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EXCEPTIONAL PARENT MAGAZINE
JULY 2017
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CREATIVE OPTIONS *for* INDEPENDENT LIVING

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HOUSING *for* LOVED ONES *with* PSYCHIATRIC DISABILITIES

INSIDE:

MANAGING EXPECTATIONS *with a* HOME REMODELING PROJECT

ACCESSIBLE HOMES

The Annual Issue

PLUS: SUSANNAH ROSEN

AN URGENT NEED *for* ACCELERATED KIF1A RESEARCH

AMERICAN ACADEMY OF DEVELOPMENTAL MEDICINE & DENTISTRY
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Susannah Rosen has a rare genetic condition referred to as a KIF1A. Her dad, Luke Rosen, explains what it's like for him and his wife to try to provide Susannah with a safe home environment, all while racing the clock for a cure. *EP's Annual Accessible Homes section begins on page 25.*
Photo provided by Luke Rosen.

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THE MISSION OF
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TO GATHER AND SHARE INFORMATION
AS TOOLS FOR POSITIVE CHANGE
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Information and Support for the Special Needs Community

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

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

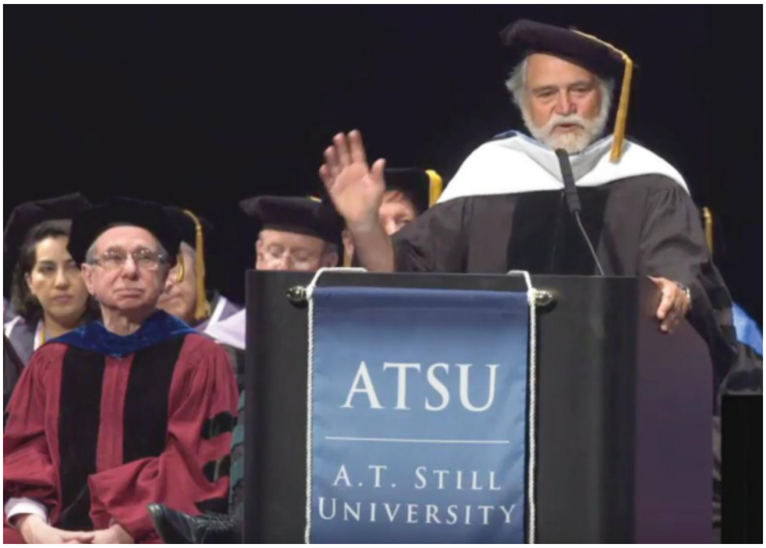
Honoris Causa

If my work in the disability arena over the last 20 odd years is deserving of an honorary doctorate from this respected medical-dental university, the honor belongs to the disability community.

My stock has just risen to new heights.

I now have something in common with the Dalai Lama, the spiritual leader of Tibet; Nelson Mandela, the leader of the movement that defeated apartheid in South Africa; Sir Winston Churchill, the charismatic Prime Minister of Britain who helped win World War II; Sir Alexander Fleming, the discoverer of penicillin; and Elie Wiesel, the Holocaust survivor and Nobel Prize winner. Not a bad lot for one to have *something* in common.

Don’t even try to connect us; there are simply too many differences and distinctions to even begin to tie a thread between us…not to mention that admittedly I’m not worthy to carry the water for any one of them.



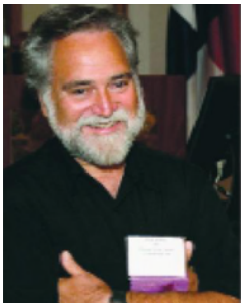
WISE WORDS: Rick Rader, M.D. delivers the keynote speech the A.T. Still University - Arizona School of Dentistry and Oral Health during the Class of 2017 commencement ceremony on May 26th.

I hate to see readers of this column, “Ancora Imparo“ (I am still learning) throw up the white flag, so I will provide you with another clue. Add Lionel Woodville to the above list of notables. Got it?

Perhaps some insider trading information will end the head scratching.

Zachary Crockett, writing in Priceonomics, helps us to understand why Woodville is a member of the above elite group. “In 1478, representatives from England’s Oxford University approached a young bishop named Lionel Woodville. At the time, Woodville was a man of great honor: he was not only the head of the Cathedral Church of Saint Peter, but enjoyed the distinction of being King Edward IV’s brother-in-law. Well connected, wealthy, and of noble standing, he was just the kind of man that Oxford wanted to curry favor with.”

So it seems that Oxford dispatches an elegantly dressed courier to Woodville and presents him with a doctorate degree. Forget the fact that Woodville was excused from meeting Oxford’s strict academic requirements. The “goat skin” provided Woodville with an automatic modern-day equivalent of a Ph.D. This was history’s first “honorary” degree.



This was obviously a strategy to pave the way for Oxford to gain some favor and influence. It proved to be successful as Woodville was then offered, and accepted, the position as the Chancellor of the University. One can only imagine the dividends that Oxford enjoyed with the issuance of that honorary degree. Brothers-in-law often are influenced by their wives, even when they are English kings. It was a proven “influencer,” and throughout the 16th and 17th century, hundreds of members of the noble elite were given similar degrees.

So that’s the tie-in. Fleming, Churchill, Wiesel, Nelson, Lama and I have all been bestowed with honorary doctorates. The honor, a Doctorate in Humane Letters, was given to me at the commencement ceremony at the Arizona School of Dentistry and Oral Health of the A. T. Still University of the Health Sciences. It was a great honor for me, especially when it was brought to my attention that I wasn’t the brother-in-law of any royalty; and that the governing body of the university thought I genuinely was deserving of the honor.

The honorary degree, while sounding impressive is even more so in its original Latin nomenclature, *honoris causa,* “for the sake of the honor.”

Getting an honorary degree is a lot like being a grandparent. Most grandparents would describe their role as having all the wonderful attributes, all the joys, the privileges and loving attention without the endless burden and responsibility of issuing discipline, authority, rules, chores and limiting Moonpies and fried Twinkies. It’s sheer pleasure and enjoyment.

The honorary degree is presented to the candidate and the university waives the usual requirements, such as matriculation, residence, a dissertation and the passing of comprehensive examinations.

While the group I named in the opening of this column (and unashamedly added my name) earned international admiration, respect and acclaim for their achievements and were worthy of being awarded honorary doctorates, there has been at least one recipient that had trouble making it to the podium to deliver his commencement address.

In 1996, Southampton College of Long

IMAGE COURTESY A.T. STILL UNIVERSITY

Island University awarded an Honorary Doctorate of Amphibious Letters to Muppet Kermit the Frog. Although some students complained about awarding a degree to a frog, after he was carried to the podium he delivered an enjoyable address. The college newspaper, The Southampton College News reported that "The degree was conferred in recognition of efforts in the area of environmentalism. His theme song, 'It's Not Easy Bein' Green,' has become a rallying cry of the environmental movement. Kermit has used his celebrity to spread positive messages in public service announcements for the National Wildlife Federation, National Park Service, the Better world Society, and others."

So my inner circle now includes Fleming, Churchill, Wiesel, Nelson, Lama – and Kermit.

> "Getting an honorary degree is a lot like being a grandparent."

If my work in the disability arena over the last 20 odd years is deserving of an honorary doctorate from this respected medical-dental university, the honor belongs to the disability community. They have provided me with the privilege and opportunity to move some anthills and fill some ditches that may have provided a more level playing field for individuals, families and professionals looking for inroads to inclusion and acceptance. To *Exceptional Parent* magazine, The Orange Grove Center, Special Olympics and the American Academy of Developmental Medicine and Dentistry I offer them ***honoris causa, "for the sake of the honor."*** •

ANCORA IMPARO

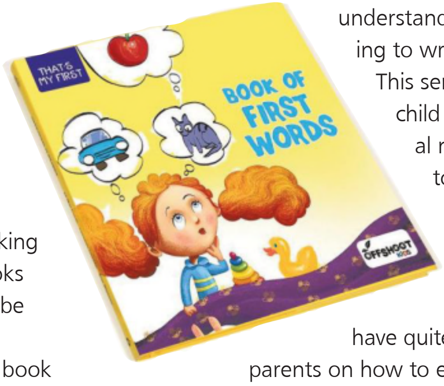
In his 87th year, the artist Michelangelo (1475 -1564) is believed to have said "Ancora imparo" (I am still learning). Hence, the name for my monthly observations and comments.

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

LEARNING & DEVELOPMENT BOOKS FOR YOUNG CHILDREN

Reading skills are one of the most important and basic set of skills toward your child's success. It can be a fun and imaginative activity for children and opens doors to all kinds of new worlds for them.

Offshoot Kids believes kids should have fun when they are learning. The quirky publishing company produces carefully structured and level-appropriate story-based books that are the perfect stepping stones for 3-5 year-olds. They focus on making learning fun. These books keep children entertained while educating, delighting, and sparking imaginations. See what books Offshoot thinks you should be reading with your child.



1. That's My First: Three book series - Book of First Words *(pictured)*, Book of Animals and Book of Numbers. These books introduce young learners to new words and numbers through rhymes and beautiful illustrations. All the three books are developed as a visual dictionary because what a child sees, he remembers.

2. To Stick is to Learn: Two book series - Amazing Alphabet and Naughty Numbers. In addition to beautiful illustrations and rhymes, these books focus on the concept of learning by repetition. The child sees the same letters and numbers highlighted and used various types and subconsciously internalizes the formation and usage of the letters and numbers.

3. The Un-alphabet Series: Two book series - How I learned My Language and How I learned My Language II. As the name suggests, both the books in this series are developed on the more usable and easily understandable format of learning to write simpler letters first. This series does not take the child through the traditional method of teaching A to Z in that order, but focuses on helping the child form letter stroke by stroke. These books also have quite a few tips for the parents on how to engage the child more productively.

4. The Baa-Baa Series: Two book series - That's How We Say It and I See I Learn. The two books on sight words and phonics are created to introduce the child to basic sounds and words in a systematic manner.

5. Ten Little Stories: This book takes the child from numbers 1 through 10 in rhymes. Each number is given seven pages. The child sees and reads the number time and again and internalizes it. •

IMAGES COURTESY OFFSHOOT BOOKS

Fullerton School District & Fullerton Cares Open New Sensory Room for Special Ed Students

MAKING SENSE: Sensory zones have been clinically recognized to provide great therapeutic benefit to children with autism and other sensory challenges.

PHOTO COURTESY FULLERTON CARES

Fullerton School District announces its new sensory room at Sunset Lane Elementary School opening in Fall of this year, with school-wide trainings and presentations being held August 11.

The sensory room is in a permanent classroom featuring many of the most high-tech and evidence-based sensory tools designed by educators and occupational therapists for regulation of the senses and behavior, including sensory swings, a "cushy corner" and more.

Fullerton Cares makes donations raised through grassroots fundraising efforts and corporate community support. Fullerton Cares, along with corporate and community supporters, presented and committed upwards of $10,000 at the March Fullerton School District in support of the creation of this space, which is now opening less than six months later.

The idea for this project came from within the school site itself, with Sunset Lane Elementary Special Day Class teachers Amy Jahn and Karina Tran working hard to make this dream a reality.

Fullerton Cares received recognition from the CA Assembly for their "commitment and dedication to providing support for autism programs throughout the Fullerton School District" from Sharon Quirk Silva of the 65th district and presented by Fullerton School district Board President Hilda Sugarman.

Said Sugarman of the founder Larry Houser: "Fullerton Cares and Founder Larry is an angel in our community. Here's a parent who was given someone special as a child and thought 'I'm going to take this opportunity to make it better for all families.'"

Fullerton Cares Board Director Summer Dabbs said, "I want to thank the teachers for recognizing there was a need for this [sensory room] at their school."

Dr. Tracy Gyurina, principal at Sunset Lane said, "I just wanted to thank Fullerton Cares and our partnerships for everything you are doing to support our vision…helping us realize our dream."

Fullerton Cares Founder Larry Houser, a dad to a child with autism himself, says of the sensory room, "Fullerton Cares is deeply appreciative of the outpouring of community support to spread autism awareness and raise funds for local autism initiatives. This donation to the Fullerton School District is truly a community effort illustrating the passion in our community for including all people of all abilities."

Awareness, acceptance and action are the pillars of Fullerton Cares, a nonprofit spreading autism awareness throughout North Orange County founded by Lawrence Houser, after being inspired by his son, Boyd, with autism. Raising funds for autism charities and programs in Fullerton schools through organized awareness and entertainment events, Fullerton Cares was founded in 2010 and has raised over $75,000 for autism initiatives. Visit them online at http://fullertoncares.com/ or on Facebook at https://www.facebook.com/FullertonCaresAutismFoundation

According to the U.S. Centers for Disease Control (CDC), autism now affects about 1 in every 68 American children affecting communication, social relationships, and is often accompanied by behavioral challenges.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WHAT'S HAPPENING

BRAILLE INSTITUTE ANNOUNCES 17TH ANNUAL BRAILLE CHALLENGE COMPETITION WINNERS

On Saturday, June 17, competitors from the United States and Canada met in Los Angeles at the University of Southern California (USC) for the 17th Annual Braille Challenge® Finals Competition, the only national reading and writing contest in braille for students who are blind and visually impaired. Sponsored by Braille Institute, the Braille Challenge is an academic competition designed to motivate students and emphasize their study of braille, while rewarding their success with fun-filled, challenging events. Knowing that braille literacy is essential for success of youth with low to no vision, Braille Institute developed the two-stage annual competition to encourage school-age children to fine tune their braille skills and celebrate their accomplishments. This year more than 1,100 braille readers participated in one of 51 preliminary regional events across the US and Canada.

"The Braille Challenge is a hallmark program for Braille Institute and our donors as it focuses on braille literacy, while supporting children with vision loss in communities across the country and in Canada to strengthen their academic skills and develop life-long friendships," said Peter Mindnich, President, Braille Institute. "This year, by bringing the event to the campus of USC, we created real-life opportunities for the best of the best braille readers and writers to experience life on a college campus. This is especially important because statistics show that many children who are blind or visually impaired struggle to make the leap to secondary education. Through the Braille Challenge we see participants blossom knowing that they can accomplish anything they set out to do."

Understanding how essential braille literacy is for success in the sighted world, Braille Institute developed the two-phase, annual competition as a way to encourage children who are blind and visually impaired to fine tune their braille skills and celebrate their accomplishments.

"This year, by moving the Braille Challenge to the USC campus, we were able to offer the 50 finalists and their families their first taste of what college life will be for them," said Sergio Oliva, MPA, Director, Programs and Services at Braille Institute. "Our 'Braille Challenge Village' on campus experience helped to demystify higher education and foster discussion about a successful high school transition to college."

Braille Institute is a nonprofit organization whose mission is to eliminate barriers to a fulfilling life caused by blindness and severe sight loss. It serves thousands of adults and youth each year through a broad range of educational, social and recreational programs designed to help people with vision loss lead enriched and fulfilling lives. For more information, visit **BrailleInstitute.org**, on twitter **@BrailleInst** or on Facebook at **Facebook.com/BrailleInstitute**

2017 WINNERS OF THE BRAILLE CHALLENGE

FIRST PLACE

Apprentice	Carmynn Blakely, Louisville, KY
Freshman	Brooke Petro, Leawood, KS
Sophomore	Audrey Bethay, Prairie Village, KS
Junior Varsity	Julia LaGrand, Grand Rapids, MI
Varsity	Mitchell Bridwell, Pittsboro, IN

SECOND PLACE

Apprentice	Miles Lima, Manteca, CA
Freshman	Emily Groves, Bettendorf, IA
Sophomore	Ciara Peterson, Tucson, AZ
Junior Varsity	Kaleigh Brendle, Freehold, NJ
Varsity	Luther Fuller, Lawrence, KS

THIRD PLACE

Apprentice	Hunter Kelly, Claremore, OK
Freshman	Christopher Morgan, Lithia Springs, GA
Sophomore	Sujan Dhakal, Glen Burnie, MD
Junior Varsity	Christopher Abel, Acworth, GA
Varsity	Cricket Bidleman, Morro Bay, CA

TEACHER OF THE YEAR

Jacinda Danner, Palmer, Alaska

SPELLING

Brooke Petro

HARLEY FETTERMAN AWARD FOR EXCELLENCE IN CHARTS & GRAPHS

Richelle Zampella

PHOTO COURTESY BRAILLE ISTITUTE

WHAT'S HAPPENING

Autism Science Foundation Announces 2017 Research Accelerator Grant Recipients

The Autism Science Foundation, a not-for-profit organization dedicated to advancing innovative autism research, recently announced the recipients of its 2017 Research Accelerator Grants. These grants are designed to expand the scope, speed the progress, increase the efficiency, and improve final product dissemination of active autism research grants. This year's award recipients are Antoinette Sabatino DiCriscio, PhD., of the Geisinger-Bucknell Autism & Developmental Medicine Institute at Bucknell University, and John Strang, PsyD, of the Children's National Medical Center and the George Washington University School of Medicine.

"Our accelerator grants allow researchers to maximize the impact of ongoing and promising autism research," said Autism Science Foundation Chief Science Officer Alycia Halladay, PhD "By providing additional support for these important research initiatives, ASF will help scientists find answers for families more quickly and efficiently."

EXPANDING KNOWLEDGE: Antoinette Sabatino DiCriscio, PhD., and John Strang, PsyD; Accelerator grants allow researchers to maximize the impact of ongoing and promising autism research. By providing support for important research initiatives, ASF will help scientists find answers for families more quickly and efficiently.

Dr. DiCriscio's research is focused on the pupil's response to light and other stimuli, called pupillometry, which serves as biomarker for arousal state, attention, and cognitive effort. The expansion or contraction of the pupil differs in people with autism compared to those without ASD. The magnitude of the pupil response also falls on a spectrum with some people showing a huge response and others showing a more moderate response. In this way, pupillometry could help define individuals with autism across a range of symptoms, expanding our diagnostic capability beyond a single "yes" or "no" classification. The ASF accelerator grant will enable collection of pupillometry data from a subset of participants in an existing genetic study of individuals with autism who have known *de novo* copy number variations, so that the genetic basis of pupil response can be better understood. The pupillometry data will be compared to behavioral features of ASD to directly examine its relationship to autism symptoms. Better understanding of this biological basis of differences across behaviors in people with autism will improve diagnosis and intervention efforts, help define different subtypes of autism, and ensure each person receives the most appropriate treatment as quickly as possible.

Dr. Strang is expanding his research examining two different interventions for autism focused on social skills and executive function in middle school-aged children. The longer term post-treatment follow-up of an additional four months will enable the team to collect data on both the immediate and longer term impacts of these interventions on autistic behaviors in the classroom and allow researchers to obtain feedback from parents and individuals with ASD about their experiences and impressions. Most research projects are only funded to track post-intervention outcomes for a limited time after the study period is over. In addition, study-based interventions are delivered in a controlled setting and generalization to other, more natural environments is typically unknown. •

AUTISM SCIENCE FOUNDATION

The **Autism Science Foundation** (ASF) is a 501(c)(3) public charity. Its mission is to support autism research by providing funding to scientists and organizations conducting autism research. ASF also provides information about autism to the general public and serves to increase awareness of autism spectrum disorders and the needs of individuals and families affected by autism. To learn more about the Autism Science Foundation or to make a donation, visit **www.autismsciencefoundation.org**

PHOTOS COURTESY AUTISM SCIENCE FOUNDATION

NEW PRODUCTS

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MINI TIME TRACKER

The Mini Time Tracker is an audio sensory integration aid, a programmable visual timer, designed for students with attention deficit-hyperactivity disorder, and disorders that require sensory integration to help ground and focus them on the task at hand. Uses colored lights and auditory cues to count down time. Mini Time Tracker features two simple dials, a volume control, and an optional warning signal. These smart visual timers can be set anywhere from five minutes to two hours. They can be used as organizational sensory diet tool for classrooms, home, and occupational therapy. Requires 3 AAA batteries (not included).

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ABLEDATA

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

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Los Angeles: **February 23-25, 2018**
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NEW PRODUCTS

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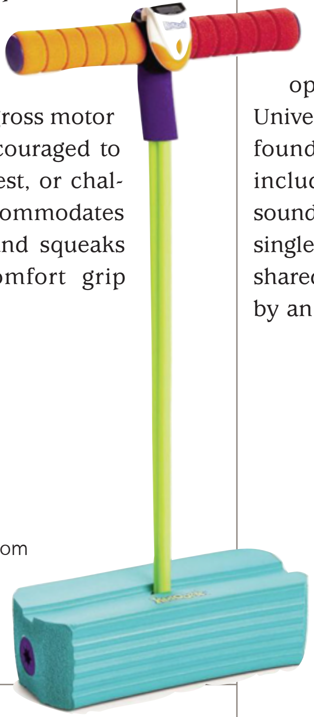

The Counting Pogo Jumper is a pogo stick with a built-in squeaker and electronic hop counter designed for children ages 3 and up to encourage gross motor play. The child is encouraged to beat their personal best, or challenge other users. Accommodates any height. Counts and squeaks with every hop. Comfort grip handles.

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AMERICAN ACADEMY OF DEVELOPMENTAL MEDICINE & DENTISTRY

Is a Parrot a Service Animal?

BY H. BARRY WALDMAN DDS, MPH, PHD, BEVERLY L. MUNTER, STEVEN P. PERLMAN DDS, MSCD, DHL (HON), MATTHEW COOKE, DDS, MD, MPH

> *"Mitchell Slaugh takes his parrot, Kai, with him everywhere because he is his registered support animal. Saturday, Mitchell was kicked out of the WinCo on Clearwater for bringing his parrot inside. 'She's my baby. She's a companion… I need her and she needs me.' Mitchell is cleared by doctors to have her on his shoulder as his support system as he deals with anxiety."* [1]

> *"…her doctor told her to get a dog for emotional support. Alton, 65, still can't work, but Scrappee Anne, her miniature schnauzer, makes it possible for her to socialize and cope with the anxieties of clinical depression and posttraumatic stress disorder… Alton's case sets two rights in conflict – her right to cope with her medical condition and the landlords' right to control and maintain their property.* [2]

Alton is part of a growing trend of people with mental illnesses relying on what are known as therapy, comfort or "emotional support" animals to stem the symptoms of their illness. However, the confusing patchwork of state and federal laws makes landlords and other businesses vulnerable to lawsuits if they impose restrictions. [2]

EMOTIONAL SUPPORT ANIMAL ("ASSISTANCE ANIMAL")

An emotional support animal is not a pet. It is a companion animal that provides therapeutic benefit to an individual with a mental or psychiatric disability. The person seeking the emotional support animal must have a verifiable disability (the reason cannot just

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.

be a need for companionship). Emotional support animals or comfort animals are often used as part of a medical treatment plan as therapy animals, Specifically, these support animals provide companionship, relieve loneliness, and sometimes help with depression, anxiety, and certain phobias, but do not have special training to perform tasks that assist people with disabilities. Even though some states have laws defining therapy animals, these animals are not limited to working with people with disabilities and therefore are not covered by federal laws protecting the use of service animals. The animal is viewed as a "reasonable accommodation" under the Fair Housing Amendments Act of 1988 to those housing communities that have a "no pets" rule. Most times, an emotional support animal will be seen as a reasonable accommodation for a person with such a disability. [3]

All domestic animals can quality as emotional support animals, including “…cats, dogs, mice, rabbits, birds, snakes, hedgehogs, rats mini pigs, ferrets, etc. and they can be of any age (young puppies and kittens, too).” [4]

DIFFERENCE BETWEEN A SERVICE ANIMAL AND AN EMOTIONAL SUPPORT ANIMAL

Service animals are defined as dogs that are individually trained to do work or perform tasks for people with disabilities. These tasks can include things like pulling a wheelchair, guiding a person who is visually impaired, alerting a person who is having a seizure, or even calming a person who suffers from Post-Traumatic Stress Disorder. Service dogs may accompany persons with disabilities into places that the public normally goes. This includes state and local government buildings, businesses open to the public, public transportation, and non-profit organizations open to the public. The law that allows a trained service dog to accompany a person with a disability is the Americans with Disabilities Act (ADA). [5]

TYPES OF SERVICE DOGS FOR CHILDREN

> *“Especially with children, there can be a tendency to think of service dogs as Lassies… Lassie does not exist! She’s a fictional character and isn’t even just one dog! In order to do all of the cool things she does on TV and in movies they have to use several dog actors. Dogs are not humans in fur suits, they do not think the same way that humans do. They are dogs, which are wonderful in itself, but we need to be realistic about what dogs are really capable of doing.”* [5]

Hearing dogs: To help individuals who are deaf or hard of hearing by responding to sounds such as a knock on the door, alarm clocks and the child’s name, by alerting their human partner to these sounds. Hearing dogs work best when the child can respond independently to the information provided by the dog.

Traditional service dogs: To help those who use aids including wheelchairs, canes, crutches and walkers by picking up almost any dropped item, turning a light switch on or off and carrying items.

Seizure alert dogs: Identify when a seizure (e.g. from epilepsy) is about to happen and alert their partner.

Guide dogs: The oldest type of service dog and the most commonly known by the general public. These dogs are trained to negotiate obstacles, overhangs, barriers, street crossings and public transportation to help individuals with sight impairments.

Dogs for psychiatric disabilities: The Americans with Disabilities Act allows for dogs to help individuals with psychiatric or other mental disabilities by preventing or interrupting destructive behavior. For example, a dog would nudge the handler when a behavior such as body rocking caused by anxiety starts to happen, so that the handler would become aware of the behavior and then be able to control the anxiety response. A dog is individually trained for youngsters and adults who have an emotional or psychiatric disability so severe that it substantially limits ability at least for one major life task.

Walker or balance dogs: These are generally large breed dogs that wear harnesses to help an individual balance in a standing position or to get up or down from a standing position, while others are trained to help prevent falls while the individual is walking.

Social dogs: Help those children who cannot assume total responsibility for a working dog, but who can benefit from the assistance of a dog can help to learn impor-

AT YOUR SERVICE: Service animals are defined as dogs that are individually trained to do work or perform tasks for people with disabilities. These tasks can include things like pulling a wheelchair, guiding a person who is visually impaired, alerting a person who is having a seizure, or even calming a person who suffers from Post-Traumatic Stress Disorder. Service dogs may accompany persons with disabilities into places that the public normally goes.

tant social skills. These dogs encourage social interaction between the child, the dog, and other individuals. This style of work is most often successful in children with the Autism spectrum disorder.[6] Specifically, these dogs act as constant companions to children with autism to help them improve social interactions and relationships, expand verbal and nonverbal communication, teach life skills, increase interest in activities and decrease stress within the family.[7] However:

> *"A dog has the mentality and the cognitive ability of a three year old human child... Would you send a three year old out to cross the street alone? Would you put a three year old in charge of another child to lead that child across the road? A service dog should not be given more responsibility than a three year old human child. Service dogs need adult supervision too.*
>
> *Service dogs are wonderful helpers, but they are not guardians, they are not nannies, and they are not babysitters. In the human/service-dog partnership, the human MUST be emotionally mature. If you would not hand off a three year old human child into the care of the would-be service dog handler, then please, do not give that person a service dog."* [6]
>
> *"(Reality)… The dog arrives and the kid falls in love. At first, there is the honeymoon period driven by hope. Then reality sets in… Now, not only does the parent have to take control of both the dog and the child, if the parent wants to maintain the dog's training, the parent have to stop right then and there and train… Gee: how confusing for the dog! Sometimes he or she is controlling the kid, sometimes the kid is controlling him or her, and most of the time no-one is really in control. "* [7]

Nevertheless, children with autism often lack the skills to decipher human emotions. However, a dog's presence is difficult to ignore and once interaction with the dog begins, the child starts to develop empathy. The dog's presence also gently encourages the child to shift attention from the inanimate to the animate. Playing a simple game of rolling a ball back and forth to the dog may open up social avenues with other children. Now the child has a "draw" for the interest of other kids who would like to interact with the dog and join in the game. [8]

THINK YOU CAN CLAIM YOUR PET IS AN "EMOTIONAL SUPPORT ANIMAL"?

Maybe - the law is murky and the answer depends heavily on your animal's skills, your frailties and your conscience. Governments and businesses increasingly sort companion animals into several categories.

> *"Numbers on companion animals of all kinds are hard to come by, but a JetBlue spokesman said more than 25,000 of its passengers boarded with animals in the first 11 months of 2014. That was 11% more than all of 2013."*[9]

- "According to airlines, hotels and government agencies, many pet owners are describing their animals as emotional support animals (ESAs). Some carry letters from licensed health professionals attesting that they suffer mental or psychological disabilities that are eased when their pets are present…
- Some who work with animals, however, see the ESA situation as a growing problem because of the pet owners who distort their infirmities (or stretch the truth) to get their pets better access. Several companies sell ESA evaluations, letters, registration cards and other accessories on the Web, sometimes requiring telephone interviews, sometimes operating on the honor system…
- In fact, federal laws are conflicted when it comes to ESAs. Some, including the landmark Americans with Disabilities Act, give no extra privileges to people with ESAs. Yet other federal laws do, which is why airlines see so many furry fliers… Therapy dogs get no particular perks outside the schools and hospitals where they work, except for miniature horses (which typically weigh about 70 pounds).
- The federal Air Carrier Access Act, on the other hand, allows ESAs to fly in the passenger cabin on commercial flights at no extra charge, usually on the passenger's lap or in a carrier under the seat. The federal Fair Housing Act permits ESAs in condos or apartments that ban pets. That law doesn't cover hotels, but many upscale lodgings accept ESAs, including some that ban conventional pets.
- As for the Americans with Disabilities Act, the U.S. Justice Department decided in 2011 that it should apply only to people with disabilities who are accompanied by service dogs and, 'where reasonable,' miniature horses.
- But under the ADA, businesses can ask only two questions when trying to determine whether an animal is truly a service dog: Is it required because of a disability? What work or task has it been trained to perform?

Facing such complexity, many businesses have decided to just say yes to ESAs." [9]

Our conclusion: A parrot is not a service animal. It is an emotional support animal.•

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RESCUE LEADERS

Due to the unknowns about how Zika will continue to affect children, everyone – not just pregnant women – should aim to protect themselves and their children from contracting the virus.

ZIKA

A THREAT TO PREGNANT WOMEN

BY CLAIRE MENA AND AVA TODD

In April 2015, a British company named Oxitec began releasing over 100,000 genetically modified mosquitoes weekly in Brazil. These mosquitoes were designed in an effort to reduce infectious disease carrying mosquitos. Months later, a growing number of infants in Brazil were born with a serious birth defect: microcephaly. Various media outlets, officials, and individuals quickly began linking a connection between the two, yet there was a serious problem with this claim: it was false.

During an epidemic, fear and panic often grow with the prevalence of the disease, and misinformation trails alongside it. While the rumors usually begin with a small kernel of truth, the information expands and morphs through the use of convenient scapegoats and prominent people to promote it. Historically, ethnic groups and institutions have been falsely blamed for the outbreak of conditions such as the plague, aids, cholera, and autism. As Dr. Howard Markel from the University of Michigan says, rumors are “the lifeblood of an epidemic.”

Although a growing number of infants were born with microcephaly after the release of genetically modified mosquitoes, this is merely a casual occurrence. The mosquitoes were released over a thousand miles away from the major microcephaly outbreaks and mosquitoes do not typically fly more than a mile during the duration of their life. Additionally, only male mosquitoes, who do not bite or spread disease, were released in the country and were genetically designed to die quickly and thus reduce mosquito related diseases, not increase them. Although there is an increasing amount of evidence that has disproved the connection between GMO mosquitoes and microcephaly, a University of Pennsylvania survey study from the Annenberg Public Policy Center shows that more than a third of respondents believe this to be the true source of the outbreak. This form of misinformation can be dangerous because if people don’t understand the true source, they cannot

GENETIC ALLIANCE

The world’s leading nonprofit health advocacy organization committed to transforming health through genetics and promoting an environment of openness centered on the health of individuals, families, and communities.

take the proper precautions.

Now, the Center for Disease Control and Prevention (CDC) has concluded that Zika infection is a cause of microcephaly and is linked to the recent outbreak. While Zika can have serious implications for women who are pregnant or may become pregnant, the contraction of Zika in a person who is not pregnant is usually minor or even asymptomatic. It is not uncommon to contract the virus and recover from it before realizing the virus had passed. For those who do experience symptoms, it typically includes nothing more than a fever, headache, rash, red eyes, and joint and muscle pain; typically limited in duration to a few days to a week. However, despite low risks when not pregnant, there are reasons to take precautions to prevent the contraction of this virus.

While your child is not at risk of serious defects if they contract Zika after birth, it is still important to take precautionary measures. Children are still at risk for contracting the virus and may experience mild symptoms to more serious flu like symptoms. If traveling to a Zika infected area, you and your family can implement typical steps to prevent mosquito bites by dressing to cover arms and legs, covering cribs and strollers with netting, and applying insect repellant on yourself and babies over two months old. Additionally elimination of stagnant water, such as water sitting in buckets and puddles, can help prevent mosquitoes from residing close to the home. For more information on ways to prevent mosquito bites and the best forms of insect repellent to use for your family, go here: *https://www.epa.gov/insect-repellents/find-repellent-right-you*

The Effects of Zika

Zika presents the biggest threat to pregnant women because of the link to birth defects when the virus is passed from mother to fetus in utero. Dr. Turan Dua, a neurologist from the World Health Organization's Zika Response Team, describes the long-term effects of Zika on babies and children as an emerging problem. With this condition, the baby is born with an unusually small head (microcephaly) and may experience slow development or underdevelopment of the brain. This often results in seizures, stunted growth, mental retardation, difficulties with coordination, and other neurological problems. Currently, there is no cure or treatment for this condition.

The effects of Zika during pregnancy can span beyond microcephaly. Complications include damage to the back of the eye, limited use of joints and spasticity, or continuous contraction of muscles. It is important to note that an infected baby will not always show symptoms of congenital Zika at birth. Dr. Dua explains that when the public health emergency arose, "some babies were infected that did not have any of the clinical abnormalities at birth, but later on they had clinical abnormalities in the first year." For this reason, Dr. Dua stresses the importance of having a neurological follow-up for newborns, especially if the mother had exposure to Zika or traveled to affected areas during or within a short time of pregnancy.

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Prevention and Treatment

If you and your partner plan to conceive in the near future, it is extremely important to take extra precautions when at risk for contracting Zika. Doctors recommend that if a woman has displayed symptoms of the virus or was potentially exposed to it, she should wait at least eight weeks before trying to conceive. While the virus is typically contracted through the bite from an infected Aedes species mosquito, it can also be passed through sexual transmission and other bodily fluids. Doctors recommend that if the male partner has symptoms or was potentially exposed to the virus, the pair should wait at least six months before conceiving. In the time prior, it is important to use condoms or practice abstinence to not further pass the disease. Therefore, if you are thinking about conceiving in the near future, both you and your partner should take steps to prevent contraction of Zika.

Returning from the trip

After returning from a trip in a Zika infected area, it is important to continue protecting yourself and your little ones from mosquito bites. Even if you are not demonstrating symptoms, continue to take preventative measures to ward off mosquitoes for an additional three weeks. While the mosquitos nearby may not have Zika, it can be spread to them if you previously contracted the virus.

If any symptoms arise, be sure to contact your doctor and tell her about your travel. If you are pregnant or planning to become pregnant and have traveled to a Zika infested area, be sure to follow up with your doctor regardless of whether symptoms have surfaced or not. Zika can be diagnosed with a blood or urine test, but a doctor will most likely first want to know if you have been recently traveling in an infected area.

While there is currently no treatment or vaccine for Zika, it is possible to ease the symptoms by getting plenty of rest, drinking a sufficient amount of fluids, and taking medicine such as acetaminophen. Additionally, if someone around you has contracted the virus, be sure to protect yourself from blood or bodily fluids and to wash hands with soap and water if in close contact.

Moving forward

While it is certain that the genetically modified mosquitoes do not have a connection to Zika and microcephaly, much about the virus is still unknown. Researchers have still not determined the long-term effects the virus can have on infants and children. Dr. Dua and others from WHO have been documenting complications from Zika in infected babies, some of whom are now one year or older. Dr. Dua states that these older babies continue to have a range of problems including microcephaly and other neurological abnormalities. Due to the unknowns about how Zika will continue to affect these children, everyone – not just pregnant women – should aim to protect themselves and their children from contracting the virus.

ABOUT THE AUTHORS:

Claire Mena is Online Engagement and Outreach Assistant and Ava Todd, intern, with Genetic Alliance.


When I grow up,
I want
to be a chef!
Sarah
now I have a chance

KRISTIN MCNEALUS, PT, DPT

Motivation to Get Moving

Write down your goals to keep you focused on why you are exercising. Are you trying to stay healthy for your children? Are you trying to cut down on medications you have to take?

We all know that exercise has many benefits for us, both physically and psychologically. It can keep our bodies and our minds healthy, and yet most people do not get enough exercise. Why is this?

The #1 excuse is limited time. We are so busy that we feel like it is difficult to make time for a workout. I am sure that you have heard that if you do not make time to stay healthy now, you will not have the choice to spend time on your ailments later. Making time to work out for 30 minutes six days out of the week is less than 2% of your time! Doesn't that put it into a bit of perspective? 30 minutes is not much time! The American Heart Association does recommend at least 30 minutes of exercise most days of the week, but they also say that if you can only work out for 10 minutes at a time and do that three times per day, you will get the same cumulative benefits. If you only have 10 minutes, that is better than nothing! Get moving! And try to fit another bout in later in the day when you have another 10 minutes.

You are also more likely to stick to a workout schedule if it is put into your calendar. Just like you put dentist appointments, or PTA meetings on the agenda as booked time, putting your workouts on the same level of importance into your schedule will help make that time a priority.

People often ask when the best time is to exercise. And the answer is: whenever you will do it! If you are more likely to work out in the morning because the day just gets away from you, and you are likely to erase it from you evening plan, then working out in the morning is best for you. If you are more likely to hit snooze through your scheduled morning workout time, then planning to exercise later in the day is probably best for you.

Another big excuse is fatigue. When we are tired, the last thing we feel like doing is working out. But exercise gives you energy! By increasing the blood flow and oxygen to the brain, you will feel more alert. Neurotransmitters will be released, and you will feel more awake. Use the 10 minute rule again; even if you are feeling exhausted, try to exercise for 10 minutes. If you still feel too tired, at least you gave it a shot, and 10 minutes is better than no exercise. Also, exercise helps us get deeper sleep; hopefully even that short bout of exercise will help you sleep better so that you are not as tired tomorrow and you can get your full workout. Likely, once you start working out, you will feel less tired, and able to finish the 30 minutes.

HALF-HOUR POWER: The American Heart Association recommends at least 30 minutes of exercise most days of the week, but they also say that if you can only work out for 10 minutes at a time and do that three times per day, you will get the same cumulative benefits.

Some people are motivated by other people's encouragement. If you like this, maybe finding local workout classes would be helpful. Exercise with other people who are focused on a similar goal, and can keep you on track by making sure you get to class (even on those days you don't really want to!) If you do not enjoy working out with other people, or you have difficulty getting to exercise classes, consider sharing your goal and progress on social media. Every Body Fitness allows people to share their workout on Facebook; it is for people who may not like to exercise with others but still like friends and family to know they are working towards a goal, and they can cheer you on.

Some people are motivated by awards. There are a number of wearable tech options to track steps or minutes of exercise, however these generally do not work well for many people who have mobility limitations. There are some options in the works for people who use wheelchairs, but they are still being finalized. Every Body Fitness has added a dashboard that provides the same visual feedback without a wearable device! You can enter the number of minutes that you spent working out that day, and this is not tied to our videos, so you can enter any time you spend swimming, dancing, cycling, etc.! You can see a graph of your entries, and you earn points for every workout. There is even a built-in allotment of bonus points if you exercise more than 20 days in a month – to motivate you to work out five days per week! You can even trade those points in for prizes! If this is something that may keep you motivated, check it out.

> "Exercise with other people who are focused on a similar goal, and can keep you on track by making sure you get to class. If you have difficulty getting to class, consider sharing your progress on social media."

Write down your goals to keep you focused on why you are exercising. Are you trying to stay healthy for your children? Are you trying to cut down on medications you have to take? Are you trying to lose weight? Write down any and all of your goals, and then be sure to write down any progress you are making toward those goals! Having your physician lower your blood pressure medicine dosage would certainly be just as worthy of bragging about as losing pounds. Also, keep track of things that get easier for you to do – maybe you can blow dry your hair without your arms getting tired, or it is easier to get out of bed. Write it down and celebrate it! •

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.

SAFETY FOR A CHILD WITH A SEVERE MOVEMENT DISORDER

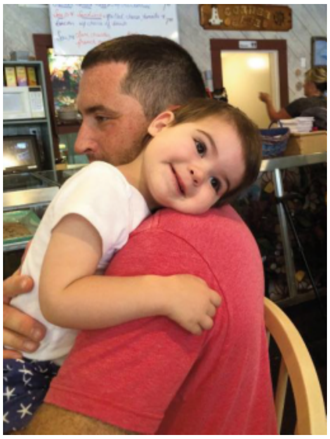
BY LUKE ROSEN

> No matter how relentless we are about making our home accessible, Susannah's movement disorder is responsible for teaching her where to go when she feels the danger of her changing coordination. I'm thankful to her disease for that — for doing my job in some strange way. For somehow teaching her to be safe.

Keeping our kids safe is every parent's number one job. Even as an adult I associate protection and safety with my childhood home and my loving parents. It's a great relief when our children finally learn where to go and who to find when they're in danger. More than a relief, it's a proud parental achievement worth celebrating: "We're super parents! Our kids know where to go when they sense danger!" Mission accomplished, big exhale.

When your kid has a rare neurodegenerative disease causing her balance to worsen every day, the safety of your home is constantly being put to the test. There is no relief, there is no deep exhale. There is only constant heartache with every face-first fall into the brick wall that she once used to pull herself up.

When Susannah was a baby she would flop onto my shoulder and rest quietly for minutes at a time – it was heaven. I live for those shoulder flops. Just after her second birthday we were told this spontaneous cuddling was a symptom of her genetic condition that would eventually cause her to fall. A lot.



SAFE FOR NOW: *(Previous page)* The author with daughter Susannah as she dozes during an electroencephalogram; *(Above)* "The progressive nature of Susannah's disease might steal away her speech and steps, but she will never lose the sincere and purposeful kindness that is cause for those quiet shoulder flops."

Around the time of her diagnosis, we learned that our daughter's seemingly intentional maneuver of affection was just another implication of her increasingly low muscle tone, or hypotonia. As she grows taller and her gait becomes severely ataxic, constant tumbles are a regular part of our new normal. Not even three years old and her daily bumps and bruises resemble those of a hockey player.

I'm the luckiest guy in the world, for so many reasons. I'm blessed to have a thoughtful, funny, intelligent and kind daughter. The progressive nature of Susannah's disease might steal away her speech and steps, but she will never lose the sincere and purposeful kindness that is cause for those quiet shoulder flops. I have complete faith in science; however, there are two things I am certain medicine has wrong: that there is no cure for Susannah's condition, and that those divine shoulder flops have a clinical explanation like "low muscle tone." She flops onto my shoulder because she loves me. She's safe there, and she knows it.

This morning one of Susannah's daily acts of kindness warmed my soul to the core. I was about to walk out the front door when she extended her hand and led me into the bedroom. When we arrived at her bed, she flopped herself onto the mattress and said my favorite words, "Daddy cuddle me." Before the tears made it from the pit of my stomach up to my eyes, she pulled me onto the bed and we cuddled. One of the best cuddles ever.

PHOTOS PROVIDED BY LUKE ROSEN

NOT ALL SUPERHEROES WEAR CAPES: *(Clockwise from top left)* Susannah celebrates her third birthday; with her mom Sally at NewYork-PresbyterianChildren's Hospital; and with her brother Nat at the baseball field, wearing her braces which help her get around.

> As kids get older, hugs become less frequent. Not with Susannah.

After a few minutes Susannah rolled over and said "Daddy I come to bed because it's safe." Crushing. The tears returned to the pit of my stomach and became a nauseating feeling of paternal helplessness. Is her bed the only place in our home where she won't fall and get injured? We haven't taught Susannah where to go when she feels danger, her disease has. Does she only feel safe in the bottom level of a New York City-sized bunk bed designed to keep her from falling out at night?

There's no great parental achievement here, no deep exhale celebrating the accomplishment of that essential hurdle: teaching our kids where to go when they're scared. That badge of honor doesn't belong to us because we didn't earn it, her degenerative condition did. When she's having an especially wobbly day, Susannah knows she immediately needs to return to her bed, or into my arms. The labyrinth of our living room and its old, uneven New York floors is overwhelming.

No matter how relentless we are about making our home accessible, Susannah's movement disorder is responsible for teaching her where to go when she feels the danger of her changing coordination. I'm thankful to her disease for that — for doing my job in some strange way. For somehow teaching her to be safe. But I'd like to meet KIF1A in a dark alley and destroy that monster for stealing away our daughter's sense of independence.

It's natural, as kids get older, for those precious extended hugs to become less frequent. That's one of the deliciously sad parts about watching our children grow up. Not with Susannah. Her genetic mutation is cause for one of my most coveted parts of the day. Selfish, for sure, but if Susannah flops into my arms and rests her head on my shoulder because of a rare genetic anomaly, I'll accept that. But that's not the reason. You see, my daughter is a trickster. The real reason she leads me into her bed for a safe cuddle is because she inherited her mother's beautiful tenderness. She's more generous than she is cautious. She knows how amazing it makes me feel when she flops on my shoulder. Susannah is a superhero who can fly around the room — and I thank her every single day for deciding to land on my shoulder. And for staying there.•

PLAYING THE RARE DISEASE CARD

BY LUKE ROSEN

Parenting a kid with special needs requires a lot of writing. It seems like I'm constantly writing, which is ok because… well, I'm a writer. Sitting at my desk typing a blog post is far less stress-inducing than the painful daily scribble that comes along with a rare genetic disorder.

Early Intervention requests; reminders that doses changed because of a seizure yesterday; letters to the mayor about the ramp our building is stalling on; financial aid applications; thank you notes to therapists; Christmas cards in February; invoices from the Tooth Fairy; camp registration and so on. By far the most difficult rare disease writing assignment is filling out new doctor registration forms.

I hate that damn clipboard. That pile of pages handed over by the sweet lady who always gives us an extra smile… Like so many diseases, these registration forms have a progressive course and deteriorate rapidly. Every epic page hurts even more.

> If your kid has a rare disease associated with 50 different horrible conditions, you need a card. A Rare Disease Card. I am armed with a KIF1A card everywhere I go.

Page One is harmless: Date of birth. Address. Phone number. Name of pediatrician. Emergency contact.

Page Two gets harder: Insurance. Siblings. Allergies. School… Thank god DOB was on Page One because I'm already so stressed I can't remember our daughter's birthday – Forget about her social security number.

Page Three makes me sweat profusely. The most difficult section: "Pain on a scale of one to 10."

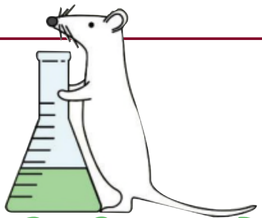
I hope it's closer to a four today. I know it's not a one. Two would be nice but she's having tiny seizures and her eyes hurt. Last night she woke up in a spastic episode, so this morning her legs are cramped. She was vomiting so her chest is sore and she had a bad fall this morning… I don't know, seven?

It's excruciating to imagine our daughter's pain. Luckily she's way stronger than me. She's a superhero. Like all superheroes, Susannah just smiles and waves at every passing baby. Sitting on the puffy, vinyl waiting room chair she looks like a movie star riding on a float in the Thanksgiving Day Parade.

Page Four: Infuriating. Two lines underneath the question "What brings you here today?" Then another two lines at the bottom for me to list "Other medical problems." TWO LINES? If your kid has a rare disease associated with 50 different horrible conditions, you need a card. A Rare Disease Card. I am armed with a KIF1A card everywhere I go. I am a card-carrying member of KIF1A.

These cards are amazing. I'm a happier person because of my card.

WE NEED A MOUSE!



PLEASE HELP US GET A MOUSE!

The first stage in discovering a cure for any genetic disease is understanding the biology of the gene and what effect a disease causing mutation has on a human being. To do that, we need a mouse. Our first mission: Develop a mouse model for scientists, researchers and doctors to work with.

The Jackson Laboratory is where our hero mouse will be born. This superhero mouse will pioneer a treatment for KIF1A Kids, we thank him. Join our campaign to tell the world #WeNeedAMouse. Developing our mouse model is an expensive task. We need to fund the work. With your support we will get our KIF1A mouse.

Our friends at Jackson Lab are some of the most supportive people in the world. These scientists care about our families and our KIF1A children. They also tell inspiring stories of how their work saves the lives of other kids with rare diseases. Why do we really need a mouse? Well, lets let the relentless scientists at JAX tell you at **www.jax.org/news-and-insights/stories/medical-progress**

#WeNeedAMouse

As many of you know, the relentless scientists at The Jackson Laboratory are instrumental in accelerating our urgent need for research, and to #StopTheClock on KIF1A. Without hesitation this incredible organization got to work on KIF1A. We couldn't have accomplished this without their generous support. These scientists make a difference in our lives and in the lives of every family affected by rare disease. Learn more at:

www.kif1a.org/day-1.html
www.kif1a.org/-weneedamouse.html

KIF1A.ORG is a 501(c)(3) nonprofit organization. All donations are tax deductible.


The Amazing Amazon
WONDER WOMAN
KIF1A CARD
Powers and Abilities
KIF1A Genetic Disorder
This is a detailed description of my rare disease. Read this so my dad doesn't have to tell you about it. And so you know that this disease is super rare.
Wonder Woman TM and © DC COMICS

Secretaries don't hate me and ER visits don't take five hours thanks to my shiny new card. First Responders will save my kid's life because that card explains the neuropathy making her insensitive to pain. A laminated card (written by somebody far more eloquent and informed than I am) explains everything one needs to know about a rare genetic mutation and what to do when things get real.

It takes 15 minutes for me to briefly explain Susannah's rare disease. Usually I can't get through the conversation without crying – which adds another five minutes to my incoherent rambling. It's difficult to articulate her condition because the genetic anomaly stopping Susannah from walking is an elusive mystery without a name. Her condition is referred to as a KIF1A-related disorder caused by a mutation in her KIF1A gene. Susannah's previously unreported genetic mutation is rarer than rare.

Thank god for my KIF1A card! I love my card so much that I carry five in my wallet, 12 in my bag and Susannah always has one in her pocket. Every family member, teacher, babysitter, friend – they all have Susannah's Rare Disease Card. When I walk into a new doctor's office and that secretary hands me a clipboard, I just snap my Rare Disease Card onto the form and hand it right back. New school or camp? No problem. My consent form isn't an illegible novel – it's a prewritten baseball card stapled to the front. In the middle of the night when her body is as stiff as a board and I'm carrying her into a crowded Emergency Room, that little card lets me massage her legs instead of filling out a form.

Thanks to my Rare Disease Card, Susannah won't see the desperation in my face when I stumble through a foggy explanation of her neurodegenerative condition. Silly as it sounds, my ever-present fear goes away for one fleeting moment as I scoop her up, kiss her face and hand somebody that card. Thanks again, card.

Our incredible social worker is there for us every single day. She walked us through Medicaid and helped us get Susannah into school. She spent hours on the phone with insurance companies so we could take a breath and remember to sleep. When I have no idea what to do next (daily) she answers the call. She is our generous navigator and Susannah's relentless advocate. And she gave us a KIF1A Card. A card that protects Susannah from seeing how terrified I am whenever I talk about the disease with no name. When somebody asks what's wrong with my daughter, I say "Absolutely nothing, she's a superhero" and hand them the card •

EVERY DAY MATTERS: DR. WENDY CHUNG ADDRESSES THE URGENT NEED FOR ACCELERATED KIF1A RESEARCH

Our mission is to save the life of every child affected by KIF1A. The only way to discover treatment is to immediately accelerate research by convening the world's leading scientists in childhood genetic and neurodegenerative disorders. This collaboration will lead to treatment and increase the quality of life of those affected by KIF1A. It is vital for us to drive science, fund immediate research and find a way to stop the progressive nature of this disease.

Dr. Wendy Chung is a board certified clinical geneticist with a PhD in molecular genetics. She is director of the clinical genetics program at Columbia University and co-director of the molecular genetics diagnostics lab there. In a brief video explaining the work she and her team are doing on KIF1A, she talks about her role in its treatment and research.

"KIF1A is just one of many unfortunately rare genetic conditions. I happen to be a doctor for children and individuals with rare genetic conditions, and my job is kind of to be their Sherpa and to help them along this process to understand what club they're a member of, in other words what their underlying genetic is, and ultimately help them with the care until we get to the point of a cure," She says. "In other words, to be able to keep them as strong and as healthy as possible while, at the same time, working towards understanding what's causing their disease so we can come up with better treatments for them."

Dr. Chung emphasizes the crucial factor of time in the fight to help her patients. "It's a ticking clock in the back of my head and in the back of the head of all the families, because we do know that we have a window of opportunity that I hope is something like 5 -10 years in terms of when the time a child is diagnosed until we can really be able to stabilize this and give them meaningful life, but every day matters, and that's why we're working so hard to be able to come up with a cure for this."

View the video at: http://www.kif1a.org/research.html

MANAGING EXPECTATIONS

WITH A HOME REMODELING PROJECT

BY DEBORAH PIERCE, AIA, CAPS

A road map
for putting your
remodeling project
on a solid foundation.

PHOTOS COURTESY KATHY TARANTOLA PHOTOGRAPHY

SOUND PLANNING: *(Opposite page)* A pedestal base, rather than corner legs, makes a wheelchair-user friendly table. Built-in furniture, rather than free-standing items, give sturdy support when it's most needed. *(Above)* Plan the yard with as much care as the home, to create places that everyone in the family can enjoy. Here, a ramped patio and raised-bed lawn area puts outdoor games within reach.

Renovation's no "walk in the park," as anyone who's remodeled an older house will attest. And when we live with disabilities, little inconvenience can loom large. Yet renovate we must, to have a home that's wheelchair accessible, or where our children can gain a degree of independence. The homes we live in today were built in a different time, with different values.

Even at it its best, renovation is expensive, complicated, noisy, and messy. Friends share stories of projects run amok. Strangers field you questions before you've had your morning coffee, and cars block the driveway as you're heading off to work. You reconsider habits that once made sense, like toileting your son in the powder room, then carrying him, bottom-exposed, to a larger bathroom for bathing. You and your spouse will disagree on questions like whether the laundry belongs near the kitchen or the bedrooms, and what color tile to use. At times you will doubt the wisdom that led you to reach out and seek help in the first place.

Relax - this is all perfectly normal! Like any complex endeavor, each construction project has its ups and downs. It can be useful to realize that anxiety feels a lot like excitement – butterflies in the stomach, lying awake at 3 AM obsessing over details. As the homeowner, each new challenge feels daunting until the matter is resolved. Then another situation arises and you're back on that roller coaster.

Remodeling is actually a kind of alchemy – out of the mud, gravel, sawdust, and sweat, something of great value and beauty is created. It pays to remember this when you get discouraged. If the project has been well planned, and if you have a competent team of designers and builders, then you will reduce anxiety levels greatly.

For over 30 years I've been remodeling homes, serving as architect, homeowner, and general contractor. These experiences have given me a good overview of the remodeling process. One clear trend is towards greater accessibility. Features like zero-step entrances and curb-less showers, multi-height countertops and lever-handle hardware are becoming commonplace. For people who have both an urgent need and high hopes for a more user-friendly home, this is good news. The stakes are especially high, and the margin for error low, when disabilities are present. Today many architects and builders are familiar with the principles of Universal Design, or "design for all." You want a house that works for your family, though - not "for all" – so even if your architect is fluent in accessible design, you'll still need to be a strong advocate for a home that's tailored to your family's requirements.

Another trend is towards greater homeowner comfort with design issues. Today many people start their projects carrying images from TV shows, books, magazines, and websites dedicated to home improvement. They're knowledgeable about net-zero design and sustainable products, and have strong preferences for materials like honed granite and bamboo. This can make for a productive collaboration, but it also leaves fundamental issues open just when closure is needed. Since having a family member with disabilities accentuates the stress of a remodeling project, it's especially important to prepare well. After all, no one knows your family's needs like you do!

FREE AND CLEAR: Accessible bathrooms have space where it's needed – beside the toilet, for transfer or assisted use, and under the sink, for a seated user.

As you prepare to begin your project, certain tasks will put you on solid footing. Knowing what you want to accomplish, and what you can spend, will focus everyone's attention on realistic options, and save you time and money over the long run.

What follows is a road map for putting your remodeling project on a solid foundation.

1. Make a wish-list. Every building project starts with a clear set of objectives, so take some time to assess your space-needs and wants. Observe each activity of daily living and each area of the home with a critical eye. Restate problems as goals, such as "my daughter wants to bathe herself" or "we need a suite for a live-in caregiver." Establish priorities in case your budget, the town's zoning, or the house's layout can't accommodate every wish. Resist the urge to try and solve problems. Design comes later, and will be easier with help.

2. Describe special coping mechanisms. Most able-bodied individuals brush their teeth in the same way, but when disabilities are present there are few standard procedures. One family I've worked with shares bath-time between three children, so the child with CP has siblings nearby. I gave them an extra-large soaking tub. Another family takes weekly deliveries of medical products, so I incorporated a shipping-receiving room in their renovation. Another child is on an all-liquids diet, so we devoted a special area of the kitchen to her needs, with its own sink, microwave, and dishwasher. What special medical or mobility devices need to be accommodated? Do not assume your architect knows how you do things – everybody is unique.

3. Identify your resources. Review your finances carefully and seek out opportunities to increase available funds. Speak with a banker about refinancing or getting a home equity loan. Ask your accountant about tax ramifications of investing in the property, and talk with your portfolio manager about shifting funds for greater liquidity. If access upgrades are medically prescribed, you'll need to have your designer and builder itemize deductible expenses. Research possible grant sources, such as catastrophic illness funds or state and local financing assistance. In Massachusetts, the Home Modification Loan Program makes zero-interest loans to income-qualified households, with the pay-back deferrable to when the property is sold. You'll need to be honest with your architect about spending limits – both for ideal and deal-breaker budgets.

4. Consider a move. Many people investigate relocating to a home that's a better match before committing to "stay put." Attend open-houses to get a sense of what's available. Ask a realtor to assess your house's value now, along with the increased appeal that various upgrades can offer. This information will help you decide whether to proceed with remodeling or to move. It will also give you confidence when a relative suggests, over Thanksgiving dinner, that you're wasting your money with renovations.

5. Assemble your team. Home improvement is a big industry, with a variety of designers, builders, and salespeople eager to help you, not to mention 3D software that can make building professionals seem irrelevant. And there are often many routes that will lead to a successful outcome on your project, as long as you comply with zoning requirements and building codes. Knowing what you can expect of others, and what they'll expect of you, will go a long ways towards producing a happy project. You don't need to reinvent the wheel – the building industry has already done that. You only need to understand how best to use it.

Architects are the go-to professionals for complex renovations and new construction. They work closely with specialists, engineers, product representatives, and the homeowner to develop the drawings and specs that describe a project, and that will form the basis for your contract with a builder. Architects take projects from initial planning through completion, helping you find a builder and oversee construction so that your project is built as intended. Most architects specialize in certain building types such as residential, commercial, or institutional, or projects of a certain size, although many have several areas of expertise.

Designer is a broad term applying to a range of skills in the building industry, including interiors, kitchens, bathrooms, lighting, landscape, and other specializations. Design is about how something works, not simply what it looks like, and so the creative problem-solving work of architects and engineers is also called design. If your project is focused on certain rooms (kitchen, bath) or systems (lighting, site grading), then seek out designers in these fields.

General contractors (GCs) are builders who coordinate a team of subcontractors (framers, plumbers, roofers, etc) to carry out the work. Design/build contractors may have in-house design staff, or simply believe that they can help homeowners choose what products to use. Homeowner-GC contracts are either Lump-Sum (a fixed amount) or Cost-Plus (labor, materials, plus markups for coordination). The more information you can give your builder before dust starts flying, the more accurately he/she can estimate project costs and duration. This is why it's essential to have drawings before you start construction – they provide a graphic record of design intent, they're the basis of your contract, and they provide instructions to everyone who works on the job-site.

What will make this a successful project for you? Affordable Cost, a high Quality of Work, and a timely Schedule are surely important, but you can't have it all. Controlling for costs usually means cutting corners on quality, or delaying start-up until the low-ball contractor is available. And how do you rank process-issues like the quality of relationships, or your own participation in decision-making? Giving some thought to these questions will help you align your own values and work-style with those of the people you hire.


DRESS FOR SUCCESS: Open storage with pull-out bins makes it easy for a child to find and reach clothing.

So make a list of the firms and individuals you'd like to consider. Seek referrals from neighbors, home improvement agencies like Home Advisors or Angie's List, and your state's branch of the American Institute of Architects. Check out websites to narrow the list, then reach out through email and phone calls. Narrow your choices to a short list of three names, then set up face-to-face interviews. Ask whatever's on your mind at each stage as you build up your knowledge base – there are no dumb questions! You'll be working closely together for weeks, if not months, so you'll have a happier project if you're generally compatible.

As the homeowner, the more you know your own needs and abilities, the better you can participate in the design process. Like any worthwhile endeavor, remodeling is a journey, and you will face choices along the way. You don't need to have all the answers, only to ask the questions that arise, and surround yourself with people with the techniques and experience to navigate what, for you, will be uncharted waters. With a capable team, the answers will come clear as you go forward. Design is a fluid process, a balancing act between your house's condition, your family's needs, and your project's budget and deadlines. You may not have the space for a kitchen island, or funds for a large addition, but you can surely add some wonderful features that make the whole project worthwhile.

MEASURE TWICE: The reach-range typically varies from 15-in to 54-in above the floor, but each person's comfort range varies, and depends on age, mobility devices and body type.

I always like my clients to be full partners in the decision-making. Whenever we have a stake in the process, we own the outcome. There is a lot that only the homeowner can do during design phase. Plan to spend time shopping, online and in person, to "test-drive" appliances – only you can know if the controls are user-friendly. Measure the use- and reach-ranges for family members. What's a comfortable work surface height? How much space do the knees and feet take up under a table or countertop? How high, or low, or deep, can people reach to retrieve items in storage? Where should light switches, outlets, and thermostats be located for easy use? What's standard practice for builders may not work for you, so to be the best advocate for your family, it's essential to check critical dimensions and make sure that everyone on the job – from designers through construction – understands your requirements, and that the drawings record them accurately.

One of the most frequently-asked questions I hear from homeowners is "what will it cost?" The truth is, you won't know until the job is completed. Surprises occur along the way in nearly every project, and these generate "change orders" – contract amendments that track changes in scope, schedule, and cost. You may find insect damage or fire-damaged framing, or hidden wires and piping, once old walls are opened up. The sink you want may be out of stock and you'll need to decide whether to put that area of the work on hold or find a substitute. Prepare for scope-creep – that urge to expand the work "just because you have the painter/tile-setter/carpenter on the job." Sometimes you really do need to spend money now to save some later, such as when fixing a leak before structural damage sets in. A successful project is not problem-free, but it's one where problems are solved quickly and responsibly. It helps to have some wiggle-room in your expectations, your budget, and your timetable. It's called "planning for contingencies."

There are also many opportunities to save money, if you're willing to spend time treasure-hunting. A used fridge on Craigslist can save significantly over the cost of a new one. Shop for overstock materials like carpet, tile, or flooring. ReStore is a non-profit donation and home improvement center operated by Habitat for Humanity, where you can find gently-used building items like kitchen and medicine cabinets, furniture, and light fixtures. Your town's land-fill may have buckets of barely-used paints for the taking. Ask a lift manufacturer if they would sell refurbished equipment rather than new items. These tasks may seem onerous, but it's important to know that there are ways to keep your project costs to a minimum.

And if you need to cut corners to compensate for change orders once the job has started, you can scale-back some of the details. Eliminate some light fixtures by capping-off the junction boxes – fixtures can be added later. Substitute less-costly plumbing fixtures – again, these can be changed-out later. Simplify carpentry trim, substitute vinyl flooring for tile, or use cellulose instead of foam insulation. Engage your builder and architect in a conversation about where savings might be obtained to offset extra costs. Most projects have a little wiggle-room, even if it's painful for all involved to make these cuts.

The best way to manage expectations in a remodeling project is to have realistic expectations. Inform yourself, communicate with your team, and be prepared to participate in decision-making. You may feel overwhelmed and inconvenienced along the way, but you'll also be rewarded with a home that makes life easier for everyone in the family. And when life is easier, we can worry about each other less and enjoy each other more. Good luck with your project! •

ABOUT THE AUTHOR:

Deborah Pierce is an award-winning architect and one of our nation's foremost experts on universal design. For the past three decades she has focused on creating homes in the Boston area that serve the unique activities of daily living for each family. Deb's book ***The Accessible Home: Designing for All Ages and Abilities***, showcases homes around the country designed for and with people living with disabilities. In the book's foreword, world-renowned architect Michael Graves, FAIA, says, "Deborah Pierce tackles the small problems along with the large in her quest to make wonderful places where people with disabilities can live comfortably and safely."

THE ACCESSIBLE HOME: DESIGNING FOR ALL AGES AND ABILITIES

Copies of the book can be purchased through Amazon, or from publisher Taunton Press:
www.tauntonstore.com/the-accessible-home-deborah-pierce-071400.html

Signed copies can be purchased from the author for $35/copy, including postage. Deb can be reached directly by email:
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LJS Fac/X

WE CAN HANDLE YOUR PROJECT

HOME ELEVATORS • STAIR ELEVATORS • AUTOMATED SYSTEMS

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.

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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.

THE RIGHT MOVE: The vexation for families comes when confronting the critical questions about housing for their disabled loved ones. The ways and means to get appropriate housing are complex, confusing, and sometimes contradictory.

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-bedrooms 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.

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

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 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 housing 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

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

keep momming.

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

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

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

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

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CREATIVE HOUSING OPTIONS FOR INDEPENDENT LIVING

BY LAUREN AGORATUS, M.A.

Families often wonder if and where their children with special needs will live on their own. Often the focus is on universal design to make housing physically accessible. But housing with supports will maximize independence for individuals with all kinds of disabilities.

PHYSICAL ACCESS

Universal design is a concept used to ensure that the home environment is accessible to all. In addition to people with disabilities, it is also helpful to assist individuals to “age in place” and not have to move later. Accessibility features can include walk/roll-in showers, lower countertops and sinks, placement of switches/outlets/doorknobs, etc.

SUPPORTIVE HOUSING

Supportive housing is permanent, affordable, lease-based housing for people of low income with access to flexible supportive services. Supportive housing is designed for people with special needs including those with mental, physical and developmental disabilities as well as people who are homeless. Supportive housing provides a safe, affordable home with access to support services so that individuals can live as independently as possible in communities of their choice.

Supportive housing can be found in a variety of settings, in different constellations, and may include scattered site apartments, individual apartments, shared apartments as well as (more rarely) home ownership. Some supportive housing exists in affordable housing complexes that are often integrated with non-disabled individuals/ families.

Supportive services can vary but often include case management, care coordination, job and education coaching, assistance with daily living skills, transportation assistance, access to public entitlements and crisis intervention. *(Excerpted from Supportive Housing Association: The Journey to Community Housing with Supports)*

OTHER MODELS OF HOUSING WITH SUPPORTS

While group homes are one model of “housing with supports,” more and more people with disabilities and their families are looking to greater inclusion and participation in the community. Some models of supportive housing are integrated, or “reverse integrated” in which a certain portion of units are set aside for people with disabilities. Sometimes people with and without disabilities share a home. Supervised living means that there is help nearby at all times if needed. Assisted living is a similar option. Personal Care Assistance (PCA) services allow many people with special needs to remain in their community. It is essential to get the input from the person with a disability regarding their preferences for living arrangements.

Some individuals with disabilities remain in their family home with supports while others live with a trained “host family.” Newer ideas include “accessory apartments” sometimes known colloquially as “granny pods” built on the lots of family homes as well as the “tiny house” movement. Technology and apps can help people with disabilities control utilities, lights, locks, answering the phone, etc. Personal emergency response systems (PERS) have features such as fall detection, waterproofed to wear while bathing, or if the person doesn’t respond to a call immediately sending emergency responders. It is important to remember that in order for housing to be successful, individuals with disabilities must also have appropriate supports and services.

IDEAS FROM FAMILIES

Families have sometimes pooled funds for a single family home shared by people with disabilities. Others have created communities on farms which also provide vocational experiences. Some families are combining funding to create multiple dwellings.

FUNDING AND SUPPORT

Housing funding is complex and comes from many sources including vouchers and help with phones and utilities (see Resources). Section 8 and HUD are other sources of housing funding based on income. It should be noted that other supports may be needed for people with significant developmental disabilities, medical complexity, or mental illness. Medicaid has Home and Community Based Services (HCBS) and other waivers. Lastly, Centers for Independent Living have institutional diversion initiatives which maximize independence and living in the community. The National Center on Supported Decision Making also has a section on housing.

There are many options for families and self-advocates to decide on regarding housing. By ensuring the appropriate supports and services are in place, individuals with disabilities can maintain their independence and be a part of their community.

ABOUT THE AUTHOR:

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

ON MY OWN : RESOURCES FOR INDEPENDENT LIVING

SHA
Supportive Housing Association of New Jersey

SUPPORTIVE HOUSING ASSOCIATION: THE JOURNEY TO COMMUNITY HOUSING WITH SUPPORTS 2nd ed.

www.autismnj.org/file/Housing_Guide.pdf

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LIFELINE: AFFORDABLE PHONE AND INTERNET ACCESS

www.lifelinesupport.org/ls

U.S. DEPARTMENT OF HOUSING AND URBAN DEVELOPMENT

(also Section 8 vouchers)

https://portal.hud.gov/hudportal/HUD

https://portal.hud.gov/hudportal/HUD?src=/topics/housing_choice_voucher_program_section_8

NCIL
National Council on Independent Living

CENTERS FOR INDEPENDENT LIVING

www.ilru.org/projects/cil-net/cil-center-and-association-directory

OFFICE OF COMMUNITY SERVICES
An Office of the Administration for Children & Families

LIHEAP: LOW INCOME HOME ENERGY ASSISTANCE PROGRAM

www.acf.hhs.gov/ocs/programs/liheap

National Resource Center for Supported Decision-Making
EVERYONE has the Right To Make Choices

HOUSING: NATIONAL RESOURCE CENTER ON SUPPORTED DECISION-MAKING

www.supporteddecisionmaking.org/tags/housing

SEX CHROMOSOME VARIATIONS

BY VIRGINIA
ISAACS COVER,
MSW, MBA

Mark had always had challenges. As a toddler, he had speech and physical therapy through Early Intervention to address delays in meeting milestones. Although he managed to earn B's and C's in elementary school with the assistance of 504 accommodations, by Fifth grade he was falling behind, academically and socially. A developmental pediatrician diagnosed ADHD.

EXTRAORDINARY: In contrast to most human trisomies, such as Down syndrome (Trisomy 21) or Edwards syndrome (Trisomy 18), that cause significant intellectual disability and medical complications, X and Y variations cause milder developmental delays.

Six months later, the school psychologist suggested an evaluation for autism spectrum disorder. Testing found Mark to score high on a number of domains, just barely missing the autism range. By Eighth grade, he admitted to feeling depressed and "different." At a pediatrician visit, the doctor asked his mother to leave the room, and began examining Mark. Mark opened up to the doctor about his fears that his body wasn't changing. The doctor noticed that his testicles were abnormally small and firm, and that Mark had not developed increased body hair distribution consistent with progress through puberty. He called Mark's mother into the room and suggested that a specialized genetic test might explain Mark's difficulties. Three weeks later, the pediatrician called Mark and his parents to tell them that the testing revealed that he had Klinefelter syndrome, or an extra X chromosome in a male.

In her first pregnancy, Jeanne was offered "non-invasive prenatal testing," also called "cell free DNA testing". This testing can determine the probability that a human fetus has additional chromosomes beyond the expected 46. Although Jeanne thought that her baby-to-be was being tested for Down syndrome or other significant disabilities, her obstetrician phoned her to let her know that the fetus had a high probability of having Trisomy X, or an extra X chromosome in a female.

Klinefelter Syndrome and Trisomy X are known as sex chromosome aneuploidy, or variations in the typical number of chromosomes. Instead of having two sex chromosomes, an X and Y in a male, or two X's in a female, Jeanne's baby-to-be and Mark had three, known as a "trisomy". Klinefelter syndrome is also known by the genetic signature of 47,XXY. Trisomy X is written as 47,XXX.

X and Y variations are surprisingly common. One male in 600 is born with Klinefelter syndrome. One female in each 1000 live births has Trisomy X. A male can also have an extra Y chromosome, known as XYY syndrome. Less common variations involve two or more extra sex chromosomes, including 48, XXYY. X and Y chromosome variations occur more often than Down syndrome.

In contrast to most human trisomies, such as Down syndrome (Trisomy 21) or Edwards syndrome (Trisomy 18), that cause significant intellectual disability and medical complications, X and Y variations cause milder developmental delays. There is little dysmorphia, unusual facial and physical features that mark the conditions. Even when the child displays a whole constellation of speech, learning and other developmental delays, such as autism spectrum disorder, pediatricians do not often think of genetic disorder and test for an extra chromosome.

X and Y variations remain relatively unknown, both to the general public as well as within the health professions. Individuals with X and Y variations display a wide range of functioning, from having no symptoms at all to those who are severely impacted and require life-long support services. Less than one-third are ever properly diagnosed in their lifetimes.

Mark and his parents learned that Klinefelter syndrome (47,XXY) is the most common of the sex chromosome aneuploidy conditions. Although some boys with XXY experience few challenges, at least two thirds will have early speech delay, fine and gross motor skill deficits, learning disabilities, ADHD, and some degree of social skill impairment. Mood disorders, such as depression, are more common in X and Y variations. XXY boys tend to be taller than normal, and to have long limbs, although this is not always the case. Approximately 20 percent will meet the criteria for autism spectrum disorder, although it will be mild. Many have expressive language skill impairment, and subtle difficulty with reading social cues. This may be why teachers will often describe these boys as immature. It also appears that men with XXY take longer to achieve independence in adulthood, to complete their educations, and to become established in careers.

Although many boys will start puberty normally, the extra X chromosome interferes with the body's ability to produce testosterone. Puberty may stall, and need to be helped along with supplemental testosterone. Although boys with XXY will usually produce some sperm in their teen years, this falls off dramatically by early adulthood. Men with Klinefelter syndrome are almost all infertile. Within the last decade, however, assisted reproduction techniques have allowed a number of XXY men to become biological parents. XXY teens are also being offered the option of providing sperm samples that can remain frozen until needed to produce a pregnancy.

Mark was referred to a pediatric endocrinologist. He and his parents, along with his doctor, decided that treatment with testosterone was appropriate. He started with testosterone injections every 10 days. Disliking shots, however, Mark soon began using testosterone gel daily. He began developing a beard and a deeper voice even as he entered a growth spurt and grew to be 6' 4" tall.

Jeanne and her husband were referred to a genetic counselor who explained that the prenatal blood test results only predicted with a fair amount of certainty that their daughter would have Trisomy X. If they wanted to know definitively before birth, Jeanne would have to undergo amniocentesis, an invasive test using a needle through the uterine wall to draw out a sample of amniotic fluid. The fetal cells are then tested to determine if they contain an extra X chromosome. The genetic counselor explained that girls with Trisomy X often have speech delays in early childhood, may be slower to walk and develop motor skills, and frequently have learning disabilities. Approximately two-thirds of girls will need special education services. While their fertility may be reduced somewhat, and they may experience premature ovarian failure, women with Trisomy X have few health care complications. Most women with 47,XXX, live fairly normal lives, although the risk of mood disorder is somewhat higher.

LEARNING CURVE: The challenge for parents is that few health care providers or educators are familiar with the diagnoses.

The genetic counselor also mentioned to Jeanne that termination of the pregnancy was an option. The couple did not think that the relatively mild disabilities the counselor was discussing with them would merit a second trimester abortion. They also decided to wait until their baby was born to confirm the diagnosis with a simple blood test.

The challenge for parents of children with one of these common genetic disorders is that few health care providers or educators are familiar with the diagnoses. Parents often have to describe the condition as ”like Asperger syndrome” or ”ADHD, learning disabilities, low muscle tone and poor coordination, all wrapped up together.”

X AND Y VARIATION RESOURCES

Please visit AXYS, the national organization for X and Y Variation advocacy and education at **www.genetic.org** The website includes information on genetic conditions involving extra X and Y chromosomes, support groups, the AXYS Clinic Consortium, and current research. There is a toll free Help Line, 888-999-9428.

As more children are diagnosed prenatally, due to the ease of newly available non-invasive testing, it is expected that schools and pediatricians will understand the disorders and the symptoms associated with them.

Mark's mother discovered AXYS, the national organization for advocacy and education for those with X and Y variations. She obtained educational materials from the AXYS website, www.genetic.org. She and Mark traveled to an AXYS Family Conference, where they met others with similar concerns. The conference featured national experts in X and Y variations, in disciplines like endocrinology, psychiatry and special education. They learned that AXYS was in the process of developing a Clinic and Research Consortium comprised of eight academic medical centers offering multidisciplinary evaluation and treatment recommendations.

Mark and his parents visited Denver for an evaluation at the EXtraordinarY Kids Clinic at Colorado Children's Hospital, one of the member clinics. With the written report provided after several days of exams and neuropsychological testing at the clinic, Mark was able to obtain an IEP (Individualized Education Plan) that addressed his need for additional special education services in high school. Mark graduated on schedule and is progressing through community college part-time. His college provides special accommodations for his learning disabilities that include a note-taker, additional time for tests and regular tutoring. He is also an accomplished golfer, playing on the community college team. Mark credits the pediatrician who suspected and tested him for Klinefelter syndrome with turning his life around so that he could obtain the medical treatment and specialized learning services that he required.

After Jeanne's baby, Arianna, was born, a blood test confirmed the diagnosis of Trisomy X. Arianna's development was normal until she reached 18 months, when the pediatrician recommended an early intervention evaluation for speech and motor delays. Arianna made substantial progress with speech and physical therapy, making up for most of her delay. She then entered kindergarten in a mainstream class, with speech and occupational therapy services. She is very shy and attends a social skills group to help her develop conversational abilities and friendships. Her mother has her followed every six months at one of the multi-specialty X and Y variation clinics. She is a quiet but happy little girl, and her parents are very glad that they had an awareness of the extra chromosome so that they could access special services immediately— rather than waiting for additional delay to develop. •

(Editor's note: Mark's and Arianna's names have been changed to protect their privacy.)

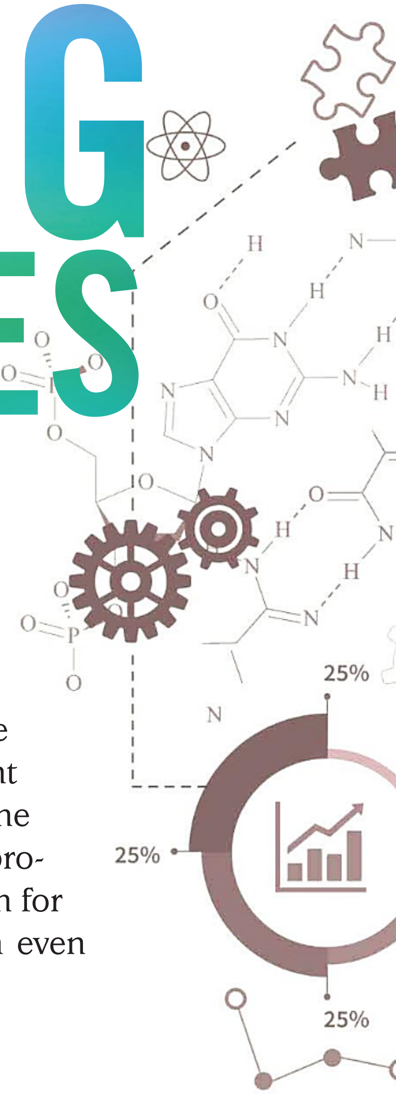
ABOUT THE AUTHOR:

Virginia Isaacs Cover, MSW, MBA, has worked with children and adults with developmental disabilities and chronic medical conditions throughout her career in healthcare agencies and universities. Now retired, Ms. Cover maintains a private practice assisting young adults and their families in developing and managing self-determination supports to permit them to live and work in the community rather than in segregated settings. She is the parent of a young adult who has Klinefelter syndrome. She serves as a Board Member for AXYS as well as a member of the AXYS Professional Advisory Board. She is the author of the book, "Living with Klinefelter Syndrome, Trisomy X and 47, XYY: **www.genetic.org/wp-content/uploads/2016/08/LivingWithKlinefelter SyndromeTrisomyX47XYY.pdf**

Parents who feel their child may struggle socially, learn differently or have a specific learning disorder, should consider schools that offer a variety of enrichment programs.

THE IMPORTANCE OF ENRICHMENT PROGRAMS FOR STUDENTS WITH LEARNING DIFFERENCES

BY EMILY MARTON, B.S.



State funding of school districts has continued to weaken nationwide since 2008. In fact, at least 31 states provided less state funding per student in the 2014 school year (end) than in the 2008 school year before the recession took hold (CBPP, 2016). These budget cuts cripple the ability for schools to maximize student learning potential and creative development, usually beginning with the elimination of arts and enrichment programs. Ironically, these are the programs that have proven to stimulate the greatest brain activity and function for children. For students with learning differences, these programs play an even more critical role in academic development and success.

For years now, research has shown that music improves brain development and even enhances skills in core academic areas such as reading and math. Music and other enrichment classes such as art, physical education, computers, crafts, home economics and science labs, engage different parts of the brain. Exposure to the arts and enrichment classes with an emphasis on a hands-on approach emphasize more critical thinking and creativity.

A multi-sensory approach to learning is essential to children with specific learning disabilities and deficits. Whereas standard teaching methods involve a more text-heavy approach, multi-sensory teaching caters to many senses. Rather than just reading and taking notes, students engage in making physical diagrams, building projects, manipulating objects and other hands-on learning methods, which engage the whole brain and allow for kinesthetic and experiential learning.

Students with learning differences need multi-sensory learning in order to be successful in school. The benefits of this type of learning are immense and can even eventually help them become familiar with how they learn best. Enrichment courses provide multi-sensory learning, allowing students to experience the following:

- *The ability to exercise creativity, which many students with learning differences have as a strength*
- *Greater sense of self confidence, further improved by guaranteed successful experiences in the classroom*
- *Improvement of gross and fine motor skills and increased spatial awareness*
- *Mental breaks*
- *The ability to exercise new ways of critical thinking and the encouragement to think outside the box*
- *Different environments to collaborate with peers – students learn how to collaborate and express ideas in more social group settings with freedom for expression and creativity.*

Social-skills learning is one of the most vital areas of development that all children could benefit from. In a public school setting, students would have to enroll, usually through a speech clinic, in private sessions called “social-skills groups”. Teaching empathy, kindness and emotional management is essential to the growth and social development of all children, but for those with learning differences and processing deficits in particular, it can be an especially challenging aspect of social development. Parents who feel their child may struggle socially, learn differently or have a specific learning disorder, should consider schools that offer a variety of enrichment programs.

While some students may have great social struggles and find life-changing strategies through social skills classes, another student may have a hard time communicating verbally, writing, or reading, and may thrive in an art class, which provides a creative outlet to help them express emotions or thoughts.

Providing multiple ways for students with learning differences to experience success—while discovering and utilizing their talents and passions— will result in higher interest, excitement and confidence throughout their learning experience. That, in turn, will yield a more successful future. The overall benefit is in creating a holistic sense of confidence and accomplishment.•

PHOTO PROVIDED BY DAWN LURIANO

ABOUT THE AUTHOR:

Emily Marton received her Bachelors Degree in Art Education from Temple University in Philadelphia and has experience in private and public art classrooms of all grades. Since February 2015, she has served as Enrichment Department Chair at The Prentice School, located in N.Tustin, California. Celebrating its 30-year Anniversary, The Prentice School is a private, nonprofit academic, Certified Nonpublic School through the California Department of Education, and is fully accredited by the Western Association of Schools and Colleges. The Prentice Approach is designed to engage students on three learning pathways, including auditory, visual, and kinesthetic. Using evidence-based curriculum and instructional methodologies, a structured literacy approach, multi-sensory instructional strategies, and ongoing progress monitoring.

SINCE 2007, SPECIAL OLYMPICS HEALTHY HEARING HAS PERFORMED CLOSE TO 85,000 HEARING SCREENINGS IN 65 COUNTRIES AROUND THE WORLD.

CAN YOU HEAR ME NOW?

BY JAMIE VALIS, PHD

A coach stands on the side-lines, providing messages of strategy and tactics to an athlete. A referee blows the whistle to signal the stoppage of play. A teammate yells encouraging words on the field. The fans roar with applause after an athlete scores a goal.

Athletes rely on hearing for direction, encouragement, teamwork, and safety. "The prevalence of hearing loss for adults with intellectual disabilities is higher than for persons in the general population," said Dr. Beth Lannon, Special Olympics Global Clinical Advisor for Healthy Hearing. Any type of hearing problem can negatively impact communication ability, quality of life, social interactions, and health. "Off the field, hearing loss can interfere with cognitive development, limit social interactions, and limit vocational opportunities" explains Dr. Lannon.

Special Olympics Healthy Hearing changes lives around the world by providing free hearing examinations, ear wax removal, swim molds, minor hearing aid repair, and other services for people with intellectual disabilities (ID).

Since 2007, Special Olympics Healthy Hearing has performed close to 85,000 hearing screenings in 65 countries around the world. The results of these screenings showed 40% of Special Olympics athletes have blocked or partially blocked ear canals with ear wax and over 25% failed hearing examinations. In addition to screenings, Healthy Hearing trains audiology professionals and students to be able to identify the specific needs of individuals with intellectual disabilities, provide screening services in a non-threatening environment, and provide follow up recommendations for each individual. Healthy Hearing is one of eight Special Olympics Health disciplines that provides screenings, trains professionals, and creates links to follow-up care providers so people with ID can get such care in their own communities.

"Volunteerism is a precious gift to the person who is volunteering, and each of those individuals who volunteers to help with the Special Olympics Healthy Athletes program is rewarded a thousand fold by the positive outcomes in better health for athletes identified with health problems," explains Dr. Gil Herer, founder of Special Olympics Healthy Hearing.

Healthy Hearing screenings have a strict protocol that is used worldwide. Upon entering a Healthy Hearing event, all athletes go through registration where they provide basic information and answer questions related to how they perceive their current hearing status. At the first station, the volunteers complete an external ear canal inspection and then the athletes proceed to the second station to have their inner ear tested. Depending on the results of the first two stations, the athlete may need to move onto the third, fourth, and fifth stations to investigate potential middle ear problems, which can include middle ear infection, confirm hearing loss, as well as determine the degree of hearing loss. At certain events, hearing aids, swim ear plugs, noise protection, hearing aid maintenance and repair, or other services may be available for athletes demonstrating need. Prior to leaving the Healthy Hearing screening, athletes will stop at the check-out station to review their results, receive education on hearing loss prevention, and receive any referral information, if necessary. Each athlete spends about

PHOTOS PROVIDED BY SPECIAL OLYMPICS

10 to 30 minutes at the Healthy Hearing screening and is encouraged to return annually.

Ricki is a Special Olympics Southern California athlete. His mother, Eva, recognizes the tremendous gift that volunteers provide to these athletes. “We are just so grateful for the people who donate their time to provide these free screenings,” she proclaims. Her son, Ricki, agrees. “They don’t even get paid. They are doing this out of their own kindness.”

Ricki attended a Healthy Hearing event in 2013, at the age of 36. For over 30 years, Ricki suffered from hearing loss in one ear which impacted him on the tennis and bocce courts and in his is job as a D.J. His mother, Eva, reported that “Ricki tended to speak much louder and people would get annoyed. Constantly, he would need to ask people to repeat themselves.” Eva was told by doctors that Ricki had a hearing problem, but his condition could not be treated. This changed when Ricki attended a Healthy Hearing event. The volunteers at the event recommended Ricki see a local audiologist who referred him to a specialist for surgery. The surgery involved the removal of a benign tumor, inserting a prosthetic device, and reconstructing the middle ear.

Ricki describes the results of his surgery as a tremendous success: “I can hear much louder and hear more things now. I can understand people better now.” Ricki loves country music and enjoys listening to *Friends in Low Places* by Garth Brooks with his improved hearing. His love of music translates to his job as a D.J. at weddings, birthday parties, outdoor events, and other private or public events, which he’s been doing since the age of 12. “As a D.J., I can understand the customers coming up to me to request things and I can make sure the speakers are set up right. I can also check the volume and balance levels.” Ricki has also seen a positive effect on his sports performance on the tennis and bocce courts, now more able to more clearly hear his coaches, teammates and, most important, the fans.

GOLD STANDARD: Since his surgery, Ricki has seen a positive effect on his sports performance on the tennis and bocce courts, and is now more able to more clearly hear his coaches, teammates and, most important, the fans.

EP MAGAZINE EDITORS’ NOTE:

Fans, athletes, coaches, families and supporters of Special Olympics can qualify for a free yearly digital subscription to *EP Magazine* by contacting us.

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Individuals with intellectual disabilities and their families should be aware of the signs of hearing loss, including: difficulty following conversation, especially in noisy environments, asking people to repeat themselves, not responding to noise at a young age, and pain or ringing in the ears. It is critical to protect your hearing to prevent hearing loss by wearing ear protection around loud noises, turn down the volume on personal listening devices, and walk away from noise when possible. The Global Clinical Advisors for Special Olympics Healthy Hearing encourage individuals with intellectual disabilities to have their ears checked by a medical doctor for ear wax, once or twice a year and have a hearing evaluation by an audiologist/ENT specialist every one to five years. Additionally, all individuals with intellectual disabilities are welcome to attend a screening at a local Special Olympics event.

Ricki encourages all Special Olympics athletes to go to a healthy hearing event and get a referral if needed. Ricki’s mom, Eva, also advises “if doctors in the past have expressed concern with your child’s ears when they were younger, it’s always good to get a regular screenings as things can change over time.” •

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

ABOUT THE AUTHOR:

Jamie Valis, PhD, is Manager of Healthy Hearing, Fit Feet, and Strong Minds, Special Olympics International.

Is it not logical and linguistically savvy to play to the child's strength and not his/her weakness?

A PROFOUND ENIGMA

Teaching Sign Language to Hearing Children and Speech to Deaf Children

BY J. FREEMAN KING, ED.D.

EARLY LEARNERS: Research has shown that sign language provides the earliest possible mode through which children can learn expressive language skills and open the door to shared meanings.

Throughout the years, many different language learning theories have emerged. The latest phenomena in the United States is the teaching of sign language to hearing toddlers and preschoolers. Conversely, there is a push to to teach speech to infants, toddlers, and preschoolers who are deaf. Herein lies the enigma: eliciting the use of vision and sign language to promote language development in the hearing child, yet prohibiting the deaf child from using a visual language. In essence, the deaf child is being penalized for their weakness (hearing), instead of promoting their strength (vision).

Linguistic competency is necessary for human interactions. Language is necessary for the flow of information between children; between children and their parents; and between children and their teachers. Language is used to develop and enhance cognitive skills, to develop literacy, and to develop social and emotional skills. It is the pathway to intellectual growth, and essential for involvement in the entirety of the educational experience. Hence, the idea that sign language can be another avenue to assist the hearing child in learning and utilizing language.

Sign language is a tool that can be used to promote speech and English language competency in hearing children, even though speech is the primary method through which the English language is produced. Is it not putting the cart before the horse when speech, which cannot be heard or impartially heard, also becomes the primary tool for the deaf child through which language is accessed and produced?

If, in fact, as research has demonstrated, the use of sign language does promote speech development and provides a bridge to English language development in children who can hear, would it not be logical to assume that the use of sign language in deaf children would also be a viable bridge to the English language in children who are deaf? Even though American education champions bilingualism in hearing children why, in the same breath, does it deny such a possibility to deaf children? Is it not logical and linguistically savvy to play to the child's strength and not his/her weakness?

Research has shown that sign language (for both hearing and deaf infants, toddlers, and preschoolers) provides the earliest possible mode through which children can learn expressive language skills and open the door to shared meanings. The reason for this is that children begin to learn language long before they are physically capable of producing speech. While speech capabilities are still maturing, children struggle to find ways of expressing

MULTILINGUAL: Research shows that children with strong language skills, regardless of the language, consistently outperform their peers on tests of intelligence and other measures of success. The language might be English or French – or it can be sign language.

wants, desires, and intentions. Given exposure to a visual language of signs, children are able to master language at an earlier stage. Signing children can communicate, while their peers are frustrated when others cannot comprehend their communication attempts.

Common sense, as well as research, has illuminated much related to language acquisition and language learning:

Early language learning experiences affect other areas of development that are critical to children's future success. Lack of language access can negatively impact cognitive, psychological, and social development. Poor language skills are often linked to behavioral problems, academic difficulties, lowered self-esteem, and social immaturity. Behavioral problems are often the end result of children's frustration at not being able to communicate with their parents or significant others. Yet, research shows that children with strong language skills, regardless of the language, consistently outperform their peers on tests of intelligence and other measures of success. The language might be English or French or another spoken language, or it can be sign language; the key is language accessibility of a deep and meaningful nature. The earlier a child acquires his/her first language, the greater the success will be in acquiring subsequent language skills and meeting other important developmental milestones.

All children (hearing and deaf) can benefit from the use of sign language, with no risk to academic, social, or emotional development, or spoken language skills. For both hearing and deaf children, sign language gives a head start in language learning, and can lead to higher achievement in measures of intelligence, academic and social development. Used in classrooms with hearing children, sign language has been shown to assist in reducing the achievement gap between underprivileged children and their peers. It is also important to note that there is no substantial body of research that indicates learning and using sign language will hinder the development of speech skills in either deaf or hearing children.

For deaf infants, toddlers, and preschoolers, sign language is a critical first step to communication. It is the key to eventual development of literacy in English and, possibly, spoken language skills. It provides the only accessible venue for natural and complete language acquisition in the early years, and serves to prevent deaf children from becoming victims of the staggering language delays often associated with deafness. Deaf children who learn sign early as their first language generally learn to read and to write English better than those who are exposed only to spoken language. It is also an established fact that expressive language ability, in any mode, is often one predictor of the development of speech. Beyond the enormous advantages to deaf children's language, social and cognitive development, children's knowledge of sign language opens the door for involvement with a strong and supportive community of other deaf individuals.

Hard of hearing infants, toddlers, and preschoolers often fall through the cracks of the educational system. This is a result of the erroneous assumption that they are primarily auditory learners. Even hearing losses so minimal that are diagnosed as being within normal limits have been shown to have significant negative impacts on children. The less significant the hearing loss, the smaller the chances of having the loss identified early. After the hearing loss is identified, technological assistance and/or added speech training are hard pressed to compensate for a profound inability to fully access spoken language. For these children, sign language provides the only bridge to fully accessing language. It also serves to provide access to the critical element of incidental learning.

Technology, even though it can be a useful tool for promoting speech, does not necessarily assure the expectations espoused. A child with a cochlear implant, or one who uses hearing aids, at best, is hard of hearing. Maintenance issues, programming/adjustment issues, and restrictions as to when and where technological devices can be conveniently and safely used can create problems. The use of sign language is a viable solution to these problems. Sign language can be utilized before audiological supports can be properly fitted and/or programmed for children. If children are able to develop spoken language skills, the use of signs should be continued to complement spoken language, especially when the need for communication is immediate, and spoken language becomes inadequate due to difficulties with the technology, poor acoustics in the environment, or other extenuating factors.

The question naturally will be raised, "Is sign language the right choice for every child? Certainly, only the child's family can make this decision; however, closely observing and letting the child take the lead regarding communication and language is an important element that should be considered. However, keeping in mind that the deaf child (with or without a hearing aid or a cochlear implant) is primarily a visual learner, it seems only logical to play to the child's strength, vision, and not his/her weakness, hearing.

Historically, many deaf children have been placed in oral-aural only programs, then transferred to signing programs when it was discovered that they were not oral-aural candidates, and were not able to access language. Perhaps, all deaf children should be initially placed in signing programs, then switched to oral-aural programs if they are failing. It is safe to say that very few would be switched to oral-aural programs due to failure to access language. Why can the child not be given the best of both worlds? That is, the opportunity and the ability to use sign language, when appropriate, and the opportunity and the ability to use speech, when appropriate.•

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BY DIANE WISCARSON, ATTORNEY AT LAW

Service animals, usually dogs, can provide excellent support for people with disabilities. Service animals are individually and specifically trained to perform tasks that help a person manage and navigate their environments. These tasks can include anticipating seizures, signaling self-stimulation behaviors, alerting to important/alarming sounds, providing deep pressure sensory input, interrupting self-harm behaviors, and preventing elopement, among others.

DIVIDE AMONG SCHOOL DISTRICTS: In recent years, there has been disagreement among school districts regarding service animals accompanying students to school. While some districts have welcomed service animals at school with open arms, reasonableness and training, others have simply refused to follow the law and allow service animals to attend school with their persons.

What is the difference between the schools that allow service animals and those that do not? The surprising answer seems to be which law is applied by the school district – the Americans with Disabilities Act (ADA) or the Individuals with Disabilities Education Act (IDEA).

SOLUTION? A recent United States Supreme Court case cleared up the confusion between the two laws and, in the case of service animals, which law applies. In *Fry v. Napoleon Community School District,* issued in February 2017, the United States Supreme Court agreed that service animals are an ADA issue, rather than an IDEA/special education issue. You can read the entire case and the United States Supreme Court's opinion and look at other documents that were part of the case at **www.scotusblog.com/case-files/cases/fry-v-napoleon-community-schools/**

AMERICANS WITH DISABILITIES ACT: The ADA protects those with a disability from being discriminated against on the basis of that disability. Known as an "access" law, the ADA guarantees, among other things, access to education for students with disabilities. This generally means that accommodations are provided to a student, which allows access to education. A simple example is a wheelchair ramp for a wheelchair user. A reasonable accommodation might also be a nut-free lunch table for a student with tree-nut allergies.

School districts that have applied the ADA to service animal requests have allowed service animals, almost without exception. There may have to be discussion regarding who provides the “handler” for the service animal, but that is a separate issue.

INDIVIDUALS WITH DISABILITIES EDUCATION ACT: The IDEA requires school districts to write an Individualized Education Program (IEP) for every student identified with a disability, when that disability impacts the student's education, and the student is in need of specially designed instruction. The IEP must be *individually* written to address that particular child's educational needs, and must be reasonably calculated to enable a child to make progress appropriate in light of the student's particular circumstances.

CLASS ACTION: Despite confusion as to which law applies to disputes about service animals at schools – the ADA or the IDEA – parents must pick one or the other in order to file a complaint in the right forum.

The most prevalent argument for keeping service animals out of school is that “It is not on a student's Individualized Education Program” (IEP) and therefore not required for a student to receive a “free appropriate public education” (FAPE). The individually written IEP must contain all of the services and supports a student requires to receive a FAPE. The school district logic is, if the student does not need a service animal to receive a FAPE, then the school does not have to let the service animal through its doors.

There are *many* documented instances when a parent has advocated for a student to have a service dog at school, only to be informed by the rest of the IEP team that the service animal is not necessary at school. Therefore, since the service animal is not “necessary,” the service animal is banned from the school.

WHO GETS IT RIGHT? As the United States Supreme Court ruled, Districts following the ADA are complying with the law. Under the ADA, school districts that allow service animals to attend school with their student correctly understand that IEPs, FAPEs, and other special education considerations miss the mark when talking about service animals. Service animals are allowed to attend school with their person without regard to any special education laws, via the ADA. The ADA *requires* schools to allow children's service animals to accompany them to school, and the IDEA is not discussed in this context.

WHERE ARE COMPLAINTS FILED? Despite confusion as to which law applies to disputes about service animals at schools – the ADA or the IDEA – parents must pick one or the other in order to file a complaint in the right forum.

ADA cases are filed in the United Stated District Court (a federal court), in the region where the family lives. Complaints about IDEA violations are filed with the State's education agency, and result in an administrative hearing. In Oregon, complaints are filed with the Department of Education, and in Washington, the Office of Superintendent of Public Instruction.

EVEN COURTS WERE CONFUSED: In several instances, children who were not allowed to bring a service animal to school filed lawsuits in federal court claiming a violation of ADA. In other cases, courts have found that service animal issues should be analyzed under the IDEA rather than the ADA, and then dismissed the case from federal court.

Other parents have tried to have the service animal put on a student's IEP as an accommodation. Some school districts have told parents that since the service animal is not “necessary for the student's education” there is no reason to discuss whether the service dog can attend school with its student. These districts simply refuse to allow the service animal, often without any discussion.

Trying to figure out which law applies to service animals, and how to educate school districts so that students can have their service animals at school, has been very frustrating for families. Where service animals have been excluded from school, some animals have unfortunately lost the bond with their student when the student was forced to attend school without them. Other service dogs sit at home, waiting for their student to return from school, unable to provide services to their person during the school day.

HOW DOES THIS HELP FAMILIES? Before the *Fry* case, most parents and education attorneys were hesitant to file cases related to service animals, because they can be lengthy, expensive, and complex. And, judges were seemingly uncertain as to which law to apply, and whether the complaint should be resolved in a judicial or administrative proceeding.

The law is much clearer, thanks to the *Fry* family. Service animals accompanying children to school fall under the ADA. There is no need to claim that the student “needs” a service animal, as is required for other accommodations put into place on an IEP for a student. Under the ADA, service animals can attend school with a student as a reasonable accommodation, and no permission or discussion of “need” should be required.

If a school district refuses to allow a service animal at school with its student, pursuing a legal remedy will still likely be lengthy and frustrating, but at least the law is now clear about where families need to go to obtain help from the legal system, and that the ADA is the correct law to be applied.

ABOUT THE AUTHOR:

Diane Wiscarson worked her way through the special education system on behalf of her son, and in so doing, found her passion for helping other families navigate special education and the law. Since graduating from law school in 1996, and founding Wiscarson Law, she has helped thousands of Oregon and Washington families obtain appropriate services and placements for their special needs children in public schools and education service districts in both states. For more information call (503) 727-0202, or go to www.wiscarsonlaw.com

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UNDERSTANDING ACCESSIBLE HOUSING: THE FAIR HOUSING ACT

You know how difficult it can be to get around on crutches or in a wheelchair. You may need a wheelchair ramp or wider doorways in order to enter a building or even your own home. An accessible home is one that allows its occupant to do what he or she wants and needs to do, as independently as possible.

The good news is, if you or your family member has a disability that requires special housing accommodations, you're protected under the Fair Housing Act. This includes military installation housing.

If you or someone in your family is disabled, your home may need specific modifications to make it accessible for daily living. Fortunately, through the Fair Housing Act, there are laws that require property owners to make, or allow residents to make, a home accessible for those with specific or special needs.

THE FAIR HOUSING ACT

The Fair Housing Act requires housing providers to:

- *Make reasonable accommodations for people with disabilities. A property owner, however, is not required to make changes that would create an undue financial or administrative burden.*
- *Allow people with disabilities to make reasonable modifications. Property owners must allow residents to make changes to their units if those changes are necessary for the tenant to use the unit fully.*

The Fair Housing Act also makes it illegal — based on your or your family member's disability — to:

- *Refuse to rent a dwelling or to accept a legitimate offer*
- *Evict someone*
- *Use different applications or criteria*
- *Segregate people to specific units or areas*
- *Ask if anyone has a disability*
- *Refuse to make or allow reasonable modifications or accommodations*

The Fair Housing Act applies to most housing options. In fact, many states have fair housing laws that provide even greater protections. For your specific state law, contact your public housing agency.

DID YOU KNOW?

Did you know that the Architectural Barriers Act requires access to all buildings designed, built, altered or leased with federal funds? According to the United States Access Board, at least 5 percent of each military installation's housing is required to be either accessible or readily and easily modifiable for accessibility.

In privatized housing on military installations, property managers are required to make reasonable alterations and accommodations that abide by the Americans with Disabilities Act at no cost to the tenant.

WHAT FAMILIES WITH SPECIAL NEEDS SHOULD DO PRIOR TO RELOCATION

The availability of affordable on- and off-installation housing varies from one location to another. Military families withspecial housing requirements should contact the housing office or the Exceptional Family Member Program coordinator at their new duty location as early as possible. You can find contact information for both of these resources through www.militaryinstallations.dod.mil/

– Military One Source

KNOW YOUR RIGHTS FURTHER RESOURCES

- Learn more about how the **Exceptional Family Member Program** and how it can help you and your family.
- Read the Fair Housing Act article, **Fair Housing - It's Your Right**
- Check out the **Equal Opportunity for Individuals With Disabilities** fact sheet to learn about legal protections for individuals with special needs

HOW TO HANDLE ACCESSIBLE HOUSING DENIALS:

- If you've been wrongfully denied accessible housing, you should:
- **File an administrative complaint.** You can file a complaint with the Department of Housing and Urban Development within one year. To bring action under state law, contact the responsible state agency.
- **File a private lawsuit.** You can file a suit in federal court within two years. However, deadlines for state court actions vary.

Moving is stressful, but for military families with special needs it can be even harder. If you or your family member has specific accessibility needs, reach out to your new installation's housing office for help in finding a home that has everything you need to make your life as easy and comfortable as possible.

ONE THING I'D LIKE TO SAY TO ALL OF YOU IS YOU'RE NOT CRAZY.

I had a complete meltdown with PTSD (posttraumatic stress disorder). I thought I was losing my mind. I'd never been out of control before, and it was hard to admit I needed help, but I wanted my old self back. I've gotten that and more. I'm strong. I'm healthy. I have tools, I have knowledge, and I have strength and courage to deal with it. I'm doing just fine.

RON WHITCOMB SGT US ARMY 1968 - 1969 SQUAD LEADER, VIETNAM

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PERSON-CENTERED PLANNING

People with disabilities no longer have to rely on assistance from total strangers. Person-center planning helps individuals with disabilities direct their own lives. Individuals with disabilities and their families now have more options to plan housing, work, finances and more. The military supports these efforts. Here are some questions and answers that can help you better understand person-centered planning, how it can help and how you might fit into the process.

WHAT IS PERSON-CENTERED PLANNING?

Person-centered planning:

- *Brings the individual together with a team of family, friends, neighbors, employers, community members and healthcare professionals to find out what is important to the person with the disability, now and in the future*
- *Matches the wants and needs of a person with a disability to existing services, adapts existing services to better suit the person or creates new services if required*
- *Gives people with disabilities and their families more control over services and the direction of their lives*
- *Helps people with disabilities accomplish their goals and fit in and contribute to society in a personalized way, rather than passively accepting services based solely on their diagnosis and condition*
- *Finds ways for the person with the disability to develop the skills and abilities needed to work toward achieving his or her goals and having more control in his or her life*

Visit **your installation's** EFMP family support office.

Get organized with the Special Care Organizational Record for an **adult family member** with special health care needs.

WHAT ARE THE BENEFITS OF PERSON-CENTERED PLANNING?

The benefits of person-centered planning:

- *Focuses on the person with the disabilities, not the planner*
- *Focuses on the person's strengths, not deficits*
- *Helps alleviate isolation, stigmatizing labels, loss of opportunity and loss of hope*

WHAT ARE SOME BASIC PLANNING OBJECTIVES?

Person-centered planning aims to help the person with disabilities do the following:

- *Live in the community*
- *Choose his or her own services and housing*
- *Develop his or her own skills and interests*
- *Be treated with respect*
- *Find a valued social role*
- *Find meaningful independent relationships*

WHO MAKES UP THE PLANNING TEAM?

- *An unbiased facilitator: Facilitators encourage brainstorming during the meeting and help identify friends, family or professionals that can help keep the plan on track.*
- *Advocates: Disability service advocates can help get resources, talk about options, help with evaluating plans and services, and help the person with the disability become a self-advocate.*
- *Family members and friends: Immediate and extended family members and close friends can weigh options and help with informed decision making.*

HOW DO YOU BUILD A TEAM OF ADVOCATES?

- *Exceptional Family Member Program: Your installation Exceptional Family Member Program family support office and Military OneSource can assist with finding person-centered planning facilitators and resources. Although facilitators and related resources will most likely come with a fee, a consultation with your installation Exceptional Family Member Program or Military OneSource is free. Call 800-342-9647 to speak with a consultant.*
- *State-Provided Resources: State-provided adult services specialists may be available in some states. You can search for programs and organizations providing advocacy at Disability.gov by entering "advocate" and your state.*
- *University Centers for Excellence in Developmental Disabilities: A Center for Excellence is another great resource for finding person-centered planning facilitators. To locate a center in your state, visit the Administration on Intellectual and Developmental Disabilities website.*

HOW CAN YOU HELP?

The more you know about how you fit into the planning process, the more you can help meet the goals of the person with the disability. To assist with planning, it's useful to become familiar with some of the following:

- *Preparation: An Internet search for "person-centered planning tool kit" should provide resources to help you prepare for the planning meeting.*
- *Disability services and rights: People with disabilities have certain rights under the law.*
- *Resource entitlements: Many benefits for people with disabilities are available. Visit Disability.gov to find out what Social Security benefits, medical services, employment, housing, transportation, respite care and other forms of assistance are available at the federal level. The site also has links to state benefits.•*

– Military One Source

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In Someone Else’s Shoes

She knew these parents care for their children each and every day, knowing the difficulties they face. These parents may struggle each day to do something as simple as transporting them to school.

I’ve always wondered if there would be more empathy in the world for people with disabilities, or for families who are raising children with disabilities, if those not affected could live in our shoes for a couple of days or even a few weeks. Then maybe, just maybe, others would understand and start to realize that there is always room to make things better for everyone. It could be something as simple as making sure crosswalks are cleared or ensuring that music is turned down to a reasonable level at shopping centers. If there was a way to truly empathize with those who live with disabilities, then we could all live with a sense of awareness that could affect people at a level that could change the way they live their lives each day.

A few weeks ago, I had a conversation with a friend who said something to me that was so compelling, I had to stop her mid-sentence and put it in my phone so I wouldn’t forget. It was such an “aha” moment that I grabbed her arm over the table and asked her if I could share her revelation with others.

Her son, unfortunately, broke his leg about six months ago. It was such a traumatic spiral fracture that there was concern if his leg would fully heal in his cast. I remember her telling me how frightened she was once she realized how severe the fracture was to his leg. She told me how exhausted and depressed she had become because it was so much more difficult to care for him. She had to help him bathe and help him get along through the day. She has a daughter too, so she talked about how challenging it was to make sure her daughter got to do all the things she wanted to do with sports and playing with her friends.

Her husband had to travel overseas for a trip. She continued to tell me how she became more exhausted and depressed because then she had to do everything alone. She recalls having to push her son in a wheelchair to school every morning. The roads were bumpy with cracks everywhere she looked. Every morning she would cringe as she would go over a crack or a bump because she was so worried that it would knock her son’s leg and that could be just enough to affect her son’s injury, not allowing it to heal properly.

Her friends would walk by and say, “Why don’t you just put the wheelchair in the back of the car and slide your son in the backseat? You can just drive him to school.” She got more emotional and said, “Shelly, I couldn’t pick up the wheelchair. I had no idea they were so heavy.” The only way she felt she could survive was to wheel him to school over the bumpy and cracked roads. She was frustrated that everyone thought it wasn’t that bad because they offered quick fixes, such as just “tossing” his gargantuan wheelchair in the back of the car each morning and afternoon. She later said, “I felt so alone and helpless. I was frustrated, angry and sad.”

She looked over the table at me and said, “How do parents do this every day for their children? I only had to do this for a couple of weeks and it almost broke me.” I smiled because, for once, I heard a mom get it whose sense of normalcy is raising two typical children. I agreed with her, “It’s hard, isn’t it? It’s hard when you feel alone and you only hear advice from those who really don’t understand.” I later told her that I was sorry that she had to endure that alone. Feeling alone is not fun. Believe me, I know.

She started to ask me questions about the roads, “Who do I talk to about fixing those roads so other parents don’t have to endure what I did with my son?” She then asked, “I wonder how many children are in wheelchairs here at Fort Benning. Do you think there are some things we could do to help them?”

Her questions and concern warmed my heart. Even though she cared for her son while he was in a cast and transported him in a wheelchair for only a few weeks, the experience forced her to empathize with parents who did this not just for a few weeks, but perhaps for the rest of their lives. I could tell she realized that after her son healed, she was able to go back to her sense of normalcy, but she knew in her heart, there was a community of parents who would never be able to experience that sense of “normalcy” again. She knew these parents care for their children each and every day, knowing the difficulties they face. These parents may struggle each day to do something as simple as transporting them to school. These parents are the true heroes, heroes that need to be seen. •

PUZZLES & CAMO

Shelley Huhtanen is an Army wife with two children, one with autism, whose husband is currently stationed at Fort Benning, GA. She is an autism advocate and currently the parent liaison for the Academy for Exceptional Learners.

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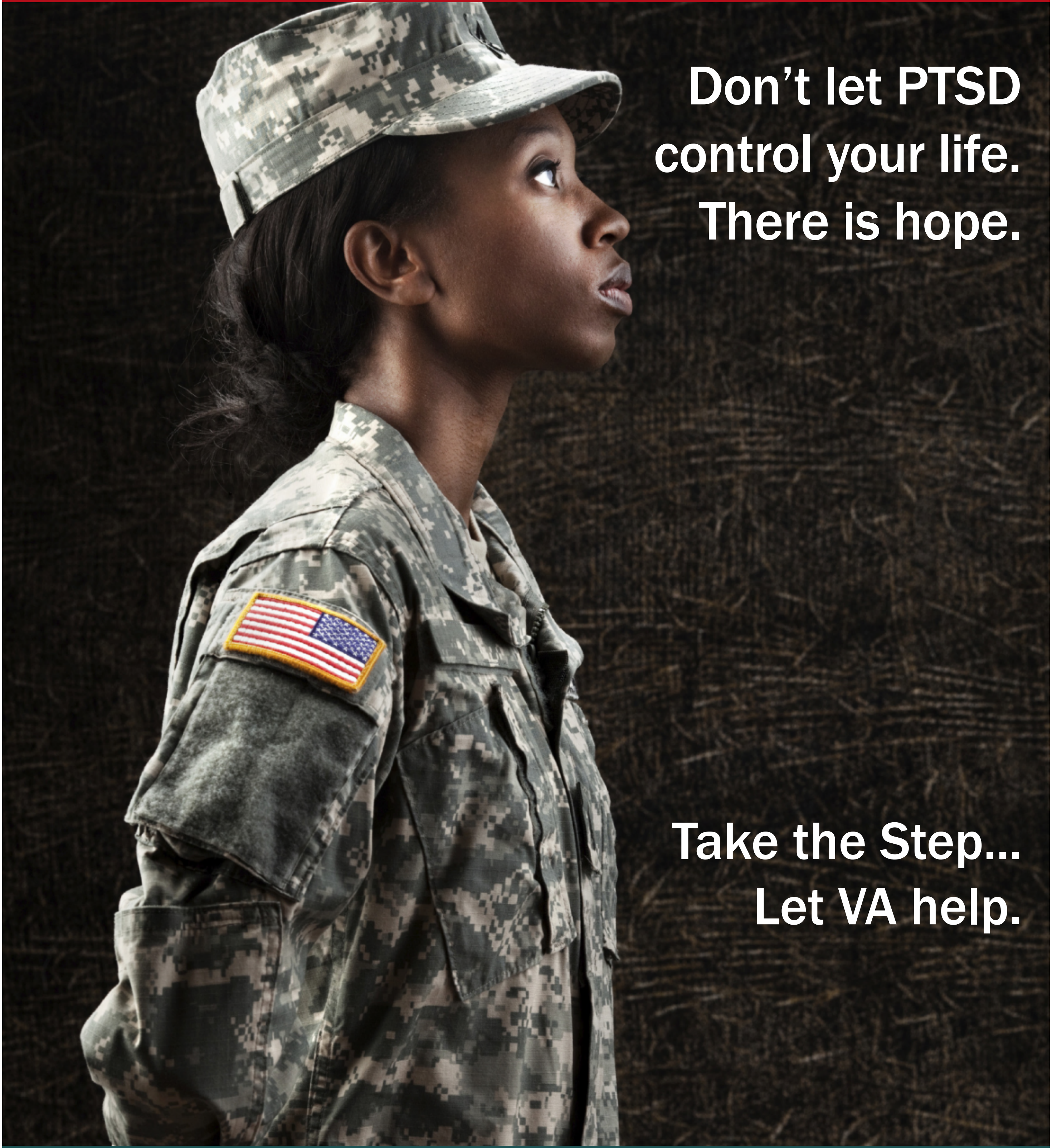

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