strategies; Unhealthy attitudes appear to have been portrayed as inevitable, and therefore justifiable.

Note the skin color, and empty eyes and you conclude that the *Halloween*, *Chucky* and *Friday the 13th* comparisons are justified. As the easily-googled comments testify, this production embraced the 1990s tragic model of autism and truly ignored everything we've since learned surrounding not only the humanity of potentially-ostracizing behaviors, but also what constitutes healthy parenting strategies vs. unhealthy parenting strategies. In this context, unhealthy attitudes appear to have been portrayed as inevitable, and therefore justifiable.

Parents who object to my way of thinking, however, rose to defend the play (like me, without having seen it), striking in them what feels like an irrefutable chord. By giving in to the natural despair that some parents are culturally conditioned to embracing, the play has won a support base, though I have doubts about how strong.

Let's just say for argument that Oates' play is a poorly-researched and ill-conceived endeavor. He supposedly worked with challenged folk for 10 years in what we (in the theatre) used to call "a stupid day job," but it doesn't look like he was listening to more than overwhelmed parents. Is this disaster all his fault? God no. There are the producers, the director (Dominic Shaw), and even though the largest autism organization in Great Britain, the National Autistic Society (NAS), withdrew its support of the play (their statement is not on their website but was relayed through

four tweets⁵) NAS was originally signed on as consultants, and don't seem to have made the turnaround until the play's unpopularity was painfully evident.

If you were at all in doubt, the picture of the puppet you see above was, believe it or not, an improvement on the original version, shown below. So you can see the intent, or where this play is going pretty clearly.



tone adjustment: The play's producers decided that the initial design for the Laurence puppet was too stylistically dark to sensitively portray the character, and a more childlike, yet still abstract, design should be explored.

The production had a surprising defender, the Simons Foundation's usually reliable autism news service, *Spectrum*. Writer Alisa Opar, who's written admirable features in the past – that I've forwarded through my newsletter – such as "How to Help Low-Income Children with Autism" and "The Healthcare System is Failing Autistic Adults," penned a long, rather inexplicable piece called, "In Search of Truce in the Autism Wars".

Opar's piece spoke of a favorable review of Oates' play in the Guardian, yet failed to not only mention the clear majority of critical reviews, but she overlooked a piece of commentary in the very same publication (the Guardian) entitled, *Casting a puppet as an autistic child is a grotesque step backward*. Were Opar a less skillful writer, her piece wouldn't carry its deceptive

and misinformative danger.

The propagandist nature of Opar's article may not be coincidental. It falls at a time in which we're again starting to see the parents

of significantly-challenged kids trying to paint autism in a tragically light, and Opar may have a personal connection that I'm not aware of. This loud minority (by no means the majority of parents with significantly-challenged children) want ownership back over the messaging of autism, control that they enjoyed before the turn of the century, when they could paint themselves as "warriors" and hero parents. It is a period best exemplified by the horrific 2009 Autism Speaks video "I Am Autism."⁶

New organizations like the "National Council on Severe Autism" (NCSA) are now emerging to combat what makes autism unique—it's vast spectrum – if not diagnostic standards set up in DSM-5 (which, oddly enough, are definitions written by clinicians whom this crowd often heralds, such as Catherine Lord). On NCSA's website⁷ they plainly attempt to resuscitate the farcical notion that one can "love the child but hate the autism."⁸ My very first "Autism Without Fear" column, the first of 30-plus that I wrote for the Huffington Post, was called, "In the Autism World, Maybe You Just ARE a Bad Parent."⁹ Do I need to do an update of that piece too?

My "Calling a Truce in the Spectrum Wars" (2006),¹⁰ as opposed to Ms. Opar's similarly-titled piece, attempted to invent a term, "the competition of suffering," to describe the warring between extreme ends of the spectrum. In trying to convey the uselessness inherent in a) articulate, verbal spectrumites invalidating the seriousness endured by the families of signif-

icantly-challenged individuals, or b) vice versa; I gave this fruitless endeavor a name/phrase that I thought was so perfect that the world would be shamed into overnight change.

"Ha-Ha!," "Yeah, right," and "How'd that work out?": I see the same comments today that I saw 15 years ago – response sections of the myriad of articles I read wherein both the authors and their subjects become the targets of rageful someone's on "the other end," only because the likely overwhelmed commenters' spectrum experience differs.

Mostly, I blame the so-called autism leaders for encouraging that anger, and not the commenters.

One could argue that the messy-headed battle for autism authority is par for the course in our world. Thanks to DSM-5, few diagnoses encompass such a range of abilities and challenges as the newly-defined "autism," and as human

beings we love (and sometimes need) to compartmentalize. Within what constitutes autism, Albert Einstein and a non-verbal individual have differing shades of the same condition. We are presented with a diagnosis whose definition often presents extreme variations demanding polar opposite needs.

Well, the masses have been somewhat accepting since the DSM-5 came out in 2013, but this particular crowd is

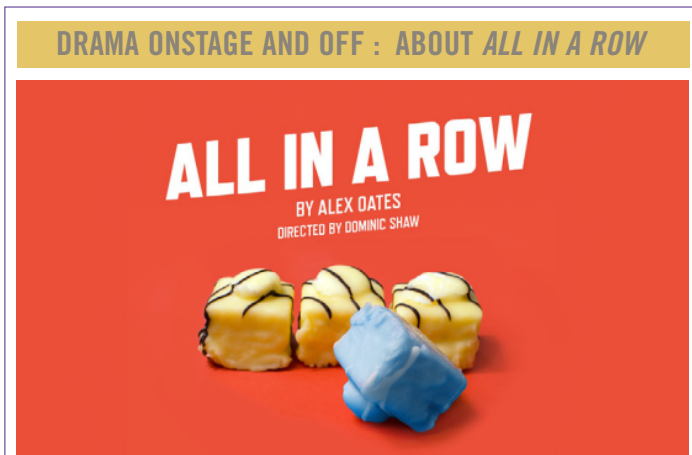
once again demonstrating no willingness or intelligence to stomach such a disparity of abilities and/or challenges. Once again people are trying to dumb down the condition that – according to the current criteria – can't be dumbed down.

Additionally, the inability to emotionally regulate is often a diagnostic tell (throughout the gene pool – that's you, parents) that can be part of an autism diagnosis. Thus, the potential in our universe for irrational super-sensitivity... is enormous.

Lastly, spectrum individuals and families endure more financial hardships than most, and poverty can be clinically-linked to intelligence-robbing anxieties, anger and depression, obstacles that people with no experience of poverty have difficulty comprehending.

Unlike the worlds of cystic fibrosis, or Down syndrome, the autism world also does not have one, primarily-unifying non-profit that everyone rallies around, goes on fundraising walks for, or volunteers for in the consensus-filled spirit of shared goals. In the autism world, we have a gajillion such organizations, almost never representing the entirety of the spectrum, and founded partly *in the rejection of existing orgs*. In our world we have three million people imagining themselves as leaders... but no followers. And with all those non-profits, no centralized guiding entity exists, or can exist. Sadly unable to coalition, they then compete for limited

“Within what constitutes autism, Albert Einstein and a non-verbal individual have differing shades of the same condition.”



All in a Row is a dramatic play by British playwright Alex Oates. It features an 11-year-old boy on the autism spectrum and his family, and focuses on the night before the child is to be taken to a residential school for children with special needs, and the emotional toll that raising a nonverbal and sometimes violent boy has taken on his parents.

The play premiered at the Southwark Playhouse in London. An early draft of *All in a Row* was long-listed for the Bruntwood Prize for Playwriting, and the play was chosen as one of the Bolton Octagon Theatre's Top Five in 2017.

The play has had a polarizing effect on critics and audiences for its use of a puppet rather than a living actor to portray Laurence, the autistic child. While some critics felt that the puppet was an effective representation, criticisms of the play started to emerge when a video trailer for the production was released showing the autistic character portrayed by a puppet. The controversy spawned the Twitter hashtag #puppetgate.

funds and press attention...by screaming. Whether it's spectrum folk like myself going after one another to jockey for attention by stating that Autism Speaks is complicit in murders,¹¹ in destroying chat group relationships over semantic issues; OR whether it's the pro-cure folks declaring that all three million of us can't use the toilet (uh, last I checked...?),¹² the b.s. statistic of an 80% divorce rate,^{13,14} the aforementioned "I Am Autism" video, or the anti-vaxxers' insinuation that people like myself are simply poisoned, chemical accidents... we get comedy worthy of Vonnegut.

The past leadership of major players in the world of autism politics – rather than trying to soothe or steer the emotions of its overwhelmed members towards healthier perspectives – often willingly, in that battle for recognition, poured figurative gasoline on the fires consuming their constituents. Instead of healing, big-picture perspective, they doused those who trusted (and needed them) with alarmist, often misinformative rhetoric.

Both Ms. Opar, and especially Mr. Oates, would have been spared so much criticism had they only lifted a finger to do their homework. And their inability to resist the unhealthy need for someone to blame (autism itself) is perhaps a sign that more troubling aspects than laziness exist. The only entity anyone should ever blame is the fact that these overwhelmed families – of significantly-challenged kids or the kids that present as I once did – are not receiving the services they need and deserve. Giving voice to overwhelmed people's opinions when they are the very product of being overwhelmed, and not wisdom, kind of goes beyond irresponsible. For instead of fighting for the services they need, these parents are then revved up, and encouraged to pick a fight with fellow, marginalized people with legitimate disabilities.

In the autism world, we fight. We fight over words, vaccines, aversives, behavioral strategies, and what research is ethical or that which is not. Most of the consequences for winners and losers of these fights surround our attitudes towards what constitutes a happy life, and this is rather big stuff, while other battles – vaccines and aversives – can determine whether people live or die. There is cause for anger, especially when services are the opposite of satisfactory, yet the majority of funding goes towards genetic studies having no impact on families living today.¹⁵

But what's the best strategy to right this ship? Is the answer *not* to fight? I'd vehemently answer "no." I believe in confrontation 100%, and even privately believe that those who are afraid of confrontation actually *do* engage in a very negative and subtle way. *How* we confront, however, is where our value can be measured.

A long, long time ago – before my diagnosis, or my son's diagnosis, I had a different career. I've written about it before, and I'll write about it again. As a Non-Government Organization Representative ("NGO Rep," a very, very, low-level diplomat) through the United Nations, I got to travel to some out-of-the-way places. I did some work in Cuba, some in Bosnia, but I spent more time than anywhere in the Middle East, as the Project

Director for an endeavor that repaired water treatment facilities in Iraq back during the Saddam days.

Because of the economic sanctions that existed before our invasion, the chemicals and coagulants required to purify water could not be imported; and, according to a 1998 UNICEF report,¹⁶ over 5,000 Iraqi children were dying every month as a direct result of sanctions – mostly due to waterborne illnesses. Eventually, by late 2001, The Iraq Water Project¹⁷ would provide clean water to 81,000 people through four restored water plants in the hardest-hit Basra region.

It was early 2000, and not only was it in question that we would be able to secure an agreement with Saddam Hussein's angry government, there was also no certainty that in the process we would keep our emotions together. Though no fans whatsoever of U.S. policy towards Iraq, we also (no surprise) despised Hussein's regime. And while we'd encountered a lot of human suffering in our work, most of us knew that we hadn't seen it on the level we were about to witness.

During our travels there, we went to special children's wards at sanctions-desecrated Iraqi hospitals... to allow the tiny victims to confront us. One of the requisites of appeasing our tempestuous government hosts was to acknowledge their suffering through a myriad of visits.

The first time we apprehensively entered one of those, roughly, 30 by 40-foot rooms, we saw it filled with all those fading children. They lay dispersed in a health care facility that rarely enjoyed electricity or hygiene. A bright desert sun lit the room through a window while overwhelmed staff tried in vain to wash floors without cleaning materials, working

around the bedside mothers and the metal-frames of their children's last resting place. It was no secret to staff, the mothers, or anyone, that no child would survive their stay. Were a bed to empty, it would be filled immediately by the same human dilemma.

But I was to discover a surprising solace as I spent time with each child. In focusing on the individual, the political angers disappeared. The big-picture frustrations were forgotten within the revelatory context that in that moment, they were not within my control. To my relief, right in front of me, was something that I *could* control, even if it was just a self-serving moment of reassurance. Fellow delegates followed suit. We did not renounce the politics; we in fact *reinforced* our belief systems by temporarily shelving them; by shutting them out so we could stop remembering that which we already knew, clear the brain, and therein learn more.

We were not traumatized by trying to "ride the wave" of these tiny individuals – our tears *discouraged* trauma. Trauma herein comes when you close yourself off and work to avoid that wave. Those kids did not share the grownups' offended sense of justice (that was our baggage) and most were past the point of fear. They just wanted to be held, made as comfortable as possible, and be told that everything would be all right, until it was all over. To overemote with them would have caused them confusion and anxiety during a time in which they sought peace.

When our delegation departed the ward, my overwhelmed dele-



OVERWHELMING: My overwhelmed NGO delegates tearfully vented about the indisputable global injustices that had influenced our visit to the children's ward. They were not articulate as they raged against the heavens. You just didn't want to quote them in that particular moment.

gates tearfully vented about the indisputable global injustices that had influenced our day. They were not articulate, nor did they make good points as they raged against the heavens. Yet the human need to speak in this clumsy manner epitomized necessity itself. You just didn't want to quote them in that particular moment.

But when they next approached a microphone, weeks later, back in the states after having time to process, they spoke differently, sensing the responsibility they had in this very different kind of moment. People needed them to clarify and enlighten, and they rose to the opportunity to inform their audience. To spew would have had a counter-effect. So instead, they led, and they led through eloquence.

Imagine my shift then, as I switched careers into a culture where having a child who couldn't talk was often treated as the worst injustice possible, where having measles was preferable to having autism, and where one prominent leader in the spectrum world confessed to me, "This is war."

In the autism world, we do the opposite: we turn the microphone on *when we're overwhelmed*. And when we are overwhelmed, we simply spout stupid, often-inaccurate, and counter-productive rhetoric.

Would more diplomacy work? Maybe not. Diplomacy worked for me for a very long time with GRASP, and the hate mail I got from both extremist ends of all the debates had me in what I thought was an ideal position. But then the day came when diplomacy wasn't working anymore; when our press (and subsequent funding) started shifting away to those organizations who engaged in the rhetoric. It took me two years (too many) to figure out that the extremists, and not I, had accurately calculated what the autism world now *wanted* from us. The press and funders merely obliged.

As someone who doesn't have to be so diplomatic anymore (and I admit, it's liberating)...

Militant spectrumites? Work on your capacity for, if not come to terms with our challenges towards emotional regulation – letting the small stuff roll more and more off our backs. This cowardly inability to face the mirror causes us to fight each other, as well as occasionally show us to be unreliable, emotional train wrecks. As a collective we'll be infinitely more powerful for it. For when compared to our potential numbers, the membership tallies in our organizations are quite low, and in most cases have recently shrunk. GRASP, my old org, is all but deceased. ASAN is currently in better shape than GRASP, but carries nowhere near the impact it once had.

And to those families who get so bent out of shape when someone accomplished comes out as on the spectrum, and is thus writ-

“When we are overwhelmed in the autism world, we simply spout stupid, often-inaccurate, and counter-productive rhetoric.”

ten about? You are attacking people with legitimate disabilities, even if the challenges they faced are not familiar to you. If you feel so assaulted with stories of potential, understand that it is to show others what we *can* do (trust me: Your dedication to what we *can't* do, was heard). I won't ask you to look in a mirror and ask if someone with a disability might be ten times the father, mother, or human being you'll ever be. But maybe I should? Maybe it's time to challenge *your* worth? If you'd look at what factored into those successful people's development you might help your child.

The new leaders need to lead with eloquence, not rhetoric. Because to confess: I cringe (if not darkly die laughing) when I hear any of us use the word "community."

Ms. Opar's article ended without mentioning the petitions asking the Southwark playhouse to pull the plug on the play during its run (one at 19,000 people¹⁸ and one at 24,000 people¹⁹). Oates continued to defend himself.²⁰ Through her inclusion of quotes by ASAN's Julia Bascom, Opar acknowledged our side's desire to help the families of significantly-challenged spectrumfolk through increased services. But she closed the piece with a quote from Oates, wherein he asked: "If there was a way for those autistic voices to turn their outrage into advice for the parents, I'd love that."

If he'd only listen, and stop paying lip service to legitimately-overwhelmed people, he'd see that the answer to his and Opar's questions is right there – it really is about the services. Those families aren't getting them. Keep blaming a genetic condition if you want, but again, the funny thing about genetics is that you can't win unless you die. Or maybe Oates is smarter than I'm giving him credit. And that he simply knew how to draw a crowd. •

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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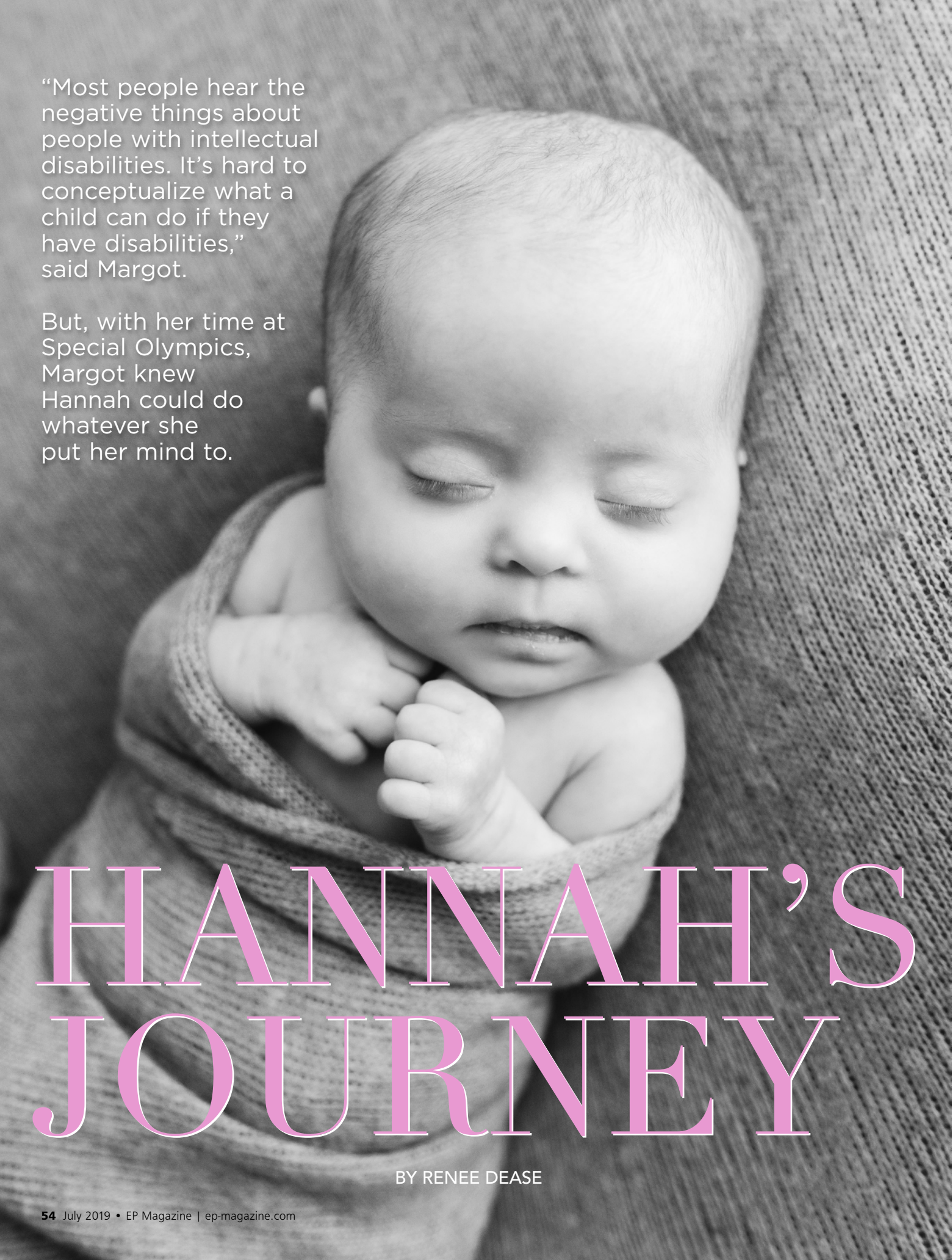
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“Most people hear the negative things about people with intellectual disabilities. It’s hard to conceptualize what a child can do if they have disabilities,” said Margot.

But, with her time at Special Olympics, Margot knew Hannah could do whatever she put her mind to.

HANNAH'S JOURNEY

BY RENEE DEASE



In 2016, I interviewed Margot, who had applied to work at Special Olympics in the role of Health Director. She impressed me and others in her interview and I knew whomever landed this position would be my next boss, so I especially wanted to get to know her. Margot accepted the position and we began our work relationship. As I got to know Margot, our relationship grew professionally and personally and into a friendship. Margot is such a sweet and understanding person.

In June of 2017, Margot shared with me that she was going to have a baby. I enjoyed talking with Margot about her pregnancy; she was feeling fine while as she talked about her trips to her prenatal visits. At ten weeks pregnant, Margot found out her child, a daughter, had Down syndrome. Margot was told the news via a phone call from her doctor. Margot didn't think he knew that much about Down syndrome and he was polite but quick with her. The phone call didn't last more than ten

minutes. Margot began visiting a maternal fetal medicine doctor who specialized in high risks births. From then on, she had hospital visits every two weeks during her pregnancy.

When she was 30 weeks pregnant with Hannah, Margot was hospitalized for the remainder of her pregnancy. Hannah was born at 36 weeks on December 16. She was in the NICU for weeks. Chris, Margot's husband, saw Hannah in the NICU first. Margot remembers Chris coming to her in the hospital room and saying, "She's perfect and amazing." Margot and Chris were able to hold Hannah for the first time on Christmas day. It was the best Christmas gift either of them had ever received.

Every mom is nervous about the future and wonders how to raise their child and Margot had the same fears. She is now a great mom with great experiences to share with Hannah. Margot

BUNDLE OF JOY: (Opposite page) After her birth, Hannah was in the NICU for weeks (photo credit: Kate Juliet); (Above left) Margot and Hannah in front of their own photo on the wall of Georgetown University Hospital (Right) Hannah celebrates her first birthday.

gained a lot of education and opportunities during her high-risk pregnancy that other mothers don't get to gain. And at the same time, this experience has contributed to Margot's being such a great parent. Working at Special Olympics helped Margot know that Hannah's life would be full of possibilities.

"Most people hear the negative things about people with intellectual disabilities. It's hard to conceptualize what a child can do if they have disabilities," said Margot. But, with her time at Special Olympics, Margot knew Hannah could do whatever she put her mind to. "When I would tell my friends that Hannah has Down syndrome, they seemed nervous and didn't understand what that would mean. My colleagues at Special Olympics didn't feel that way. They knew that Hannah would have all the support she needed from the larger Special Olympics movement and would be welcomed fully as herself," explained Margot.

Margot has observed that it's hard to make friends as an adult, but it's easy to make friends with other mothers who have children with Down syndrome. "It's an immediate connection. We bond over the shared experiences of our children's lives," said Margot.

Margot's mother group meets once a month and with them she feels like just a mom, not a mother of a child with Down syndrome. "Hannah is 95 percent just like every other child. There's so much of her that's like other children. That remaining five percent can be time consuming though," said Margot. "It's difficult to call my friends. Their kids are going to be on a different level."

Margot encourages her friends and neighbors to understand both sides of the coin: Hannah has



BEAUTIFUL GIFT: Chris, Hannah and Margot during the holidays; "When I would tell friends that Hannah has Down syndrome, they didn't understand what that would mean. My colleagues at Special Olympics knew that Hannah would have all the support she needed from the larger Special Olympics movement and would be welcomed fully as herself." Hannah will be two years old in December.

I have worked at Special Olympics for 35 years. I am also a poet who likes to compose poems for fellow staff members, for big announcements and the celebration of happy times in their lives. When Margot was pregnant with Hannah, I wrote her a poem to celebrate the news. In it, I celebrated the joyful feelings with all the parents who are growing their families as well.

A FAMILY'S POEM

*A parent right from the start,
the love of caring is straight from the heart.
At first any parent doesn't know what to do
to be a parent of a child with a disability.
The more grateful power to you,
you are an extraordinary family with pride.*

Down syndrome but she's still a little girl. Margot admires her neighbor and their children because they play with Hannah all the time. They say hi and treat her like a normal child. "Those small acts really matter. That's what true inclusion is about."

Hannah will be two years old in December. She goes to music class and is a happy and social baby. Margot continues to advocate for the inclusion of children with intellectual disabilities. She started first with the Georgetown University Hospital Labor & Delivery Ward. She looked around at the photos of newborns on the wall and realized there was not one featured of babies with disabilities. She encouraged the staff to be more diverse in their photos. A picture of Hannah and Margot now hangs proudly on the wall there. •

ABOUT THE AUTHOR:

Renee Dease is Coordinator, Healthy Athletes, Health Programs at Special Olympics International. Renee has been with Special Olympics for 35 years.



FROM OUR FAMILIES... TO YOUR FAMILIES

MILITARY MAGAZINE

MILITARY LIFE

58 SIX WAYS TO LEAN ON YOUR
MILITARY COMMUNITY TO SETTLE
INTO YOUR NEW HOME FASTER

60 MEDICAID FOR FAMILY MEMBERS
WITH SPECIAL NEEDS

PUZZLES & CAMO

62 IT'S NOT ANY EASIER

By Shelly Huhtanen





6 WAYS TO LEAN ON YOUR MILITARY COMMUNITY TO SETTLE INTO YOUR NEW HOME FASTER

After months of planning your PCS, you've now landed at your new destination. Now it's time for the fun part – building a nest and making it home. Here are a few ways to tap into the military community so you can settle and get into the swing of things more quickly.



NOT ONLY SURVIVING, BUT THRIVING:

Family readiness programs empower service members and family members with the support and information they need to thrive in their military lives. Each service branch has a family readiness program, but the names and resources available may differ.

program). A sponsor can be a friendly face with a wealth of personal experience who can make those critical first introductions, guide you to important resources and give you an insider's perspective of your new duty station and community. It's best to reach out to your sponsor before moving day.

2. WORK WITH A RELOCATION ASSISTANCE PROFESSIONAL TO GET REFERRALS TO OTHER SERVICES

A relocation assistance professional (www.militaryonesource.mil/moving-housing/moving/planning-your-move/seize-your-move-with-the-relocation-assistance-program) can help you embrace your new home by offering one-on-one consultations on everything from setting a budget, providing resources for spouse employment and child care to stress management. Find a relocation specialist by selecting Relocation Assistance Program and your installation from the drop-down menu on MilitaryINSTALLATIONS (<https://installations.militaryonesource.mil>).

3. CHECK OUT ARMED SERVICES YMCA PROGRAMS FOR FAMILY BONDING OPPORTUNITIES AND MEETING NEW NEIGHBORS

Armed Services YMCA (www.asymca.org) provides several programs designed to help military families – with a particular focus on helping junior enlisted service men and women – grow their networks of support. Operation Outdoors (www.asymca.org/operation-outdoors) sponsors family, youth and teen camps at their 34 branches and affiliate locations. These meaningful experiences help families bond with other members of the military community while offering tools to cope with the unique challenges of military life. The Parent and Me education program (www.asymca.org/parent-and-me) teaches strategies to help with early childhood development in a community of support where parents and children can learn from each other.

4. EXPLORE MORALE, WELFARE AND RECREATION ACTIVITIES TO HAVE FUN AND MEET NEW PEOPLE

Meet new people and connect with fellow military families as you hit the links, go bowling or play air hockey with your kids at the recreation

center. As the military's network of support and leisure activities, the Morale, Welfare and Recreation program (www.militaryonesource.mil/recreation-travel-shopping/recreation/single-life/morale-welfare-and-recreation-your-source-for-affordable-fun) sponsors a variety of activities. There's something for everyone to enjoy, both on and off on the installation. Take advantage of opportunities to relax, laugh and bond with your new neighbors.

5. JOIN A MILITARY SPOUSE NETWORKING GROUP TO “TALK JOBS” WITH OTHER SPOUSES.

For military spouses seeking employment at their new duty station, joining a networking group can be a great opportunity to meet fellow military spouses while advancing your career. Begin with the Military Spouse Employment Partnership spouse group on LinkedIn (www.linkedin.com/groups/4159976) and the Spouse Ambassador Network, (<https://myseco.militaryonesource.mil/Portal/Content/View/1494>) which is a group of organizations united to help military spouses achieve their education and career goals.

6. BENEFIT FROM YOUR FAMILY READINESS GROUP TO WIDEN YOUR NETWORK OF SUPPORT

Family readiness programs (www.militaryonesource.mil/family-relationships/spouse/military-life-for-spouses/connecting-to-the-community) empower service members and family members with the support and information they need to thrive in their military lives. You'll find intel on benefits and get connected to services and organizations that promote readiness and quality of life for you and your family. Each service branch has a family readiness program, but the names and resources available may differ. Special focus is given to helping families prepare for short- and long-term deployments and boosting unit morale. These groups host family-related unit activities, where families can meet and learn from fellow members of their military community.

Make your new destination home by connecting with your military community. Connecting helps you to get to your new normal faster.

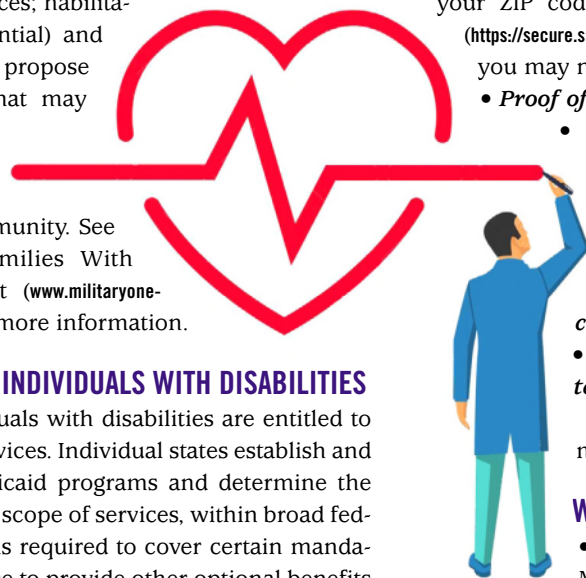
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MEDICAID FOR FAMILY MEMBERS WITH SPECIAL NEEDS

Medicaid is a federal program that provides eligible military families with benefits beyond TRICARE. It covers basic health and long-term care services for eligible children, adults, pregnant women, individuals with disabilities and the elderly, and for families with low income and limited resources. This benefit may be available for military family members who have special needs and require medical care. Medicaid coverage and income restrictions vary from state to state (www.medicaid.gov/medicaid/by-state/by-state.html).

WAIVERS

States can offer a variety of medical and non-medical services (www.medicaid.gov/medicaid/hcbs/authorities/1915-c/index.html) under a waiver program. Standard services include but are not limited to: case management (i.e. supports and service coordination); homemaker; home health aide; personal care; adult day health services; habilitation (both day and residential) and respite care. States can also propose other types of services that may assist in diverting and/or transitioning individuals from institutional settings into their homes and community. See Medicaid Waivers for Families With Special Needs Fact Sheet (www.militaryonesource.mil/products#!detail/192) or more information.



MEDICAID BENEFITS FOR INDIVIDUALS WITH DISABILITIES

Medicaid-eligible individuals with disabilities are entitled to all medically-necessary services. Individual states establish and administer their own Medicaid programs and determine the type, amount, duration and scope of services, within broad federal guidelines. Each state is required to cover certain mandatory benefits and can choose to provide other optional benefits through the Medicaid program. Mandatory benefits include:

- **Hospital, home health, clinic and laboratory services.** Benefits include coverage for inpatient and outpatient hospital, home health, physician, certified pediatric and family nurse practitioner, rural health clinic, federally qualified health center, and laboratory and X-ray services.
- **Early and periodic screening, diagnostic and treatment services.** This benefit provides comprehensive and preventive health care services for Medicaid-enrolled children under age 21. These services are key to ensuring children and adolescents receive appropriate preventive, dental, mental health, developmental and specialty care.
- **Nursing facility services.** Nursing facility services, through Medicaid-certified nursing homes, provide three types of services: skilled nursing or medical care and relat-

ed services; rehabilitation needed due to injury, disability or illness; and long-term care.

- **Transportation.** Mandatory benefits include transportation for medical care.
- **Optional benefits.** Depending on state guidelines, benefits could include coverage for: prescription drugs; physical and occupational therapy; speech, hearing and language disorder services; respiratory care services; other diagnostic, screening, preventive and rehabilitative services; and services in an intermediate care facility for the mentally impaired.

HOW TO APPLY FOR MEDICAID AS A SUPPLEMENTAL SECURITY INCOME RECIPIENT

Supplemental Security Income recipients should apply at the local Social Security office. To find the nearest office, enter your ZIP code using the Social Security Office Locator (<https://secure.ssa.gov/ICON/main.jsp>). When applying for Medicaid, you may need to bring the following:

- **Proof of income, such as check stubs**
 - **Proof of assets, such as bank statements, value of car, etc.**
 - **Social Security card**
 - **Two forms of identification, which can include your military ID or other photo ID, and your driver's license, birth certificate, etc.**
 - **Proof of residence such as a utility bill, telephone bill or a rent receipt**

Contact your Social Security office to determine which documents you'll need to apply.

WHERE YOU CAN FIND MORE INFORMATION

- Review more information on the general Medicaid (medicaid.gov) program with links to Medicaid information by state (www.medicaid.gov/Medicaid-CHIP-Program-Information/By-State/By-State.html).
- Learn more about benefits for family members with special needs (www.militaryonesource.mil/special-needs-benefits).
- Read more about the Exceptional Family Member Program (download.militaryonesource.mil/12038/MOS/Brochures/EFMP-Brochure.pdf).
- Find more information through the Military OneSource eLearning module on government assistance (download.militaryonesource.mil/12038/EFMP/eLearning/Government%20Assistance/Government%20Assistance/Government_Assistance%28web%29/player.html).
- Access everything you need to know about Social Security Disability Insurance (www.militaryonesource.mil/-/what-is-social-security-disability-insurance-).

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It's Not Any Easier

I can't count how many hours Nikki sat next to me in IEP meetings, helping Mark and me fight for Broden and knowing that she was always on our side. There are no words to say how grateful I am for the comfort she provided.

No matter how many times we do it, it still doesn't get any easier. I'm talking about moving. You'd think it would be old hat after doing it seven times as a family. In some aspects we are more prepared. Our to-do lists seem more detailed due to minor corrections from lessons learned in the past. We purged liked never before because we are sick of moving boxes that have never been opened and I think we are doing a better job of getting rid of furniture that we know will not fit into the house we are moving into at our next installation. These things are the easy part.

What our family is having a hard time with is saying goodbye to the people that have been in our lives these past four years. I've noticed that some of these goodbyes are harder than I thought they

would be this time around. I get teary-eyed every time I remember that this afternoon, this will be the last time that Jina will cut my boys' hair. Some may think I'm being too sentimental, but I can't explain how good it feels to be able to walk into a salon, sit down and relax, while my son with autism receives a haircut. Some days are better than others, but what I can say that never changes, is how she treats my son. It doesn't matter if he's had a rough day with behavior or not, she still looks at him the same. To her, he was always a child that has worth. I will miss that feeling every few weeks.

I was in a local boutique last week



wandering the aisles aimlessly trying to find gifts for Broden's tutors and the clinic director who have had such an impact on not only my son's life, but mine. The gal working there at the time came over to me and asked if I needed any help. I responded, "I'm looking for a gift for someone that will never be good enough. It seems almost useless, but I have to try because I can't leave with just saying thank you." She smiled and said, "I get it. I had cancer when I was younger. There were people who helped me and I never could quite find a way to show them my gratefulness." As she followed me around for a while, she looked at me and said, "Find something that makes your heart

warm and puts a smile on your face. That may be the best way to make a decision." I finally found a necklace for my son's clinic director, Nikki. I found the one piece of jewelry that I was drawn to and something I came back to time and time again. That must be the one.

Saying goodbye to Nikki is going to be tough. The weaker side of me wants to leave the gift on her desk with a sticky note that says "thank you" and then run

out the door. The weaker side of me realizes that whatever I say or do, it will not be enough. If she had a dollar for every tear I shed in her office while feeling

defeated, she would be a rich woman. I can't count how many hours Nikki sat next to me in IEP meetings, helping Mark and me fight for Broden and knowing that she was always on our side. There are no words to say how grateful I am for the comfort she provided.

Moving and knowing Nikki will not be there for support is quite scary, to be honest. I remind myself that she will be a phone call or text away. Will I find someone that truly understands my fears and worries for Broden? I don't know if I will, but my hope is that I will leave here somewhat wiser because of the guidance

and undeserving grace she has given Broden and me.

As our family embarks on a new adventure, I hope to "be strong enough to stand alone and fight for what is right when others may not, smart enough to know when I need help, and brave enough to ask for it." I don't think Nikki would expect any less from me. •

“Will I find someone that truly understands my fears and worries for Broden? I don't know, but my hope is that I will leave here somewhat wiser because of the guidance and undeserving grace Nikki has given us.”

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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