

PLUS: UNITED STATES MILITARY SECTION



EP's ANNUAL ISSUE:

**TRANSFORMER
HOMES:
FUN *and*
FUNCTION**

EXCEPTIONAL PARENT
MAGAZINE
JULY 2020
\$7.95

AND:

**FINANCIAL CHECK-UPS
AFTER A CRISIS**

ACCESSIBLE HOMES

AN EP SPECIAL FEATURE:

**TRAVEL
TWISTS**

PLUS • AADMD:

**THE INCREASING NUMBERS
of RESIDENTS WITH
DISABILITIES**



your ad could be here

Consider advertising your product or service in the pages of EP Magazine. We offer extremely competitive advertising rates and reach a wide audience of motivated readers.

Advertising with EP has wide range of positive benefits:

- Demonstrates your company's commitment to the special needs community and the value it places on their caregivers and loved ones
- Reaches a wide readership of family members, physicians, clinicians, nurses and academics as who rely on EP's award-winning news and information concerning the special needs community.
- Offers a number of different strategies to promote product or service, including digital and print media, web advertising, email blasts and newsletter sponsorships. Custom plans are available upon request.

To learn more, please contact Faye Simon
at fsimon@ep-magazine.com



CONTENTS

JULY 2020 VOLUME 50 ISSUE 7



22

30



ACCESSIBLE HOME ISSUE

HEARTSIGHT

16 TRANSFORMER HOMES: FUN AND FUNCTION

By Christina Llanes Mabalot

22 UNIVERSAL DESIGN: TIPS FOR AGING IN PLACE IN YOUR OWN HOME

By Susan Berry

BEST OF EP

26 CREATING ACCESSIBLE HOME BATHROOMS FOR CHILDREN

By Becky Wright



AN EP SPECIAL FEATURE

30 TRAVEL TWISTS

By Jem Llanes Mabalot

40



FEATURES

36 COVID-19 & ADULTS WITH INTELLECTUAL DISABILITY, AUTISM, EPILEPSY, OR BRAIN INJURIES: FINDINGS FROM AN ONLINE SURVEY

By Charles E. Drum, MPA, JD, Ph.D., Roberta Carlin, MS, MA, JD, Karl Cooper, JD, Anthony Oberg, MA and Jacob Ditsch, OTD

40 RESTARTING SCHOOL FOR STUDENTS WITH DISABILITIES SPECIAL CHALLENGES CONTINUE

By Lauren Agoratus, M.A.

43 INDEPENDENCE

By Kimberlee Rutan McCafferty

44 EMOTIONAL HEALTH IN ISOLATION: SUPPORTING SOMEONE WITH DISABILITIES AT HOME DURING COVID-19

By Johnny Payne MEd CPD

46 THE CHALLENGE OF PANS AND PANDAS: OVERCOMING IGNORANCE, EXPLORING POSSIBLE TREATMENTS

By Kara Jolliff Gould, Ph.D.

50 FINANCIAL PHYSICAL... FINANCIAL CHECK-UP AFTER A CRISIS

By Rob Wrubel, CFP

53 SUBSTANCE ABUSE AND THE DEAF ADOLESCENT

By J. Freeman King, Ed.D.

44



53



ON OUR COVER

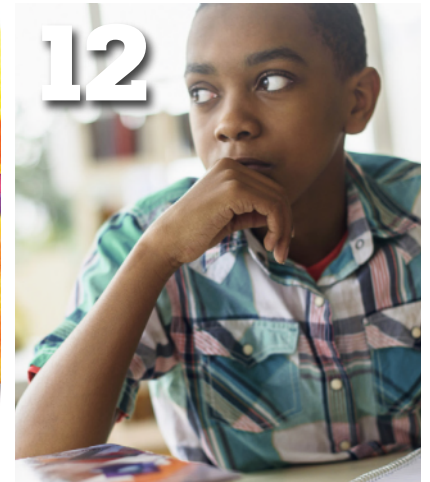
EP's Annual Accessible Home Issue highlights the fun and function of Transformer Homes, offers tips for integrating universal design into your lifestyle, as well as a special feature, "Travel Twists." Coverage begins on page 16.

CONTENTS

JULY 2020 VOLUME 50 ISSUE 7

DEPARTMENTS

- 10** **ANCORO IMPARO**
14 ON THE LONGEVITY OF THE SCREAM
By Rick Rader, MD
- 6 WHAT'S HAPPENING**
- 10 NEW PRODUCTS**
- AMERICAN ACADEMY OF DEVELOPMENTAL MEDICINE & DENTISTRY**
- 12 INCREASING NUMBERS OF RESIDENTS WITH DISABILITIES (EVEN FOR VERY YOUNG CHILDREN)**
By H. Barry Waldman, DDS, MPH, PhD,
Rick Rader, MD, DHL (Hon)
and Steven P. Perlman, DDS, MScD, DHL (Hon)
- 64 PRODUCTS & SERVICES**



MILITARY SECTION

- MILITARY LIFE**
- 58 TOP 10 WAYS TO PRACTICE RESILIENCE SKILLS DURING CHALLENGING TIMES**
- 60 MOVING WITH PETS**
- PUZZLES & CAMO**
- 62 LEVEL 3**
By Shelly Huhtanen

EP FOR FREE!

THE MISSION OF EXCEPTIONAL PARENT MAGAZINE IS TO GATHER AND SHARE INFORMATION AS TOOLS FOR POSITIVE CHANGE FOR THE SPECIAL NEEDS COMMUNITY.

To subscribe to the free eMagazine or for the printmagazine (\$95 per year) go to:

www.ep-magazine.com



FROM OUR FAMILIES... TO YOUR FAMILIES

MILITARY SECTION

MILITARY LIFE

58 TOP 10 WAYS TO PRACTICE RESILIENCE SKILLS DURING CHALLENGING TIMES

60 MOVING WITH PETS

PUZZLES & CAMO

62 LEVEL 3
By Shelly Huhtanen

ARMY
NAVY
AIR FORCE
MARINES

The contents of EP magazine's Military Section are not necessarily the official views of, or endorsed by, the United States Government, the Department of Defense, or the Department of the Army. The appearance of advertising adjacent to the Military Section does not constitute endorsement by the United States Government, the Department of Defense, or the Department of the Army of the products or services advertised.



Information and Support for the Special Needs Community
VOLUME 50 ISSUE 7 ■ ESTABLISHED 1971

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

Exceptional Parent magazine was founded in 1971 by Maxwell J. Schleifer, PhD

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

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

Publishing & Editorial Office
 1360 Clifton Avenue, Ste. 327
 Clifton, NJ 07012



Exceptional Parent (ISSN 0046-9157) is published monthly 11 times per year plus the special January Annual Resource Guide by TCA EP World, LLC, dba Exceptional Parent Magazine, 1360 Clifton Avenue, Ste. 327, Clifton, NJ 07012. Internet address: www.ep-magazine.com. All rights reserved. Copyright ©2020 by TCA EP World, LLC. Exceptional Parent™ is a registered trademark of TCA EP World, LLC. Postmaster: Please send address changes to: Exceptional Parent, 1360 Clifton Avenue, Ste. 327, Clifton, NJ 07012. Any applicable periodical postage paid at Johnstown, PA and additional mailing offices (USPS 557-810). Basic annual subscription for EP Digital is free. Limited edition print subscription \$95.00. Subscriber Service: Direct all inquiries & address changes to: Exceptional Parent, 1360 Clifton Avenue, Ste. 327, Clifton, NJ 07012 08758. Customer Service/New Orders: E-mail: fsimon@ep-magazine.com or call toll free: (800) 372-7368 extension 119. Back issues incur a charge of \$10.00 each and depend upon availability, call (800) 372-7368. Agreement #1420542

EP EDITORIAL ADVISORY BOARD

Lauren Agoratus

Parent, NJ state and MCH Region II (NJ, NY, PR, VI)
 Coordinator for Family Voices, NJ CCAN (Caregiver
 Community Action Network), National Family
 Caregivers Association, Mercerville, NJ

Mark L. Batshaw, MD

Prof. and Chairman, Dept. of Pediatrics, The George
 Washington University Medical Center,
 Washington, DC

Jean F. Campbell

Principal, JF Campbell Consultants; Founding Board
 Member, Professional Patient Advocates in Life
 Sciences (PPALS)

Henry G. Chambers, MD

Director, Southern California Cerebral Palsy Center at
 Rady Children's Hospital-San Diego, Co-director 360
 Sports Medicine Program

David Fray, DDS, MBA

Associate Professor, Department of General Practice
 and Dental Public Health, University of Texas School
 of Dentistry, Houston, TX

Allen Friedland, MD

Pediatrician and Internist Pediatric to Adult care
 Advisor, Wilmington, DE

Saadi Ghatan, MD

Site Chair, Neurosurgery, Mount Sinai West, Mount
 Sinai St. Luke's, New York, NY

Matthew Holder, MD

CEO, Lee Specialty Clinic, Louisville, KY Global Medical
 Advisor for Special Olympics International

Gary Liguori, Ph.D.

Fellow of the American College of Sports Medicine
 (ACSM), Dean, College of Health Sciences, University
 of Rhode Island

Patricia E. McGoldrick, CPNP

Pediatric Neurology & Epilepsy, Associate Director,
 Developmental Disability Center, Roosevelt
 Hospital, NY

Steven P. Perlman, DDS, MScD, DHL (Hon)

Clinical Professor, Boston University, School of
 Dentistry, Boston, MA

Tera Roberts

Executive Director, Orange Grove Center, Chattanooga, TN

Robert K. Ross Ed.D., BCBA-D, LBA

President of the Autism Special Interest Group,
 Association for Behavior Analysis International, Senior
 VP at Beacon ABA Services of MA & CT

Amged M. Soliman, Esq.

Attorney, US Federal Government

Stephen B. Sulkes, MD

Pediatrician, University of Rochester Medical Center,
 Rochester, NY

Steven M. Wolf, MD

Associate Professor of Neurology and Director of
 Pediatric Epilepsy, affiliated with Mount Sinai Beth
 Israel, Mount Sinai St. Luke's, Mount Sinai West,
 New York, NY

Allen Wong, DDS, EdD, DABSD

Professor and Director AEGD Program/Hospital
 Dentistry, University of the Pacific, Dugoni School of
 Dentistry, AADMD President

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.



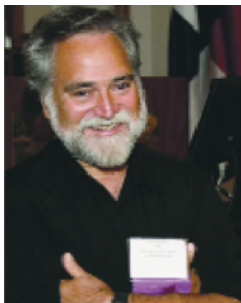
On the Longevity of The Scream

Screams are a familiar outlet for parents of children with special health care needs. The screams have followed the initial diagnosis, the denial of services, exclusions, unfulfilled promises from school officials, waiting lists, indifferent clinicians, and termination of programs that used to make sense.

Whenever I find myself in

in the Orange Grove Center’s Art Studio, I get energized. Our art program, under the tutelage of Dennis Wilkes, our artist-in-residence and inspiring art teacher, has a knack for encouraging our artists with intellectual disabilities to

find a pathway to expressing themselves. Over the years, many of their paintings could have been displayed in museums, galleries and



exhibits. Displayed, not because they were created by individuals with special needs, but simply because of the depth, quality and intensity of their composition. Dennis has stated that when he finds innate talent, he does what other great art teachers have done for centuries – gets out of their way.

Paintings have been part of our “humaneness” since the Neanderthals smeared red ochre and black pigment on the walls of caves and tried to explain the relationship between humans and lions, buffalos and mammoths; how they found food, found fire, how they survived, and how they evolved.

If there is one single painting that captures how an artist can implant an image into the human psyche, it is probably the Mona Lisa by Leonardo Da Vinci. It has been described as “the best known, the most visited, the most written about, the most sung about, the most parodied work of art in the world.”

Despite popular opinion, in terms of implanting an image into the human psyche, I think Da Vinci takes a back seat to Edvard Munch, and the Mona Lisa runs close behind The Scream.

While hearing the name of the painting, The Scream, may not immediately connect you to the painting, when you see it, you may immediately realize some familiarity



with it. Comments like, “Oh yeah, that guy,” “Can’t imagine what’s going on with him,” “That really creeps me out,” and “It hurts just to look at it,” are clearly a testimony to Munch, who produced the painting in 1893.

As Wilkes remarks, “Get out of their way,” this was exactly the concept of the styles of both “naturalism,” and “impressionism”, the two avenues of composition that Munch explored.

The agonized face in the painting has become one of the most iconic images of art, seen as symbolizing the totality of anxiety, grief, despair, pain, and depression as an overwhelming consequence of being human.

Munch described how he came to paint The Scream, “One evening I was walking along a path, the city was on one side and the fjord below. I felt tired and ill. I stopped

and looked out over the fjord – the sun was setting, and the clouds turning blood red. I sensed a scream passing through nature; it seemed to me that I heard the scream. I painted this picture, painted the clouds as actual blood. The color shrieked. This became *The Scream*.”

The thing about a “scream” is that it is among the most extreme manifestations of emotion that we have all experienced. How do the screams from witnessing an atrocity compare to the screams of the Beatles fans in 1964? Both may be thought to be comparable to the strange, sexless creature in the foreground of Munch’s painting.

There is probably no other painting that has been so widely adopted by popular culture as *The Scream*. The image has been used on T-shirts, coffee mugs, posters, napkins, coasters, note cards and skin tattoos.

Over the years *The Scream* has found itself on the cover of dozens of medical monographs on depression, pain, loneliness, stress, suffering, and compassion fatigue. A patient resource group for trigeminal neuralgia (which has been described as the most painful condition in existence) have also adopted the image as a symbol of the condition.

Screams are a familiar outlet for parents of children with special health care needs. Certainly, the screams have followed the initial diagnosis, the denial of services, exclusions, unfulfilled promises from school officials, waiting lists, indifferent clinicians, and termination of programs that used to make sense.

But screams have also followed parents watching their child win an event at Special Olympics, being named the Homecoming Queen, brushing their own teeth, or reaching out to pet a cat, or seeing their child decide on what kind of dessert they want.

Screams are nothing more than a loud vocalization in which air is passed through the vocal folds with greater force than is used in regular or close-distance vocalization. This can be performed by any creature possessing lungs. The unique aspect of a

scream is the instinctive decision to muster it; the innate desire to designate your response to what conditions you are confronted with, and why it necessitates a scream.

All screams come to an end. Whatever the function of a scream is, to warn, to resign, to surrender, to battle, to confront, it has a life of its own. And so, apparently does Munch’s painting. It has been reported that *The Scream* is deteriorating fast. The demise of the painting is due to two co-occurring conditions. First, the paint was of low quality. Munch used poor paint, resorting to low-quality cadmium sulfide pigments. He also painted it on cardboard.

The other factor, the one I find to be of keen interest is that fans and visitors viewing the painting may be partly to blame. Humidity from the breath of museum goers have gradually degraded

the colors of the famous painting. It’s as if the heavy breathing of viewers (and heavy breathing is the number one response from experiencing *The Scream*) is causing it to fade. Onlookers are so troubled, moved and negatively transfixed by the painting that they respond with forceful breaths. Perhaps it is symbolic that the reaction, the concerns, the empathy, the outpouring of emotions that the painting elicits from viewers are sealing *The Scream*’s fate. What if the empathy of supporters in our own lives was enough to diminish the need to scream?

Munch shared his decision to reorient his approach to painting. “No longer shall I paint interiors with men reading and women knitting. I will paint living people who breathe and feel and suffer and love.”

It’s ironic that it is “living people who breathe and feel” that may be responsible for the fading of *The Scream*. •

ANCORA IMPARO

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

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

CONNECT AND DISCOVER

Join EP’s Facebook Community



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

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

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

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

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

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

WHAT'S HAPPENING

A MESSAGE FROM AADMD'S NEW PRESIDENT

BY ALLEN WONG, DDS, EDD, DABSCD

The American Academy of Developmental Medicine and Dentistry (AADMD) is an organization that was born out of the need for collaboration among healthcare professionals to help improve the healthcare of individuals with intellectual and developmental disabilities (IDD), subsequent to the 2000 Surgeon General's report on healthcare disparities. We were but a local group with great aspirations; our original idea started to gain momentum – and we have since been on a sure path to growth.

As president, I am privileged to represent the AADMD and help lead it in its journey. In our infancy, we were limited to projects, size of membership, and volunteers. Along the way, we grew in our scope as well as our influence among other organizations. Our strength has been our agility to respond and our willingness to get involved. Our advocacy program has matured and expanded. The AADMD today is making major differences in the area of changing educational curriculum, an investment for future practitioners.

We have been blessed with expansion in medical and dentals schools, with student/ resident groups who have awakened the minds and hearts of healthcare students in the US and internationally. I would be remiss if I did not mention that organizations like Special Olympics International, Golisano Foundation, and the WITH Foundations among others, have contributed greatly to our successes.

The momentum of the AADMD has allowed us to expand the structure of our Board, making it more inclusive and representative of our programming and the constituents we serve. While on this journey, we will learn new things and also have to make adjustments along the way. We look forward to more self-advocacy input, community collaborations, the support of our student/resident groups, our educational programs, and international influences. Amid the COVID-19 crisis, the AADMD has responded with education and its support of petitions relating to the rights of people with IDD (equal access to ventilators and the ability to have a caretaker accompany them to emergency rooms); a growing Coronavirus Resource Website; and a phenomenal Virtual Grand Round through our student/ resident group.

A little about me. I grew up in Northern California, blessed to work in our family business, a Chinese restaurant. Both my parents were immigrants from China with minimal formal educa-



MAKING A DIFFERENCE: "As we volunteer to help others, we are blessed with joy." Dr. Wong has taught postdoctoral general dentistry for over 20 years in advanced education residency programs and is the director of Pacific's Hospital Dentistry Program and Director of Highland Hospital Restorative Implant program. He has lectured nationally and internationally in the areas of special care dentistry, rotary endodontics, and minimally invasive dentistry. He is active with Special Olympics Special Smiles program as an International Dentist Trainer and an Editorial Advisory Board member for EP Magazine.

tion, as even primary education was expensive in China. I worked in our restaurant since I was in elementary school and continued through college. My parents started with little but showed me how important it was to give back as well as appreciate our blessings. They instilled in me the value of education and taught me to strive to do my best in whatever I did. The lessons I learned working in a restaurant made me appreciate the value of service; they taught me that if you truly put your mind to a task, you can achieve your goal.

I chose dentistry as a profession for my love of science and working with my hands. But working with people with special needs is what has touched my heart—it helped channel my career towards the education of the next generation of care providers. The many mentors I have met and continue to meet assure me that I am on right path.

The secret to happiness, in my opinion, is volunteerism. The sharing of one's time, energy, and talents is a gift that gives back. As we volunteer to help others, we are blessed with joy.

I am looking forward to working with an outstanding new and expanded AADMD Board and eager to start our journey in our pursuit of joy.

Yes, You CAN!

Abilities EXPO

Serving the Community
Since 1979

At Abilities Expo, you can...

- Build independence with the latest products
- Learn tips and life hacks at workshops
- Improve fitness with adaptive sports
- Open doors with service animals
- Change the game with new tech
- Get answers from the experts
- Embrace your abilities through dance
- Access facts on therapeutic cannabis
- And so much more!

**FREE
ADMISSION**



Follow Us!
#AbilitiesExpo

Abilities.com
Register online today. It's free!

Precautionary health procedures will be in place at the Expo. Stay safe, everybody!

Toronto
Oct. 2-4, 2020

Houston
Oct. 30-Nov. 1, 2020

Dallas
Dec. 11-13, 2020

Los Angeles
Feb. 26-28, 2021

New York Metro
April 30-May 2, 2021

Chicago
July 25-27, 2021

Phoenix
Sept. 10-12, 2021



PHILLIP FIORE
Financial Advisor, ChSNC®

LEVEL UP.

Overcome Financial Challenges with a ChSNC® Advisor.

Families caring for a person with special needs face unique financial challenges—which is why you need a financial advisor who's leveled up with the Chartered Special Needs Consultant® (ChSNC®) designation. An advisor with the specialized training that comes with the ChSNC® can help parents and caregivers plan for immediate and long-term considerations by providing expert guidance in disability law, government benefits, estate planning, tax deductions, special needs trusts, and other financial strategies your family needs to thrive. Choose a ChSNC® professional.

LEARN MORE AT
THEAMERICANCOLLEGE.EDU/chsnc



WHAT'S HAPPENING

THE 2020 RARE ARTIST CONTEST

Who can enter into the contest?

According to RareArtist.org, anyone connected to the rare disease community can submit artwork; including caregivers, patients, physicians, siblings, and friends. There are three different categories dependent on age; anyone who is 4 and up can enter. You do not need to be a professional artist or hold any sort of credentials in order to enter into the contest.

Anyone can participate in the voting portion of the contest for the public vote via Facebook. Individuals participating in voting are requested to respect the rules. Voters are allowed one vote per art piece every 10 days. You do not have to have a submission in the contest to vote. You do not have to be affiliated with a rare disease in order to vote. The spirit of the contest is about spreading awareness. You are encouraged you to share artwork with your communities in the public vote.



RARE TALENT: *Resilient* by Jenn Arnold, who lives with Hidradenitis and Suppurativa, was an award winner in the Adult Digital Art & Photography category in the 2019 RareArtist program.

What are the prizes?

Contest awardees are granted cash prizes and an opportunity to showcase their art work at the Rare Artist Reception during Rare Disease Week on Capitol Hill (<https://rareadvocates.org/rdw-2>). When entering the contest, the artwork entered should represent the age of the artist. If you are submitting on behalf of someone else, please submit by the age of the artist, not of your own. Cash prizes according to age groups are as follows:

▪ Children (4-11): \$100 ▪ Teen (12-18): \$250 ▪ Adult (19+): \$500

Additionally, your artwork will be uploaded to the Rare Artist Website Gallery. Rare Art will also showcase throughout the year at various patient and industry events.

When are the deadlines?

- The 2020 Rare Artist Contest will be accepting submissions on Facebook (for the public vote) between June 16th and October 1st @5pm EST.
- The 2020 Rare Artist Contest will continue to accept submissions

through email until October 30th @5pm EST. Voting for the public vote will also close on October 30th @5pm EST.

- Once all categories of awards have been deliberated, awardees will be privately notified by December 11th, 2020.
- Public announcement of all 2020 Rare Artist awardees will be on January 15th, 2021.

Where do I go to submit?

For those interested in being included in the public Facebook vote, please go to: www.facebook.com/RareArtistContest.

For those who do not have a Facebook account, or DO NOT wish to participate in the public vote, please send submissions to lcundiff@everylifefoundation.org

Why should I enter?

The primary goal of the Rare Artist program is to spread awareness about rare diseases and amplify the stories behind the art work. Participating in the Rare Artist Contest is another way to get your voice heard. Sharing your artwork in front of Congress and other attendees during Rare Disease Week on Capitol Hill is advocacy. Participating in the voting process on Facebook and cheering on your fellow advocate through social media is advocacy. •

WHEN TRANSITIONING A CHILD WITH SPECIAL NEEDS FROM CRIB TO BED, CHOOSING THE RIGHT BED MAKES ALL THE DIFFERENCE...



Hannah Series for Ambulatory Children



Ida Series for Non-Ambulatory Children

KAYSERBETTEN'S UNIQUE FEATURES:

- Sturdy solid beechwood construction for long term use.
- Specially treated wood can be repeatedly cleaned.
- Vertically hinged doors allow easy access for care, cleaning and changing sheets.
- Crib-like design for full view of child inside the bed and proper ventilation.
- Versatile design for child's changing medical / physiological conditions.
- Lowest available thresholds for independent or assisted transfers.
- Available in manual, semi-electric and full electric.

CONTACT US TODAY FOR A FREE CONSULTATION



KayserBetten-U.S.
Beds for Special Needs

515 N 12th Street, Allentown, PA 18102

1-800-574-7880 Ext 308 • www.KayserBettenUS.com

NEW PRODUCTS

HEATING UP



GRIP IT FOOTBALL CHEWY & FIDGET

The Grip It Football Chewy & Fidget are flexible football-shaped fidgets that double as chewies. They offer an outlet to engage busy fingers while helping redirect children from biting their hands or clothing. They are made of smooth silicone and bumpy laces for added texture for mouths to explore. Chewing provides oral motor and sensory input that many children find calming when they feel anxious. Can be used to help improve focus and concentration at school. The chewies are safe for teething babies and large enough for little hands to grab on to. They are for moderate chewers, encourage tactile and oral motor exploration, support challenges of ADHD, sensory processing disorder, and autism. Includes two footballs. Dimensions: 5.1 inches x 2.1 inches x 0.2 inches. Each weigh 1.5 ounces. Made a food grade silicone, designed without BPA, phthalates, and latex.

FUN AND FUNCTION

PO Box 11
Merion Station, PA 19066
Phone: 800-231-6329
Fax: 866-343-6863
Web: www.funandfunction.com
Email: CustomerCare@FunandFunction.com

MONSTER BOWLING

Monster Bowling is a fuzzy monster-themed bowling set that adds color, texture, and a whole lot of eyes to a familiar game. Six wacky plush pins with goofy expressions have weighted bottoms for extra stability, touchable textures, and detailed stitching. Users can set up the pins in different formations, then use Klunk, the silly stuffed ball, to knock them down. The set

stores in a handy mesh bag to take the bowling fun wherever kids go. Dimension: 13.25 inches x 12.25 inches x 3.25 inches.

MELISSA & DOUG

PO Box 590
Westport, CT 06881
Phone: 800-718-5365
Web: www.melissaanddoug.com
Email: Owners@MelissaAndDoug.com

ROCKET DREAM SHIP

The Rocket Dream Ship is a soft rocket ship that glows and plays five minutes of music and sound when the user activates their capability switch. Just press the music icon on the rocket's soft red fins to activate the melody and the soft nightlight. The Rocket Dream Ship can increase sensory awareness and teach cause and effect. This can also be used as a night light with and without music. It also works with or without a switch. Dimensions: 8 inches x 8 inches x 10 inches. Weight: 1 pound. Battery requirement: 3 AAA.



ENABLING DEVICES

50 Broadway
Hawthorne, NY 10532
Phone: 800-832-8697
Fax: 914-747-3480
Web: www.enablingdevices.com



ABLEDATA

The ABLEDATA database of assistive technology (AT) and rehabilitation equipment contains information on more than 50,000 products for persons of all ages who have a physical, cognitive or sensory disability. Products are chosen for these pages by the ABLEDATA staff based on their specific applicability to or design for children who have disabilities. ABLEDATA, operated by New Editions Consulting, Inc., is funded by the National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR). For more information on these and other assistive devices, or to submit product information for the database (and possible inclusion on this page), contact: ABLEDATA, 103 W. Broad Street, Suite 400, Falls Church, VA 22046; phone: 1-800-227-0216; TTY: 703-992-8313; website: <https://abledata.acl.gov/>; email: abledata@neweditions.net; Twitter: [www.twitter.com/AT_Info](https://twitter.com/AT_Info); Facebook: www.facebook.com/abledata; Pinterest: www.pinterest.com/AT_Info

NEW PRODUCTS



WALKING WHEELS

Walking Wheels is a set of platforms that turn walking into rolling. The Walking Wheels encourages gross motor skills, coordination, balance, concentration, and active play. It is a way for children to get up and get moving. Each step makes the wheels roll half a rotation forward, and children try to hone their skills to create smooth, seamless movement. The Walking Wheels features sturdy handles on either side for extra stability and security. The handlebars feature soft foam covers for added comfort and grip. The rubber wheels roll smoothly, and can be used for indoor or outdoor play. Includes one set of Walking Wheels. Dimensions: 24.5 x 14.5 x 14 inches. Weight limit: 125 pounds.

FAT BRAIN TOYS

20516 Nicholas Circle
Elkhorn, NE 68022
Phone: 800-590-5987
Web: www.fatbraintoy.com
Email: cs@fatbraintoy.com

P-POD POSTURAL SUPPORT SYSTEM

The P-Pod Postural Support System is a molded positioning pod that is incorporated into a bean bag base to help children maintain proper postural alignment while seated. This postural support system is a good alternative seating solution for home, clinical, or school environments. It offers a seating experience for those with specialized seating needs. It can be used for ages from infants to young adults. There are three components to the P-Pod: the seat, a bolster support, and the beanbag or Pod. Features include a quilted stretch velour cover in a range of colors that is easily removable for cleaning. The bean bag allows change of positions yet maintains support, and a range of accessories are available. Four sizes are available: Small, Medium, Large, and Extra Large.

ESPECIAL NEEDS

1850 Borman Court
St. Louis, MO 63146
Phone: 877-664-4565
Fax: 800-664-4534
Web: www.especialneeds.com



ABLEDATA

*Your Source
for Assistive
Technology
Information*

AbleData is the premier source for impartial, comprehensive information on products, solutions and resources to improve productivity and ease with life's tasks.



*AbleData organizes information
into 20 categories:*

- Blind & Low Vision
- Communication
- Computers
- Controls
- Daily Living Aids
- Deaf & Hard of Hearing
- Deaf-Blind
- Education
- Environmental Adaptations
- Housekeeping
- Orthotics
- Prosthetics
- Recreation
- Safety & Security
- Seating
- Therapeutic Aids
- Transportation
- Walking
- Wheeled Mobility

*Over 40,000 assistive technology
products in an easy-to-use
database!*



AbleData >>>
Tools & Technologies to Enhance Life
www.abledata.com
800-227-0216

Increasing numbers of residents with disabilities (Even for very young children)

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

A series of previous writings in *Exceptional Parent Magazine* emphasized the inadequate reports by the U.S. Census Bureau in its annual American Community Survey demographic findings that an estimated 155,000 children less than five years of age among the civilian noninstitutionalized population had one or more severe disabilities. The reality is that the Census Bureau only includes children with disabilities in the less than five-year count who have hearing and vision difficulties. For all other age groups, six disability categories (hearing, vision, cognitive, ambulatory, self-care and independent living difficulties) are collected and described.^{1,2}

A report from the National Center for Health Statistics on “The Prevalence of Developmental Disabilities Among U.S. Children Aged 3-17 Years” (*emphasis added*) listed the current status which indicated increases between 2009 and 2017.³ Recognizing the difficulties associated with determining the type and degree of disability for very young children, the previous writing in EP Magazine suggested a third category for youngsters less than five years of age with disabilities: “1) hearing limitations, 2) sight limitations and 3) other disabilities with the *Type and severity to be determined at an older age.*”²

The 2020 report by the Data Resource Center for Child and Adolescent Health for the 2017-2018 *National Survey of Children’s Health* takes on this controversy by including at the state and national levels information for the: 1) mental and emotional development, 2) attention deficit disorder (ADD)/attention deficit hyperactive disorder (ADHD) and 3) autism or spectrum among children 3-17 years.

In addition, the study report provides an extended series of child-related health information, including: 1) the children’s

physical, oral health status, 2) health insurance availability, 3) general health care access and 4) the quality of care.⁴

Unfortunately, while the study includes information in the 3-5 years of age range, it does not segregate the data from the overall general 3-17 years information. This separate arrangement would demonstrate the need for the Census Bureau to consider increasing the range of disabilities for children in the under-five age category.

SPECIFICALLY

- **Mental emotional development:** Across the nation, 13.5 million children (21.9%) between ages 3-17 years, have mental or emotional development difficulties or currently have one or more behavioral problems; ranging from 13.6 percent in Hawaii to more than double the proportion at 29.0 percent in Louisiana (see Table 1).

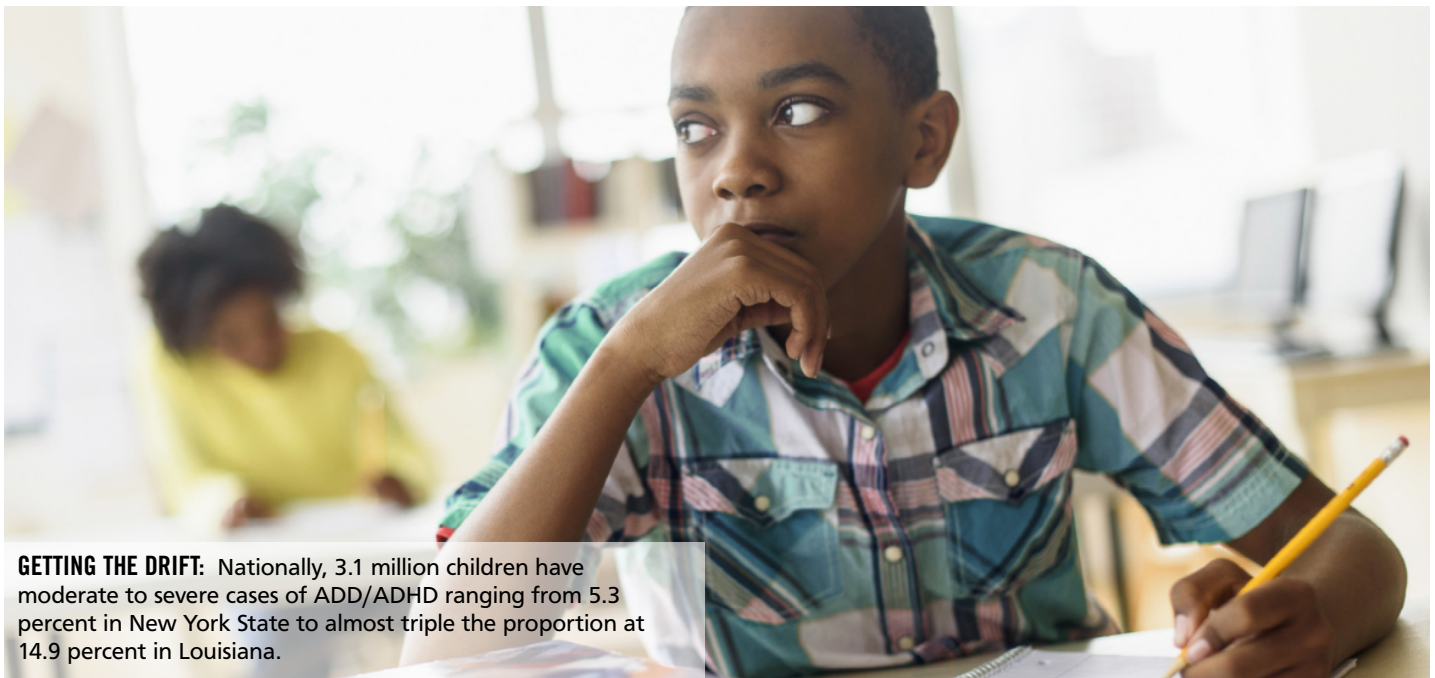
Table 1. Mental emotional development or currently have one or more behavioral problems among children 3-17 years: 2017-18: U.S. and highest and lowest state proportions¹

Louisiana	29.0%	
W. Virginia	28.0	
Mississippi	27.6	
Delaware	26.0	
Maine	25.9	
United States	21.9%	13.5 million children
New York	19.6%	
Florida	19.0	
Nevada	18.9	
Nebraska	18.3	
Hawaii	13.6	



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.



GETTING THE DRIFT: Nationally, 3.1 million children have moderate to severe cases of ADD/ADHD ranging from 5.3 percent in New York State to almost triple the proportion at 14.9 percent in Louisiana.

- **Attention Deficit Disorder/Attention Deficit Hyperactive Disorder:** Regarding the nation, 5.3 million children (8.7%) between 3-17 years, have ADD/ADHD ranging from 5.3 percent in New York State to almost triple the proportion at 14.9 percent in Louisiana. Nationally, 3.1 million children have moderate to severe cases, 3.2 million children sometimes or never have adequate health insurance, 3.3 million children take medication and 2.4 million children receive behavioral treatment (see Table 2).
- **Autism or spectrum:** Across the nation 1.8 million children (2.9%) between 3-17 years have autism or the spectrum ranging from 1.2 percent in Florida to almost four times the proportion at 4.6 percent in Pennsylvania and Virginia. Nationally, 955,500 have moderate/severe cases and 465,700 are taking medication (see Table 3).

QUESTION

Why are the low to high ranges of the proportion of children ages 3-17 years in the U.S. states for the three disability categories, respectively, **more than double, almost triple and almost quadruple?** (see Tables 1-3) Yes, the actual number of children with disabilities, to a great extent, reflect the marked differences in the total state populations. But why are there such differences in the proportions between the state levels?

SOME RESPONSES

In addition to differences in state (and federal government-supported programs, e.g. Medicaid and Children Health Insurance Program [CHIP]), variations in demographics and economics, as well as social and health factors, explain much of the marked proportional differences between states.

“Poverty and disability are intricately related... (decades) after the passage of the Americans with Disabilities Act (ADA), adults with disabilities are twice as likely to live in poverty as those without a disability... (In addition, there are) important differences in the poverty rate among demographic groups who face additional economic challenges — women, members of

Table 2. Attention Deficit Disorder/Attention Deficit Hyperactive Disorder among children 3-17 years: 2017-18: U.S. and highest and lowest state proportions ¹

Louisiana	4.9%
Mississippi	14.3
W. Virginia	13.4
Georgia	12.0
Alabama	11.8
United States	8.7%
	5.3 million children
	Mild cases: 2.1 million
	Moderate/severe cases: 3.1 million
	Health insurance adequacy
	Always: 5.1 million
	Usually: 3.0 million
	Sometimes or never: 3.2 million
	Medication
	Taking: 3.3 million
	Not taking: 1.9 million
	Receives behavioral treatment
	Yes: 2.4 million
	No: 2.9 million
Arizona	6.9%
Hawaii	6.4
California	6.2
New Mexico	5.7
New York	5.3

minority groups, people with lower levels of education and assorted age groups.” ⁵

One quarter of black residents (about the same rate as Native Americans) have incomes below the poverty level compared to approximately 12 percent of the national proportion and about 8 percent of non-Hispanic whites.

- *Poverty rates of children in the Southern Region of the country (an area in which states generally have a greater proportion of black residents) are higher than other parts of the country.*

Table 3. Autism or spectrum among children 3-17 years: 2017-18: U.S. and highest and lowest state proportions ¹

Pennsylvania	4.6%	
Virginia	4.6	
Georgia	4.3	
California	4.0	
Connecticut	4.0	
United States	2.9%	1.8 million children
		Mild cases: 1.3% - 769,500
		Moderate/severe cases: 1.6% - 955,500
		Medication
		Taking: 465,700
		Not taking: 1,345,000
South Carolina	1.6%	
New Mexico	1.3	
North Dakota	1.3	
South Dakota	1.3	
Florida	1.2	

- In both urban and rural areas, larger proportions of families with persons who have a disability live in poverty, than families with members who have no disabilities. In addition, women with disabilities are overwhelmingly more likely to live in poverty. The economic differences between those with and without disabilities grow as education levels increase.
- Among children with special healthcare needs living in poverty, a greater proportion need emotional, behavioral or developmental services.
- Almost one-in-five black residents lack health insurance. Lack of insurance compromises the health of the uninsured because disabilities and disease conditions are diagnosed at more advanced stages and these individuals tend to receive less preventive and therapeutic care.

The disparity in the poverty rate between people with and without disabilities grows with age: Among those:

- 18-30 years old, the poverty rate is 21 percent for those without disabilities and 32 percent for those with disabilities.
- 30-45 years of age, 12 percent without disabilities live in poverty, as compared to 33 percent with disabilities.
- 45-64 years old, nine percent without disabilities live in poverty, compared to 26 percent with disabilities. ^{5,6}

FINAL QUESTION

When will all government agencies recognize the need to detail the increasing number of very young children with a range of disabilities, so that funding will be made available to provide the required care? •

ABOUT THE AUTHORS:

H. Barry Waldman, DDS, MPH, PhD is a SUNY Distinguished Teaching Professor, Department of General Dentistry, Stony Brook University, NY. E-mail: h.waldman@stonybrook.edu.


Rick Rader, MD, DHL (Hon) is the Director of the Morton J. Kent Habilitation Center, Orange Groove, Chattanooga, TN; Senior VP Public Policy, American Academy of Developmental Medicine and Dentistry; Adjunct Professor, Human Development, University of Tennessee-Chattanooga. He is Exceptional Parent Magazine's Editor in Chief.

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

References


1. Waldman HB, Perlman SP, Larsen CD. Surely there are more than about 155,000 children less than five years of age with disabilities in the U.S. EP Magazine 49:14-16, December 2018.
2. Waldman HB, Rader R, Perlman SP. Undercounting young children with severe disabilities: a need for change. EP Magazine 51:14-16, February 2020.
3. Zablotsky B, Black LI, Maenner MJ, et al. Prevalence and trends of developmental disabilities among children in the United States 2009-2017. Available from: <https://pediatrics.aapublications.org/content/early2019/09/24/peds.2019-0811>.
4. Data Resource Center for Child and Adolescent Health. 2017-2018 National Survey of Children's Health. Available from: <https://www.childhealthdata.org/browse/survey/results?q=7096&r=1>
<https://www.childhealthdata.org/browse/survey> Accessed June 11, 2020.
5. Morris M. Poverty and disability in America Matter Available from: https://www.huffpost.com/entry/poverty-and-disability-in_b_9557142 Accessed June 14, 2020.
6. Waldman HB, Perlman SP, Kucine, AJ. Social and health conditions of the Black/American population: the setting for children and adults with disabilities. Exceptional Parent Magazine, 38:65-67, February 2006.

CORONAVIRUS DISEASE 2019 (COVID-19)



You can help prevent the spread of respiratory illnesses with these actions:

- Avoid close contact with people who are sick.
- Avoid touching your eyes, nose & mouth.
- Practice social distancing by putting space between yourself & others.
- Wash hands often with soap & water for at least 20 seconds.



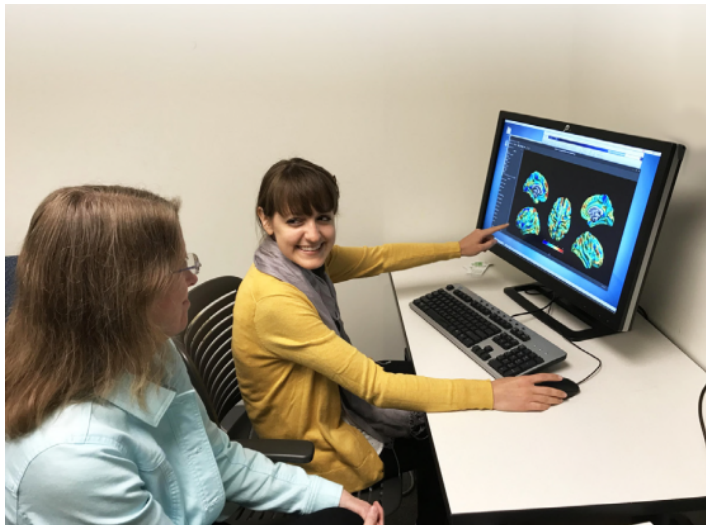
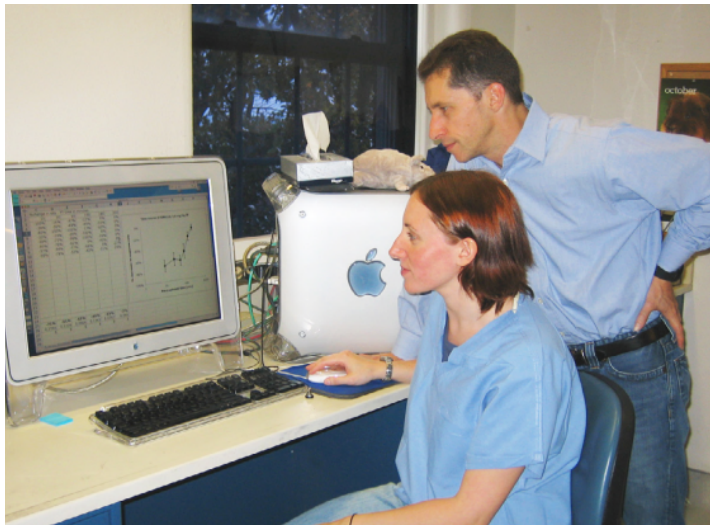
cdc.gov/coronavirus

316159-A March 25, 2020 8:00 AM



VOLUNTEERS ARE NEEDED. IF INTERESTED, EMAIL IESBRAINRESEARCH@GMAIL.COM

WE MOURN THE RECENT PASSING OF THE INSPIRATION FOR THIS FOUNDATION, A GREAT MAN AND OUTSTANDING SCIENTIST, ERIC J. SIMON, PHD, THE "E" IN IES



www.iesBrainResearch.org

(973) 726-6218 • iesBrainResearch@gmail.com

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

Transformer Homes: Fun and Function

In the new norm, an accessible home also breaks distance, cultural, attitudinal, informational, and spiritual barriers. The truly fantastic thing about working or schooling from home is that obstacles that required special considerations in the classroom or office can be eliminated altogether.

The first place I called home was my parents', where I grew up and got established. At that time, accessibility was unheard of. Out of sheer common sense, my parents brightened up our house and study tables with fluorescent lights to aid their four visually-impaired children's vision. Nothing fancy, but our home was a place of nurture, security, and love. I cherish the memories of my home when I was a little girl. I remember sitting on my father's lap as he read me stories, savoring my mother's yummy meals, playing with my siblings and puppies, and riding my three-wheel bike in the yard.



ACCESSIBLE HOMES

As a schoolgirl, I anticipated coming home to my family, who understood how visually-impaired children did things differently. Home was where I could spend hours on the phone talking to friends, including boyfriends when I was a teenager. In college, our home was a weekend destination after a week of rigorous academic work and living in the dorm in starvation. Later, as a young entrepreneur, the house would become my little schoolhouse, where I developed my skills as a young educational leader.

As I advanced in years, homes also shifted with changing roles, status, and locations. I can never forget moving into my husband's house in a city on top of a mountain, about 200 miles away from an older home. Their original family house crumbled after a catastrophic earthquake, so he built a makeshift house from materials he salvaged from the ruins of the building. Initially, I was thrilled with the fantasy of playing house, but that soon became a nightmare. The walls were sharp-edged metal sheets, and the creek beside the house had no safety ledges. All I could

think of was self-preservation. This precarious situation pushed my husband to build my dream house, one that accommodated our unique needs, as well as our vision for the family. That apartment building became the base for all our business ventures and was to be our retirement home.

Today, the pandemic expands our imagination of the uses of rooms and houses for multiple purposes. Homes are no longer just a place people retreat to after work, school, church, or a long, tiring day. Home is where you grind, learn, exercise daily, and worship weekly. The same home



HOME IS THE NEW WORKPLACE

September 2018 marked a breakthrough in my perception of the possibilities of home and career. Home businesses had always worked for me, but working from home in corporate America seemed foreign. Regardless, I transitioned into working from home, from a brick and mortar business setting to my residence. It was a win-win situation for a visually-impaired employee. I would gain my independence, not relying on someone to drive me to the office. I could use an extra four hours more for self-improvement because I wouldn't have to dress up,



WORKING SMART: The author's desk with laptop, Braille display, and noise cancelling headphones - a simple set up for people who are blind and working from home

must also be a haven where individuals and families get to bond with its members, rest and play.

Homes today have become like Transformer robots that conveniently turn into different forms.

pack lunch and snacks, and travel. Operating in the comfort of my own home would be less stressful; I could eat anything I wanted in my kitchen, and use my private restroom. I could even wear my comfy panda pajamas.



TECH CHECK: (Clockwise from top left) Chippy, a toddler with low vision, studying on an adjustable desk with integrated lamp; Chippy’s computer, a Chromebook with large print for people with low vision, has a keyboard labeled high contrast stickers to make typing easier; and the items on Jem’s desk show that people with low vision use more hardware and assistive peripherals.

It took months for our company to equip their visually-impaired employees to function at an optimum when working from home and making support and assistance accessible when needed. On my end, I had to set up an accessible office area and fix up our house so that I could conveniently run from my office to the restroom, kitchen, or anywhere I needed to go. Fortunately, we had a flex room over the garage. It was my exercise room, a graveyard for old furniture, and storage for things we hoarded.

DECLUTTERING

Truth is, we would have been wealthier if we hadn’t purchased all the things we hoarded. The first step to repurposing a room is decluttering. These days, my set up is simple. It consists of my laptop and Braille display on a sit-stand desk. There’s ample space for my water bottle and, more important, my snacks. Relying entirely on my hearing for information, I use noise-cancelling headphones. Under the desk is a basket of hygiene supplies and miscellaneous items. On the other side is a trash bin with a motion sensor. My ergonomic chair makes me feel like I’m the chief executive officer. But sitting through an eight-hour shift triggers sciatic nerve pain, so I stand on a gel pad periodically and adjust my desk height to comfort level.

“Homes are no longer just a place people retreat to after work, school, church, or a long, tiring day. Home is where you grind, learn, exercise daily, and worship weekly.”

During short breaks and one-hour lunchtimes, I rejuvenate my mind by rejoining my family, playing with my dog, or doing chores. As my activities are timed, easy and quick access to and from the office is essential. My husband, whose passion is decorating, once lined the walls of our house with ornamental plants, jars, and a credenza. I had hoped that I could safely and quickly trail around the house clutter-free, but the decorations made it quite difficult. When the battle is between aesthetics and accessibility, the deciding factors are purpose and priority; in other words, my employment and safety. So, my husband eventually made a sacrifice by removing his precious decorations along the wall—so I can securely glide across the house.

MY DAUGHTER’S WORK SPACE

A year later, my daughter got her foot in the door to the promising world of online English teaching. It was a perfect fit for Jem, an ambitious, visually-impaired, and fresh graduate, determined to further her education while working part-time. There was room for her in my office, size-wise, but setting up her work area entailed more labor. We went through a second round of decluttering, only this time, more painful since we needed to clear out a bigger space.



KITCHEN CONFIDENCE: (Clockwise from top left) In a well designed kitchen, under-the-counter lights aid people with low vision when preparing food; Induction stove technology puts an end to the safety hazard for people who are blind or visually-impaired when cooking. One can touch and even clean the stove while it's on and not get burned; "Clean" and "dirty" large print or Braille dishwasher signs for people with low vision or hearing impairment; and this special packaging with a sliding cutter makes cutting plastic wrap easy and neat.

People with low vision usually utilize more assistive hardware and peripherals for better perception, so she occupied the inner and more significant part of the room. A tall shelf borders our workstations, and we also installed a desk huge enough to accommodate two large monitors, a laptop, keyboard, mouse, and lamps. Since our accessibility configurations are so different, we laid out house rules to maintain a healthy work environment. Conditions included the following: things we needed, like remote controls for the AC and fans, were supposed to be returned to the designated area. She shouldn't move anything in my workstation, and I am technically restricted from her workstation since I might trip on wires or mess up her gadgets. Respect for our individual preferences and differing requirements resulted in productivity and harmony.

THE PANDEMIC THROWS A CURVEBALL

Thus far, we had a room dedicated as an office for my daughter and me, until the

pandemic threw a curveball. During the lockdown, my husband, too, had to work from home, and my son's classes were to be conducted online. Since all rooms were occupied, we decided to enclose my hus-

“We laid out house rules to maintain a healthy work environment. Respect for our individual preferences and differing requirements resulted in productivity and harmony.”

band's side of our bedroom and convert it to his office. On this third round of decluttering, shelves, books, gadgets, electronic devices were sold. My husband has a mobility impairment. He needed a wider walkway to his cubicle, more leg space

under the table, as well as an area where he can do stretching exercises when needed. Afflicted with carpal tunnel, he also needed the best ergonomic desk and keyboard to limit pain. He enjoyed his work station so much that it has become his man-cave.

The three office areas in our house are laid out differently and explicitly configured for the individual end-users. I'm blind, my daughter has low vision, and my husband is mobility impaired. Home office accessibility is the set-up that optimizes productivity, effectivity, and comfort, designed according to personal preferences, space, and household activities. There is no one-size-fits-all accessibility design according to differing disabilities.

Take, for example, a colleague who is also a blind, home-based employee. Although there's a spare room in his house he could use as his office, he chose to set up his workstation in his bedroom so he could roll out of bed and log in for work. If I were in his place, I'd probably stay in bed, clicking my snooze button all day, and work would turn out to be my worst nightmare.

THE BENEFITS OF WALLS OR GLASS DOORS

Installing glass doors or walls could be an option for home-based working mothers. They would benefit from a quiet environment while supervising a child with special needs participating in online classes. The structure could provide both the mother and child the reminder they need to perform their roles. This glass structure could also work well for people with hearing impairment who may feel isolated while working. An uninterrupted view of activities in the house through the glass wall could make one feel connected with the family. Cameras linked to apps on mobile devices or laptops might be a cheaper option if such devices could serve their purpose. For people with hearing impairment, I recommend early warning devices like security systems and smoke alarms to be always connected to their mobile devices.

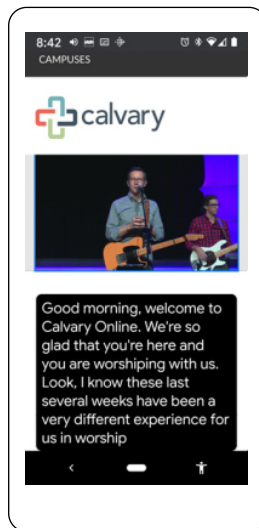
HOME IS THE NEW SCHOOL

After my daughter's graduation, my husband and I thought we were going to be empty nesters, but the pandemic brought our fledglings back home. However, living at home is one thing, and studying from home is another. One would assume that the kids would attend their virtual classes in their bedrooms, but that isn't the case with mine. The kids feel that sitting at a desk next to the bed while listening to a lecture would put them to sleep. Longing to be in a physical classroom environment, my daughter, my son, and his girlfriend take their laptops to the dining table where they study. What a perfect e-school, learning at your fingertips amidst co-learners, snacks within reach, and just a few steps away to the bedrooms.

For children with short attention spans, parents can schedule short breaks for them every few minutes depending on how long they can stay focused. Eliminating possible sources of distraction such as

THE GREAT EQUALIZER : TECHNOLOGY EXPANDS ACCESSIBILITY FOR PEOPLE WITH DIFFERING ABILITIES

New technology innovations have features that people with special needs can utilize to increase efficiency of homemakers, students or workers with disabilities.



DEVICE SQUAD: Developers are helping those impacted by the pandemic as well as those with differing abilities get their school and office work done. (Clockwise from top left) Zeb holds a phone with Live Transcribe, an app for people with hearing impairments that transcribes speech to text in real time; a large screen TV and a phone with the Chromecast application help people with low vision read textbooks; a screen capture of a live video of a church service; and Google Home Hub showing the time, an important convenience for people with low vision.

flashy lights, fancy decorations, or the TV could also be helpful. For accessibility purposes, often, less is more. If a child gets anxious or claustrophobic in a tight area, moving the desk next to a window might help. Parents may opt to set a screen or painting of nature, use aromatherapy, or play calming white noise in the background. The idea is to make their workspaces feel comfortable and enhance productivity.

HOME IS THE NEW CHURCH

As the lockdown included the closure of church buildings, worship services and activities were brought to the living rooms of homes through various digital platforms. Churches have grown in attendance more than ever before, and families have never been as united in participating in religious activities. People with hearing impairment mostly benefit from online church through the Live Caption app. According to Google, Live Caption is an impressive technology that you can use to create real-time captions for videos, podcasts, or even voice notes on your phone.

HOME IS THE NEW GYM

Isolation from the world outside is not an excuse for a sedentary lifestyle. Gyms are temporarily closed, but we can still find ways to stay active and healthy. I can't go to the gym regularly unless someone drives me, but I have exercise equipment at home that

I can access anytime. If buying equipment is not in your budget, there are various ways you can improvise. For example, you can go up and down a single step in your house the way you would on an aerobic stepper. Large laundry detergents with handles can be used as weights, or you can search for videos of home workouts that can be done in a small area. You can be creative about exercising at home for as long as it's safe.

CONCLUSION

Accessibility goes beyond the physical layout of the house. In the new norm, an accessible home also breaks distance, cultural, attitudinal, informational, and spiritual barriers. I encourage individuals to follow routines, respect spaces and seek resources, technology, materials, and services to achieve goals efficiently and cost-effectively. This way, family members can handle the demands of work, school, church, and gym – now relocated to what had typically been a living and entertainment space.

The truly fantastic thing about working or schooling from home is that obstacles that required special considerations in the classroom or office can be eliminated altogether. Those who are blind don't need orientation and mobility sessions, one-on-one instructions, or notetakers. For the hearing-impaired, interpreters could be replaced by close captioning or voice-to-

text technology. Moms can now actually sit in their children's classes and connect more with online communities for networking and additional resources.

Accessibility gives freedom, but it requires responsibility, a vision, and discipline. If we are accountable to ourselves before an educational institution or workplace, then liberty can thrive in our homes. Finally, accessibility in the home begins with the mindset that we are able, not disabled, so home is what we make it to be. •

HEARTSIGHT

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

PLEDGE TO SPREAD
INCLUSION! ON
SpreadTheWord.global

Inclusion
become a fan

SPREAD THE WORD INCLUSION
UNITED STATES OF AMERICA
Special Olympics

What You Can do if You are at Higher Risk of Severe Illness from COVID-19

Are You at Higher Risk for Severe Illness?



Based on what we know now, those at high-risk for severe illness from COVID-19 are:

- People aged 65 years and older
- People who live in a nursing home or long-term care facility

People of all ages with underlying medical conditions, particularly if not well controlled, including:

- People with chronic lung disease or moderate to severe asthma
- People who have serious heart conditions
- People who are immunocompromised
 - Many conditions can cause a person to be immunocompromised, including cancer treatment, smoking, bone marrow or organ transplantation, immune deficiencies, poorly controlled HIV or AIDS, and prolonged use of corticosteroids and other immune weakening medications.
- People with severe obesity (body mass index [BMI] of 40 or higher)
- People with diabetes
- People with chronic kidney disease undergoing dialysis
- People with liver disease

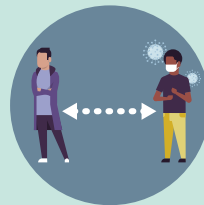
Here's What You Can do to Help Protect Yourself



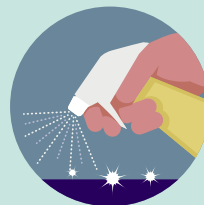
Stay home if possible.



Wash your hands often.



Avoid close contact (6 feet, which is about two arm lengths) with people who are sick.



Clean and disinfect frequently touched surfaces.



Avoid all cruise travel and non-essential air travel.

Call your healthcare professional if you are sick.

For more information on steps you can take to protect yourself, see CDC's [How to Protect Yourself](#).



cdc.gov/coronavirus



ACCESSIBLE HOMES



**Plan now for
your future by
incorporating
Universal
Design and
Aging-In-Place
ideas into your
home.**

UNIVERSAL DESIGN

TIPS FOR AGING IN PLACE IN YOUR OWN HOME

BY SUSAN BERRY

HOW DOES UNIVERSAL DESIGN HELP PEOPLE AGE IN PLACE IN THEIR OWN HOME?

At the beginning of the 21st century, those aged 65 or over made up five per cent of the population. Across the globe the number of those aged over 60 will nearly triple by 2050, rising to 2.4 billion, up from 894 million in 2010.

Universal Design is the principle of designing spaces for maximum usability for people living with disabilities, of varying size or limited mobility. There are no specific codes for Universal Design. There are suggestions. Universal design is not law, it is a way of viewing how things work in our world. These design principles compensate for a reduced range of motion, reduced sight, reduced sound and reduced strength. Many universal design inventions were originally developed for military use.

Universal design solutions make life easier for people with mobility, agility, balance and coordination differences. Successful

universal design creates a barrier-free living environment.

Since no two individuals are alike, no code solves every situation. Everyone needs to be their own advocate for their individual abilities and aging in place. Homes must be designed for the individual user's unique capabilities. There is no "one size fits all" solution. Children grow and adults change.

Consider designing your next home with the future in mind. When selecting a designer for a home where you intend to "Age-In-Place," find one who listens to YOU. There are many CAPS certified designers and builders, but not all of them are looking at the individual's needs. Explore options and solutions. Create a design that gives you maximum ability within the constraints of your budget. Strive for safety. When people feel safe in their home, they gain self-confidence and increase independence.

Design Smart Solutions, with 30+ years in the architectural design industry, knows that great design solutions are limitless.

WHAT IS THE DIFFERENCE BETWEEN UNIVERSAL DESIGN AND ADA, THE AMERICAN DISABILITIES ACT?

The American Disabilities Act provides legal guidelines for designing public buildings and space that accommodate the disabled. The guidelines are a minimum standard based on the general population.

Universal Design is not law. It is a free-thinking way of creating design solutions to address individual challenges. Universal Design

and Ease of Use design decisions can ease the transition as we age or suffer from injuries affecting our mobility.

None of us want to admit that someday we will be old and our bodies will not be as quick, our eyes not as focused and our reflexes not as sharp. The home we live in and our reaction to it will change.

Our homes will either enhance our ability to live by our own choices or force us to move. By planning ahead during construction, with a few Universal Design tips, we can all extend the time we remain in our own homes.

DOORS, WINDOWS AND HALLWAYS

1. Have a covered outdoor entryway.
2. Allow space for a future ramp.
3. Minimize the front threshold.
4. Make sure that there is at least one step-free entry into the home with easy access to the driveway
5. Install 3'-0" wide doors with lever door knobs throughout the house.
6. Do not block doorways.
7. Consider a 3'-0" out-swinging or 6'-0" sliding glass exterior door in a downstairs Accessible Guest Suite for easy emergency medical support access.
8. Consider 3'-0" pocketing doors or 6'-0" bi-pass doors on closets.
9. Make all Hallways a minimum of 5'-0" wide and use the extra space for book shelves, a computer desk, or display furniture until a time when you need the additional access space.
10. Make sure that windows are easy to open and easy to lock.
11. Install towel bars that are rated as pull bars.
12. Install 48" high robe hook and towel bars near the shower.
13. Consider towel bars that are also grab bars.
14. Install a shower curtain rod or create an open shower area. Avoid tight glass shower enclosures.
15. Create a shower without a step.
16. Install a comfortable seat in the shower.
17. Install soap and shampoo niches near the shower seat.
18. Install a hand held shower that mounts on a slide bar.
19. Consider installing a blow-drying machine to dry your entire body.
20. Check the size of a step in bath tub with the door that closes after you enter the tub. Many people do not like having to sit in the tub while it fills and then again while it drains.
21. Add an instant hot water heater by your bathroom.
22. Install lever faucets at sinks with pull out sprayers.
23. Consider a heat lamp if you chill easily.
24. Consider radiant floors for heat
25. Add a large linen closet with a 3'-0" wide door in the bathroom for large towels and personal products.



BATHROOMS

1. Have the Builder put wood bracing behind the drywall and tile in the bathroom walls for future grab bar locations.
2. On the first floor, have a roll-in curbless shower without a step or lip (slope floor to drain in at least one bathroom).
3. This shower should be a minimum of 5'-0" wide by 4'-0" deep.
4. This shower could be located near a Guest Suite or used as the Pool Bath.
5. Consider multiple shower heads.
6. Have a hand held shower head mounted on a slide bar, with a separate valve to control it from a seated position.
7. Install lever faucets in this bathroom and an adjustable handheld shower head. Do the closed fist test, by seeing if you can turn the water on and off with a closed fist.
8. Provide a toilet in the same bathroom with a 3'-0" clear empty space next to it for transferring.
9. Install comfort level toilets for ease of use.
10. Install a bidet if you have space.



FLOORS, STEPS AND STAIRS

1. Select slip-resistant flooring that is comfortable.
2. Limit stairs. Design stairs wide enough to fit a future chair lift.
3. Consider building a 5 x 5 closet on the first floor with a 5 x 5 closet above, for a future elevator.
4. Minimize changes in floor level throughout the home and outdoor spaces.
5. Anywhere that there is a step-down, select two different colors of flooring material.
6. Minimize any step down to the garage. Provide enough clear floor space for a future ramp.
7. Make sure that there is adequate space in the garage to maneuver a wheelchair with an assistant around a parked vehicle.
8. Add extra lighting to the Garage for maximum visibility.
9. If you need to walk through a laundry room to access the garage, make sure that it is large enough for both a wheelchair to turn around in and clothes hampers on the floor.



KITCHEN & LAUNDRY

1. Create work areas in the kitchen.
2. Install pull out racks and drawers in base cabinets.
3. Keep everyday storage at waist level.
4. Install dishwasher drawers.
5. Add a 9" high kick plate under a standard size dishwasher.
6. Install a Microwave drawer.
7. Add under counter safety lighting.
8. Bring outlets to the front of the cabinets for easy reach.
9. Leave a minimum of 48" clearance between surfaces in kitchen aisles.
10. Buy a front-loading washer and dryer set and mount them on a pedestal.
11. Consider an adjustable height sink that raises and lowers at the push of a button.
12. Consider an adjustable height range that raises and lowers at the push of a button.
13. Buy a side by side refrigerator freezer.
14. Provide a pull out shelf below a wall oven door.
15. Use "D" shape cabinet pull handles.
16. Have multi-level countertops for different tasks.
17. Use light colored countertops to make items easier to see.
18. Use easy slide and close drawers.
19. Use a 3'-0" pocket door on the pantry.
20. Mount wall ovens at a height where they can be reached from a seated position.
21. Add an instant hot water faucet at the sink.
22. Install a pull-out flexible faucet at the kitchen sink and laundry sink.
23. Select lever faucets.
24. Locate the faucets to the side of the sink for easier reach.
25. Put lockable caster wheels on a kitchen island for flexible space.



LIGHTING AND ELECTRICAL

1. Automate Lighting Systems.
2. Maximize natural light.
3. Locate extra security system and lighting controls in the rooms where you plan to spend most of your time.
4. Install adequate lighting throughout the home for safety and visibility.
5. Locate electrical service boxes, security boxes, main water disconnect valve and any system controls that you might need to access in an emergency, where they can be comfortably reached from a sitting position. 42" to 48" off of the floor.
6. Make sure that the thermostat is not higher than 48" off the floor.
7. Make sure that electrical outlets are 18" to 24" off of the floor.
8. Make sure that all switches are easy to reach from a seated position.
9. Consider easy touch lighting and electrical switches.
10. Install task lighting in all areas.
11. Make sure that kitchen some electrical outlets can be reached from a seated position.
12. Install flood lights equipped with timers on all corners of the outside of the house. Have them on timers.



(Reprinted from DisabilitySmartSolutions.com with permission from the author.)

ABOUT THE AUTHOR:

Susan Berry of Disability Smart Solutions is an architecture graduate, NCIDQ Nationally Certified Interior Designer, NCBDC Nationally Certified Building Designer, and an International Code Council Certified Accessibility Inspector and Plans Examiner, along with her 30+ years in the Florida construction industry, she knows accessibility. Email: info@DisabilitySmartSolutions.com

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.

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

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

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

LJS FAC/X, Inc.
430 Commerce Blvd, Unit C
Carlstadt, NJ 07072



LJS FAC/X, INC. | 430 COMMERCE BLVD, UNIT C | CARLSTADT, NJ 07072 | 201-777-6610

COMPETENT ■ PROFESSIONAL ■ COMPASSIONATE





CREATING ACCESSIBLE HOME BATHROOMS FOR CHILDREN

BY BECKY WRIGHT

The conversion of a home bathroom to an accessible bathroom can be a huge challenge for a family, both logistically and financially. When making bathroom accommodations for a child with disabilities, it is important to consider the age and size of the child. Using a smaller toilet, sink and shower seat may be the best option.

If there is an option, modifying a first-floor bathroom will allow for easy access on a daily basis. Creativity in the design process may be required especially if your home is older. An interior designer with experience in Universal Design is able to offer suggestions and recommendations for a highly functional bathroom that allows for accessibility for people with mobility challenges. If you seek assistance with Universal Design, contact your local bath showroom or an experienced home remodeler.

Most accessible toilets, sinks and showers are designed for an adult-sized person and they are installed at a height that works for adults. This can make it complicated for children to use the bathroom successfully. It is a much more pleasant personal care experience for children when toilets and sinks are the proper size and installed at the correct height for someone small.

Child-sized toilets have rims that are 10 to 12 inches from the floor making them much easier for young children (age 2 to 7) to use on their own. Toilets can be purchased from both on-line or bathroom showroom suppliers. Before selecting a small, child-sized toilet for your home, determine what rough in plumbing is in place, to do this, measure from the back wall to the center of the floor hole. Rough in can range from 10 to 16 inches but the typical rough in is about 12 inches from wall to hole center.

A standard height toilet will measure 14 to 15 inches from floor to bowl rim. In older homes, this is likely to be the toilet height if a remodel hasn't happened in recent years. The standard height toilet is appropriate for older children who are age 7 to 12 and for shorter teens and adults. Usually when purchasing any size new toilet the toilet seat is sold separately. The toilet seat selected can add varying heights to the toilet but will usually add about 1 inch.

The comfort height toilets that are now available are taller than a standard height unit and will measure 17 to 19 inches from floor to rim. These work well for adults, very tall individuals or older people since they make sitting down and getting up easier. The comfort height toilet is designed to be the same sitting height as a regular chair.

ONE SIZE DOESN'T FIT ALL: (Above) It is a much more pleasant personal care experience for children when toilets and sinks are the proper size and installed at the correct height for someone small.

Finally, there are elevated toilets used by those who have a hard time getting up and down. These are often raised toilet seats that are installed on standard or comfort height toilets and add 3 to 4 inches to the height of the seat. Elevated toilet seats are also available with arms to give an added sense of security. For a child that needs a parent to help them transfer from a wheelchair to the toilet, having the highest seat possible makes it easier for the parent, especially as the child gets older and is less likely to result in caregiver injury.

In addition to floor mount toilets there are also wall-hung toilets that have the plumbing and flange on the wall rather than the floor. A wall-hung toilet can be easier to clean around since a mop is able to get everywhere under the unit. There can be weight restrictions on wall-hung toilets so be sure to confirm everyone who will be using the toilet is within the guidelines.

If adding a child-sized toilet to your bathroom, consider adding a child-sized sink as well. Pedestal and wall-mount sinks are available in smaller sizes to accommodate young children. A standard pedestal sink is usually 33 to 35 inches high. The smaller child-sized version is 20 to 22 inches high. The down-side to having a pedestal sink is the loss of storage in the bathroom but the advantage is there is more floor space and easier access. To prevent burns and injuries, insulate the hot-water and drain pipes under a wall mount or pedestal sink.

A child using a wheelchair may need to have the standard height sink with the

open access under the sink found in a wall-mount or pedestal unit to accommodate the wheelchair rolling close enough. There are wall-mount sinks available that offer curved fronts that will allow a child (or

The basic ADA guidelines are based on adult dimensions, but there are alternate guidelines based on children's dimensions. The ADA guidelines don't work for everyone, especially children and individuals who are shorter or taller than "average."

adult) using a wheelchair to get closer to the faucet. There are also sinks available with hand pulls in the front (a grab bar that is part of the sink) that allow an individual using a wheelchair to maneuver easily.

Many practical changes that are used for seniors, who are Aging-In-Place, can also be used when modifying a home for a child with a disability. Lever handles on doors and levered faucets are easier to use and require less strength to operate. Tile and hardwood floors are easier to navigate than carpet and area rugs. Installing handrails on both sides of steps assists with going up and down. Adding motion sensor lighting, especially in walkways and stairs within the home will make a safer environment for everyone living there.

When a child is very small it is not too difficult to bathe them, however, as they get older it is important to have a bathroom layout that will allow for easy access to the shower or tub. A roll-in shower for children in a wheelchair or a walk-in shower without barriers will make self-care easier as a child

ages and grows. If a child is able to step over the side of a bathtub, then adding a wall mount bathtub seat provides an added level of security. Using a shower curtain rather than a shower door will make caregiver

access easier when assistance is needed.

Another bathroom safety product that can be adapted for children is the shower seat. The shower seat is usually mounted at the same height as the toilet seat, so for adults that would be most comfortable in the 15 to 19 inch range. For children the recommended height would be 10 to 15 inches, keeping in mind a child will feel safer and less likely to slip off a wet seat, if their feet can touch the shower floor while seated.

Showers and bathtubs should have grab bars installed to assist with both entering and exiting. Vertical grab bars in showers are best if standing and balance are issues. Using a vertical grab bar can be easier if strength in wrists, elbows and shoulders is an issue. There are rounded grab bars that can be installed around the faucet. Hand-held shower holders on vertical grab bars can be adjusted and lowered so children can reach the shower head on their own. Additional horizontal shower grab bars are great for storing and easy access to shampoo, washcloth and other bathing supplies.

Grab bars come in many finishes and designs. Especially when being used in a private home, grab bars do not need to look institutional. There are many attractive options available, including colored vinyl and painted finish grab bars that work great and look fabulous in a home. Selecting a contrasting color makes it easier for anyone with any visual impairment to see the grab bar. Grab bars should measure 1 ¼ to 1 ½ inches in diameter so they are easy to grip. The smaller size 1 ¼ inch diameter grab bar will be easier for a child to hold on to. When mounted, there should be 1 ½ inches of clear space between the grab bar and the wall. Do not install a towel bar to do the work of a grab bar, towel bars are decorative and do not offer the same strength and durability of a grab bar.



Placement of grab bars around a toilet area should be at a comfortable height for the user. For example, a young child may find grab bars work best when at a lower height than an adult would use. Most frequently, grab bars are placed on one or both sides of the toilet, behind and above the tank, on a wall directly in front of the toilet and above the toilet paper holder.

When there is a caregiver assisting with toileting, including additional grab bars where the caregiver might need to balance or brace themselves may be beneficial as well.



FINDING ANSWERS: Today, parents who have a child with a disability have much greater access to information on the internet than Kathy had when Lexi was younger.

when Lexi was younger. Networking and connecting with other parents, physical therapists, and the resources at Special Olympics were very helpful for Kathy; she says “parents were really on their own for finding answers.” When Lexi was small, Kathy was able to carry her, but by the time Lexi was 10 years old it became too much of a physical challenge for Kathy and they installed a roll-in shower with a rubber lip for Lexi’s shower chair. Kathy states that she learned to look at everything in her home differently, “everything must be at a level your child can use, things like towel bars should be lower and for my daughter the sink needed to be higher.”

Kathy states, “Installing a taller toilet and elevated toilet seat would have been easiest for me as the caregiver because Lexi requires assistance with all physical moves. But I hadn’t thought of that and we managed with just a normal height toilet.” Today, Lexi lives in an adult group home.

When doing a home remodel it is not necessary to follow the guidelines of the Americans with Disabilities Act (ADA) which was signed into law in 1990. The law was enacted to insure the civil rights of individuals with disabilities and established guidelines for creating a barrier-free environment for everyone in public buildings and bathrooms. The basic ADA guidelines are based on adult dimensions, but there are alternate guidelines based on children’s dimensions.

The ADA guidelines don’t work for everyone, especially children and individuals who are shorter or taller than “average.”

In summary, here are some tips for making the home bathroom more user friendly for children:

1. *Install smaller, child-sized toilets, 10 to 12 inches in height from floor to rim, either floor mount or wall-hung models are available.*
2. *Transition toilet height as children age and grow to make accessibility easier for them. Standard toilets are 14 to 15 inches from floor to rim. Comfort height toilets are 17 to 19 inches and are easiest for adults to use. Finally, installing an elevated seat, which can be attached to any toilet, will add 3 to 4 inches.*
3. *Install grab bars at the height most comfortable for users.*
4. *Smaller sinks that measure 20 to 22 inches high are easier for children to use.*
5. *Install shower seats at child height of 10 to 15 inches so children feel safe.*
6. *Never install a towel bar to do the work of a grab bar.*
7. *All accommodations should be made to address the specific needs of the child. •*



ATTENTION GRABBER

Colored vinyl and painted finish grab bars work great and look fabulous in a home. Selecting a contrasting color makes it easier for anyone with any visual impairment to see the grab bar.

Kathy Wu of Janesville, Wisconsin has made bathroom accommodations to their home over the years to assist daughter Alexis Horne, now age 30, who has Cerebral Palsy. When Lexi was younger and began using a wheelchair they faced challenges because the chair would not fit into the bathroom with normal sized doors. The family remodeled and removed a closet, flipped and raised the sink and widened the door to 36 inches to allow Lexi access to the bathroom.

Today parents who have a child with a disability have much greater access to information on the internet than Kathy had

ABOUT THE AUTHOR:



Becky Wright is the Division Manager for Showrooms at Ponte Giulio USA, a manufacturer of bathroom safety and accessibility products. She is the author of nine educational games and activities including Bullying & Harassment Situation Cards. She lives in Janesville, Wisconsin. She can be reached at becky.wright@PonteGiulioUSA.com

INNOVATION AT NEW HEIGHTS

Public safety, government and commercial applications throughout the world



LAW ENFORCEMENT



FIRE FIGHTERS (SEARCH & RESCUE)



U.S. INDUSTRY



U.S. GOVERNMENT




DRONE USA™

INNOVATION AT NEW HEIGHTS

**DRONE USA IS YOUR COMPLETE ONE STOP
SHOP FOR ALL YOUR DRONE NEEDS.**

Our Difference that Matters:

We sell high quality drones, counter-drone technology, pilot training and custom designed drone programs to **U.S. Law Enforcement, Firemen, U.S. Industry** and to the **U.S. Government**. Our competitive advantage stems from our **Three Pillars of Excellence:**

1

We respond immediately to our customers' needs.

2

We provide our customers with drone products, training and services that greatly improve their job performance.

3

We establish and nurture life-long customer friendships.

DRONE USA is dedicated to providing cutting-edge technology to those who protect and serve all members of our communities, particularly those with special medical, mental or psychological needs and their caregivers.

16 HAMILTON STREET, WEST HAVEN, CT 06516
(203) 220-2296 • INFO@DRONEUSAINC.COM
WWW.DRONEUSAINC.COM

TRAVEL TWISTS

BY JEM LLANES MABALOT



If you're a person with special needs like I am and would like to chase your dream, I urge you to challenge your limitations. Face them head-on and focus on your strengths rather than your weaknesses. Only then will you find the door to a much bigger, more colorful world full of wacky events and rich with learning.

I have low vision, but I set my sights on travel. My dream is to experience the diverse cultures of the world. So, when I was in my junior year of college, I grabbed the opportunity to study abroad in Japan, one of my favorite countries. From day one of my study abroad, I faced not only language and cultural barriers, but also visual disability challenges. I was thrown into a multitude of situations, some scary, others humiliating, but mostly hilarious.





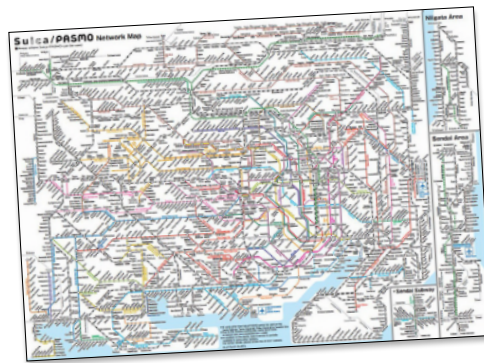
THE BUS

The hardest thing for me to learn in Japan was how to travel independently. I was forced to rely on friends to get around. For me, the bus system was difficult to get used to. The schedules are wacky. They're different on weekdays, weekends, and holidays, which are abundant in Japan. The bus numbers were tiny as ants, and there were no announcements that tell which bus is coming. Furthermore, the buses aren't always on schedule. On the bright side, onboard, there were automated announcements for every stop, a minute before arrival.

One evening, I rode the wrong bus getting home from school. I somehow ended up getting off in the middle of nowhere. It didn't look like the suburbs that I knew, but a rice field area with zero lighting. Initially, I thought I was alone, until some funky animals greeted me with hungry noises. Luckily, I had enough charge and data for Google maps on my phone.

I treaded across an open field using my phone as my flashlight and guide. I felt like the star of *Man vs Wild*, except the wild won a hundred to zero. I wished I had paid attention to my O&M (orientation and mobility) trainer in high school, instead of challenging my blind friend to a cane sword duel during our rural training. Boy, would that have been useful. After two long hours of walking, I finally found myself back in civilization. Actually, two police officers found me. They led me in the right direction and away from a dangerous construction

site. Woo! My exciting adventure was finally over, and I was still alive. From then on, I became cautious about taking the bus. I planned to go to my stop early and opted not to ride a bus if I wasn't confident where it would go. More important, I always remembered to bring extra portable chargers for my pocket Wi-Fi and phone in case I got caught up in another Indiana Jones mini adventure.



THE JOURNEY BEGINS: (*Opposite page*) The author visits Kyoto; (*Above, left to right*) Osaka Castle is certainly one of the most famous landmarks in Japan with a history that dates back almost 450 years; The Meiji Jingu Shrine features a huge collection of sake barrels, which the sign illuminates; (*Inset*) and the bewildering public transport map of Tokyo, the largest metro in the world serving 38 million people.

THE TRAIN

Catching the right bus was like playing darts, but navigating around by train was akin to finding a way out of a labyrinth. I noticed that even some sighted people, both foreigners and locals, found the rail system confusing. Thing is, you need to identify your route and buy the ticket for it. But, the different routes on maps, coded with all colors imaginable, were muddled into one another like a rainbow of chaos.

"Did they really want to sell tickets?" I wondered.

I felt doomed! Desperate to gain independence, I scoured around for a solution. Eventually, I discovered that majority of locals don't buy tickets, they use prepaid IC (integrated circuits) cards to pay for public transport fares. I immediately joined the bandwagon and got an ICOCA, Western Japan's brand of IC card.

Sayonara to frustrating ticket purchases and confusing maps!

Fortunately for me, Japan's rail system turned out to be accessible for the visually impaired. Trains are distinguishable by line and always arrive precisely on schedule. The structure saved me the



horror of hopping on the wrong train, as long as I was on the right platform. A lifesaver, Google Maps told me which train to take, in which platform, at what time, down to the last minute. Announcements in Japanese and English informed passengers which train was arriving on the platform, and which stop the train would arrive at when onboard. All I needed was my ICOCA, Google Maps, and lots of courage. One day, I conducted an experiment. I blindly hopped on a couple trains and got off on random stops. Voila, I found my way back home! Of course, I rewarded myself with takoyaki (baked octopus ball). Since then, I was able to go anywhere I wanted and explore places alone.

▲ TRIP TO THE DRUG STORE

Usually, Japanese characters have too many strokes clumped together, and I would just see the blurry blocks and lines on signs from afar. So, I would take photos of signs and labels to zoom in and be able to read them up close. This became my modus operandi to get by daily. Locals are used to seeing tourists taking shots and admiring their photos of attractions like Fushimi Inari, Osaka Castle, or of Instagram-worthy meals. I, on the other hand, was the weirdo that took random pictures of products in stores. I wondered what people thought when they saw me happily staring at a photo of two-for-50 percent-off beef on my iPhone 6s plus, as if I'd discovered a new attraction. Hey, it was a good deal!



GETTING THERE: (Above, left to right) The metro system can be daunting at first, but with a prepaid ICOCA card and Google maps, traveling around the city is viable for even those with disabilities; Takoyaki, or octopus balls are a delicious reward for learning how to navigate the train system; (Inset) The ICOCA has an integrated circuit that tracks usage at the stations.

At a drug store, I discretely took pictures of different products in search of aromatic bath salts. A store clerk noticed my struggle and approached me to help out. I hadn't found a picture of the product, and I didn't know how to say "bath salts". Distressed, I quickly looked up the translation on my phone. As luck would have it, the dictionary didn't have an accurate translation. I did my best to explain what I wanted in my limited Japanese, but to no avail. So, the store clerk and I started playing numerous rounds of awkward charades. "Bath salts," I repeated in both English and Japanese pronunciations. The clerk watched closely as I theatrically enacted myself using bath salts in the tub. I felt like we were performing a Dumb and Dumber skit. Forget about saving face. I was past the point of embarrassment and was determined to get a good soak that night. Finally, I showed him a picture of bath salts.

His face lit up and eagerly shouted, "Ah benpi." I didn't know what the word meant at the time. But, pretentious, I played along and enthusiastically said, "Yes, yes!" I was hoping to get a box of bath salts. Low and behold, he proudly surprised me with a box of constipation medicine. I was mortified. In a desperate attempt to end my torture, he frantically called the manager. Now, we were Dumb, Dumber, and Dumbest. Miraculously, after a good while, the manager pieced the puzzle together. Finally, I got what I wanted! Never did I forget the words for "constipation" and "bath salts" in Japanese ever since.



MY FIRST DAY OF INTERNSHIP

I rely on Google Maps to go places, but, sometimes, it throws me off and into a mystery adventure. On normal days, I would have enjoyed the detour. But not on my first day of internship! My internship was at a school, in a town close to where I lived. I visited the school only once, and I vaguely recalled the way there. As always, I typed the address onto Google. Initially, the route looked familiar, and I passed the 7-Eleven I designated as a landmark. I was on the phone with my worried mother, but I assured her I could find my way around the area. Soon, I saw the front gates of a school building with familiar characters written on the sign. I felt relieved to arrive early, unusually early.

I entered the school. A tall and handsome teacher welcomed me. I felt excited to work with a good-looking young man. He volunteered to help me locate my shoe locker while I tried to flirt with him. My advances were cut short when we couldn't find my locker. I followed the man to the teachers' room, my shoes on hand. The man asked the other teachers for my desk space, name tag, and schedule.

Shortly after the teachers started searching, I suddenly heard them panicking, yelling out in Japanese exclamations and saying, "Eh, what do you mean?"

The handsome man explained the situation to the principal. "This is Katano School. Your school is Katanoshi School," she informed me, cackling.

After that, I didn't know which was louder, my mother's hysterical laughter piercing through my earphone, or the principal's howling that reverberated in the room. I couldn't believe I went to the wrong place! Fortunately, the principal was kind enough to take me to the right school. The rest of the day went well, except for my disappointment that I didn't get to work with the handsome teacher.

So much for abiding by the Japanese code to not trouble others. I was reminded that day to always be cognizant of my surroundings and to double-check the route for my destination.



TAKING IT IN: (Above, left to right) Takarazuka is a city known for its hot springs and its all-female Takarazuka Revue, both of which are now the main draw for visitors; The lively Dotonbori area is renowned for its gaudy neon lights, extravagant signage, and the enormous variety of restaurants and bars. (Inset) Dotonbori at night.

MY INTERNATIONAL FLIGHT EXPERIENCE

Before flying abroad, my mother advised me to acquire wheelchair service because the airlines didn't provide sighted guides. It seemed like a good idea at the time. I wanted a smooth, predictable, on schedule flight to Osaka. I was fine being wheeled away to my plane in New York. When I asked to walk alongside the airport staff, they let me. When I wanted to sit back down, I could. The JFK staff even offered to take me to my desired meal stop and shops. Onboard my domestic connection flight, I was well taken care of,

and they let me sit on my favorite spot, the window seat, in an empty row. But as soon as I left New York, my situation became disastrous.

My flight to China, the next stopover, was terrible. They gave me a window seat, beside two annoying old men who were bantering

with each other in Chinese. Passengers were prohibited from opening the window shades or using their phones, even on airplane mode during the flight. I was stuck for 14 hours, irked by the two men yapping away, gazing at the closed window shade, or staring blankly at my tiny PTV (personal TV), which I couldn't see nor use. My only relief was the bathroom, mealtime, and sleep, of which I didn't get much.

Exhausted from the flight, I wanted to walk to stretch my legs, but they didn't let me off the wheelchair. *Grrrrr!* I was livid. Placing my hands on my hips, I felt a medicine bottle in my jacket pocket. My anger instantly turned to fear. It was Tylenol. My mom slipped it in for my chronic headaches, which I often get on planes. Japan didn't allow a certain dosage of Tylenol in their borders. I knew the bottle had to go before leaving the airport. But I also didn't know the restrictions in China, and I was terrified.

"Can I go to the restroom?" I asked the wheelchair lady, hoping to ditch the bottle. She responded in broken English, "Sorry, wait please. Bathroom after check." Scenarios of me being questioned by the Chinese government flashed in my imagi-

nation. Luckily, I saw a trashcan on the way. "This is my only chance," I thought.

"If this doesn't shoot, I'm dead." I wrapped the bottle with a used tissue inside my pocket and nonchalantly threw it. I never found out if the bottle went in or not, but the lady continued to wheel me to check-in. The Tylenol was gone, but my anxiety wasn't. Needing to vent, I tried opening Facebook to post my experience after check-in. Facebook wouldn't load. The great firewall of China blocked the app. The good news is, I made it to Japan safely, but I swore to myself that I would never take the same airline and stopover.

My trip back home was more bearable than my trip to Japan. I didn't have to use a wheelchair because Kansai airport provided sighted guides. The flight to America was peaceful.

FINAL THOUGHTS

As I look back on this part of my life, I feel a sense of accomplishment from overcoming barriers, even though, at that time, some of my experiences were unsettling. I learned to be stronger and independent by stepping out of my comfort zone. I don't regret a single moment, and I would gladly

snatch the chance to go through more life-changing travels to broaden my view of the world.

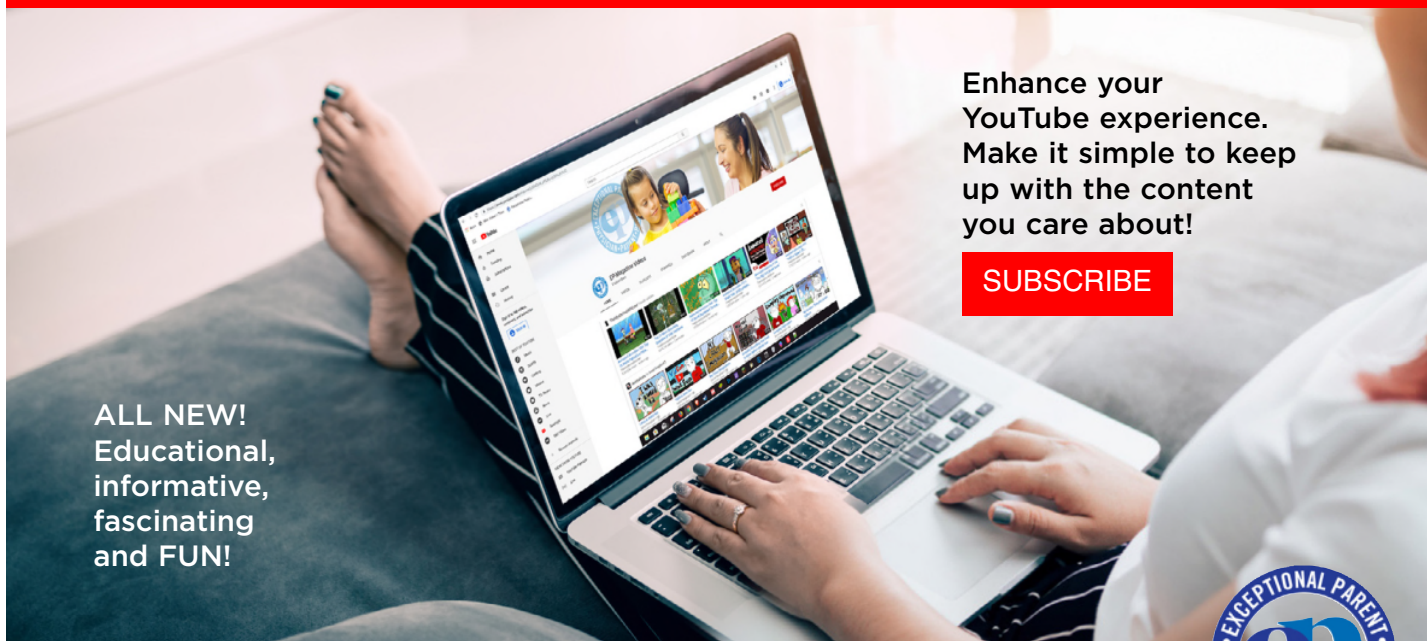
If you're a person with special needs like I am and would like to chase your dream, I urge you to challenge your limitations. Face them head-on and focus on your strengths rather than your weaknesses. Only then will you find the door to a much bigger, more colorful world full of wacky events and rich with learning. •

ABOUT THE AUTHOR:



Jem Mabalot, born with aniridia and legally blind, is a fresh graduate of the College of Charleston with a B.A. in International Studies. Her passion is teaching the youth and learning languages such as Japanese, Korean, and Chinese. She loves exploring different cultures and wants to be a media influencer to inspire and lead the youth from different backgrounds and abilities to pursue their dream. Her calling is to establish a nonprofit organization for talent development and empowerment for children in Asia. Currently, she is teaching ESL online and working on her Certificate in Teaching English to Speakers of Other Languages (CELTA). She is planning to launch her YouTube channel soon. •

EP MAGAZINE'S YouTube CHANNEL IS NOW ONLINE!



ALL NEW!
Educational,
informative,
fascinating
and FUN!

Enhance your
YouTube experience.
Make it simple to keep
up with the content
you care about!

SUBSCRIBE

EP Magazine recently launched its all-new YouTube channel – access it [here](#). This new platform provides practical advice, emotional support, and the most up-to-date educational information for families of children and adults with disabilities and special healthcare needs. Subscribe today!



STOP THE SPREAD OF GERMS

Help prevent the spread of respiratory diseases like COVID-19.

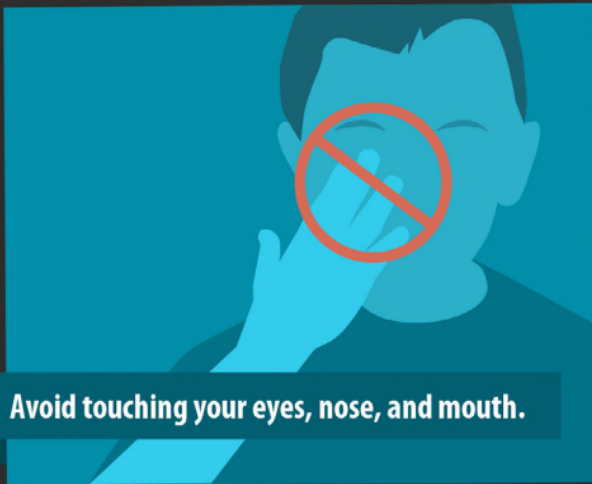
Avoid close contact with people who are sick.



Cover your cough or sneeze with a tissue, then throw the tissue in the trash.



Avoid touching your eyes, nose, and mouth.



Clean and disinfect frequently touched objects and surfaces.



Stay home when you are sick, except to get medical care.



Wash your hands often with soap and water for at least 20 seconds.



For more information: www.cdc.gov/COVID19

COVID-19 & ADULTS WITH INTELLECTUAL DISABILITY, AUTISM, EPILEPSY, OR BRAIN INJURIES

FINDINGS FROM AN ONLINE SURVEY

BY CHARLES E. DRUM, MPA, JD, PHD., ANTHONY OBERG, MA, JACOB DITSCH, OTD, KARL COOPER, JD AND ROBERTA CARLIN, MS, MA, JD

INTRODUCTION

People with disabilities, including persons with intellectual and developmental disabilities (IDD), experience unique risks during emergencies, disasters, epidemics, and pandemics that can impact health and health care (White, 2009). Yet, little is known about the full impact of COVID-19 on people with disabilities. The American Association on Health and Disability (AAHD) conducted the COVID-19 & Disability Online Survey to obtain rapid, real-time information on the coronavirus pandemic's impact on adults with a range of disabilities. We used four of the American Community Survey's disability identifiers (Vision, Hearing, Mobility, Difficulty Concentrating, Remembering or Making Decisions). Respondents could also identify if an intellectual disability, autism, epilepsy, or brain injury was the underlying condition that caused the difficulty concentrating, remembering, or making decisions (other response options were available, too).

METHODOLOGY

Existing COVID-19 surveys were reviewed and items were either modified or new ones created. Items included demographic questions (disability identifiers, gender, ethnicity, race, geographic area, and type of health insurance), questions on COVID-19 information and impact and access to regular (non-COVID-19) health care and services. Survey responses were solicited through AAHD's dissemination networks and through existing partnerships. The survey was available online from April 17, 2020, until May 1, 2020.

RESULTS

This article summarizes results from a report that focused on respondents with an intellectual disability, autism, epilepsy, or brain injuries. Additional reports by different disability types and a summary report are also available. Survey completion rates varied by item, ranging from a low of 88% to 100%, with an overall completion rate of 94% (exclusive of skip patterns). Descriptive statistical results are summarized below.

DEMOGRAPHICS

Out of a total of 2,469 respondents, 930 reported experiencing serious difficulties concentrating, remembering, or making decisions due to an intellectual disability, autism, epilepsy, or brain injury (38%). The majority of the respondents were 18-44 (80%), followed by adults that were 45-64 (18%), and adults 65 and older (2%). The majority of adult respondents were either Female (59%) or Male (37%). The sample was primarily White (79%), followed by Black or African-American (11%), Hispanic (5%), Asian (4%), American Indian or Alaska Native (2%), and Native Hawaiian or Other Pacific Islander (0%). Respondents selected their location as Urban (19%), Suburban (57%), Rural (23%), or Frontier (0%). Respondents reported having Medicaid/CHIP (68%), Medicare (40%), Private Insurance (31%), VA/Government insurance (6%), and Other (5%), although respondents could select "all that apply." One percent of respondents had no insurance.

COVID-19 INFORMATION SOURCES

Respondents were asked to rank their three most important sources of information about COVID-19 out of nine options. As displayed in Table 1, among the nine information sources, the three most important were Relatives (31%), Television (29%), and the Internet (15%). Respondents identified the Television (27%), the Internet (20%), and Relatives (14%) as the three second-

ABOUT AAHD



The mission of the American Association on Health and Disability (AAHD) is to promote the health and wellness of children and adults with disabilities and reduce health disparities. AAHD achieves this by advocating for community inclusion and promoting full accessibility, integrating disability into the public health agenda, advancing disability research and knowledge translation, and conducting training and advocacy.



most important sources of information. Most respondents identified Television (15%), followed by Friends, Relatives, and Social Media (13%), as the third-most important source of information (See Table 1).

COVID-19 RECOMMENDATIONS & TESTING

Ninety-three percent of respondents reported following pandemic recommendations and 7% reported they were not following recommendations. Only 2% of respondents had received a test for COVID-19. Table 2 displays why respondents had not received a COVID-19 test. The largest percentage was among respondents who said they didn't need a test (84%), but the test being unavailable was the second largest percentage (12%). Respondents were able to identify multiple reasons. (See Table 2, next page)."

ANXIETY & DEPRESSION

Respondents who felt anxiety or depression because of COVID-19 were asked if they were able to access emotional support or services. Eighty percent of respondents reported having access to emotional support or services and 20% reported not having access.'

ACCESS TO DIRECT CARE WORKERS & REGULAR HEALTH CARE

Respondents were asked if they used a Direct Care Worker (e.g., Home Health Aide,

Personal Care Aide, or Unpaid Family Caregiver), if this care continued during the pandemic, and if respondents had been able to maintain a safe distance from their Direct Care Worker (e.g., six feet). Seventy-two percent of respondents received Direct Care Worker services and 76% of respondents continued to receive these services during the pandemic. But only 50% of respondents were able to maintain a safe distance from Direct Care Workers.

ACCESS TO REGULAR HEALTH CARE TREATMENT & PRESCRIPTIONS

Many persons with disabilities receive regular health care treatment such as physical therapy, dialysis, bloodwork, etc. Among respondents who needed regular health care, 56% reported access had been disrupted and 44% reported that access had not been compromised. Among respondents taking prescriptions, 98% reported that access had not been affected and 2% report-

ed access had been disrupted. Thirty-eight percent of respondents reported experiencing new challenges to accessing health care.

DISCUSSION

One of the limits of using a convenience sample is that results cannot be generalized to a larger population, although they can be informative for planning purposes and, in particular, assessments of health care quality (Bethell, et al, 2004). Below, we discuss observations about the survey results in relation to the sample.

COVID-19 Information & Impact:

Several important findings emerged from the information and impact survey questions. Relatives were an important COVID-19 information source whether as the most important, second-most important or third-most important source, as well as Television and, to slightly lesser extent, the Internet. This suggests an important role for parents and families in communicating information about the pandemic and how

Table 1. Most Important Sources of COVID-19 Information (N=849)

	HCP/HS	Internet	TV	Radio	Social Media	Print Media	Friends	Relatives	Other
Most Important	14%	15%	29%	0%	3%	2%	1%	31%	5%
Second Most Important	10%	20%	27%	4%	10%	4%	6%	14%	5%
Third Most Important	12%	12%	15%	6%	13%	8%	13%	13%	8%

public health and health care professionals need to be represented on television in order to provide credible information on how to respond to the pandemic.

Table 2. Reasons for Not Obtaining COVID-19 Test (N = 815)

Reason	Percentage
Didn't Need Test	84%
Test Was Unavailable	12%
Other	4%
Health Care Provider Would Not Approve Testing	4%
Lacked Transportation to Site	2%
Cost/Insurance Wouldn't Cover	2%
Information About Testing Not in Accessible Formats	2%
Site Was Physically Inaccessible	1%
Site Had No Accessible Parking	0%
Site Had No Sign Language Interpreters	0%

While several national polls report varying levels of endorsement for COVID-19 guidelines, this sample reported high levels of compliance with guidelines at 93%. This suggests that this sample is taking the risks of the coronavirus pandemic very seriously. Echoing national findings, only a small percentage (2%) of respondents had received a COVID-19 test. Of concern is that 12% of persons had not received a COVID-19 test because the test was unavailable and, to a lesser extent, that health care providers would not authorize the test (4%). These may become more acute issues (at least for this sample) as the impact of the pandemic continues over time. Similarly, although 66% of respondents were experiencing anxiety or depression as a result of the pandemic, 20% lacked access to emotional supports/services. Emotional issues could grow among other respondents over time as the pandemic continues and lack of services/supports may make these problems more acute.

Access to Regular Health Care & Services: A high proportion of the sample used Direct Care Worker services (72%). While a majority of respondents (76%) continued to receive these services during the pandemic, the loss of these services among 24% of the sample could contribute to major problems. Moreover, the lack of safe distancing among 50% of respondents could increase infection rates. Clearly, safeguarding information is needed by a substantial proportion of the sample.

Of concern is that 56% of respondents experienced disruptions in their regular health care treatment services during the coronavirus pandemic. Ensuring needed health care for the respondents is an important but challenging problem. In contrast, 98% of respondents taking medications reported that they could access their prescriptions. Yet, for the 2% of the sample who had prescription medication access disrupted, this represents a potentially life-threatening situation. Moreover, 38% of the sample reported experiencing new challenges to obtaining health care treatment, health care access, and/or prescriptions. In many ways, the novel coronavirus pandemic is presenting unfamiliar and unanticipated challenges for persons with and without disabilities. A key difference is that persons with disabilities already encounter documented disparities in accessing health care treatment and services (Krahn et al., 2015). A careful analysis of the open-ended responses describing the new barriers is underway.

Limitations: The findings in this report are subject to a number

of limitations. The sample is atypical from population-based disability samples on a number of dimensions. The overall sample includes a higher than typical proportion of persons with intellectual disability, autism, epilepsy, or brain injury (as the underlying condition contributing to DCRD), is younger, predominately female, White, and Suburban (47%), and has some type of insurance. The survey data are also self-reported and may be subject to reporting or recall bias. The responses represent a snap shot between April 17, 2020, until May 1, 2020, and the coronavirus pandemic situation has changed since these responses were given. Lack of internet access may bias the sample and persons with multiple disabilities may not be accurately identified since we asked for a person's "main" disability. Finally, because of the use of a convenience sample, the results are not generalizable to the overall population of persons with intellectual disability, autism, epilepsy, or brain injury.

CONCLUSION

The results of this survey provide insights into a moment in time during the coronavirus pandemic. The challenges revealed for this sample need to be examined with population-based research, and tracked over time. Moreover, the intricacies and changing dynamics of the pandemic establish a critical need for policy and programmatic responses to this extraordinary health and public health challenge.

Acknowledgements: Funding for this research was provided by the Bristol Myers Squibb Foundation. Contents are solely the responsibility of the authors and do not necessarily represent the official views of the Bristol Myers Squibb Foundation. (Published with Permission from the AAHD)

ABOUT THE AUTHORS:

Charles E. Drum, MPA, JD, PhD., is the founding Director of AAHD's National Center on Research, Knowledge Translation, and Dissemination. Prior to joining AAHD, he had a 30-year career in academia and is a national and internally known expert in health and disability, specifically in health disparities, access to care, health promotion research, and knowledge translation.

Anthony Oberg, MA, is a Project Associate and Accessibility Specialist with AAHD, where he coordinates a training project and ensures the accessibility of AAHD materials.

Jacob Ditsch, OTD, is a Project Associate with AAHD, where he coordinates the Venous Thromboembolism project.

Karl Cooper, JD is an attorney, disability advocate, and Director of Public Health Programs at AAHD. He specializes in training, technical assistance, and dissemination activities at AAHD and leads several disability and public health initiatives. Roberta Carlin, MS, MA, JD., has been Executive Director of AAHD since 2002. She has been involved in the disability and health field for over 30 years working in the areas of health promotion, disability research, women's health, community engagement and community inclusion, strategic information dissemination and knowledge translation, stakeholder engagement, and emergency preparedness.

References

- Bethell, C., Fiorillo, J., Lansky, D., Hendryx, M., & Knickman, J. (2004). Online consumer surveys as a methodology for assessing the quality of the United States health care system. *Journal of Medical Internet Research*, 6(1), e2. <https://doi.org/10.2196/jmir.6.1.e2>
- Krahn GL, Walker DK, Correa-De-Araujo R. (2015). Persons with disabilities as an unrecognized health disparity population. *Am J Public Health*. 2015 Apr;105 Suppl 2:S198-206. doi: 10.2105/AJPH.2014.302182. Epub 2015 Feb 17.
- White, GW. (2009). Nobody Left Behind: Disaster Preparedness and Public Health Response for People with Disabilities. In Drum, C.E., Krahn, G.L., & Bersani, Jr., H. (Eds.), *Disability and Public Health*. Washington, DC: American Public Health Association & American Association on Intellectual and Developmental Disabilities.

EP FOR FREE!

**RECEIVE
EXCEPTIONAL PARENT
eMAGAZINE AT NO COST!**

Exceptional Parent Magazine, a 47-year-old award-winning publication, provides practical advice, emotional support and the most up-to-date educational information for special needs families.

IT'S EASIER THAN EVER!

Simply visit us at
www.ep-magazine.com
and click
"SUBSCRIBE"

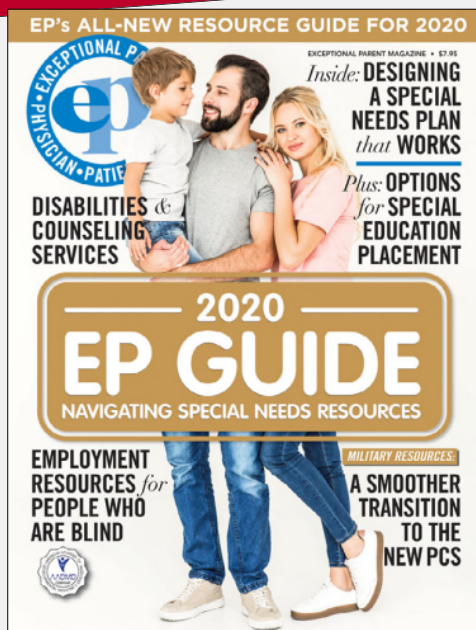
and you will receive a link
to the magazine every month.

Print subscriptions: \$95 a year;
email subscriptions@ep-magazine.com

Empowering the
Special Needs
Community
since 1971



Subscribe Today at www.ep-magazine.com



AN AMAZING ADVERTISING OPPORTUNITY

With a dedicated readership and a rapidly expanding audience, more and more advertisers are taking advantage of the unique opportunities that **Exceptional Parent** can offer. Whether it's a full or half page ad in our print and digital magazine editions, or a dynamic banner ad on our all-new **www.ep-magazine.com** website, there has never been a better value enabling your products or services to capture a large and motivated readerhip. Discounts and special offers are available for cross-platform insertions.

We are now offering many additional opportunities for lasting partnerships that can affordably and effectively communicate your brand's message.

For more advertising opportunities, email us at
sales@ep-magazine.com



EP MAGAZINE: THE JOURNAL FOR SPECIAL NEEDS FAMILIES AND PROFESSIONALS

Parents and schools are still concerned about the changing landscape of special education during the pandemic. Some districts will be starting ESY (extended school year) in July; some districts are reopening in the fall.

RESTARTING SCHOOL FOR STUDENTS WITH DISABILITIES SPECIAL CHALLENGES CONTINUE

BY LAUREN AGORATUS, M.A.

What Will Reopening Schools Look Like?

This will depend upon what is happening in each state. In the hardest hit states like New York and New Jersey, there will be delays. The CDC (Centers for Disease Control and Prevention) has recommended guidelines, but some districts are concerned that they may be difficult to implement. Per CDC:

- *Lowest Risk: Students and teachers engage in virtual-only classes, activities, and events.*

- *More Risk: Small, in-person classes, activities, and events. Groups of students stay together and with the same teacher throughout/across school days and groups do not mix. Students remain at least 6 feet apart and do not share objects (e.g., hybrid virtual and in-person class structures, or staggered/rotated scheduling to accommodate smaller class sizes).*
- *Highest Risk: Full-sized, in-person classes, activities, and events. Students are not spaced apart, share classroom materials or supplies, and mix between classes and activities.*



COVID-19 PHASED OPENING

Opening Up America Again, White House Guidelines

Some suggestions include cancelling all field trips, events, and extracurricular activities. Other ideas include spacing desks 6 feet apart and distancing students on buses. These may be impractical for districts that have large populations and class sizes. Still other recommendations include closing cafeterias and playgrounds, which would put students in the classroom all day. Lastly, it is recommended to keep the same group of students in the same room, which would be difficult to implement in a typical middle or high school as well as for students with disabilities who may have pull-out instructional or related services, or a mix of general and special education classes. The CDC also has good recommendations for disinfecting schools, and protocols if a student or staff member shows symptoms, etc. (see Resources). Some states, like New Jersey, are surveying parents to determine the needs of their students.

91 Questions


District administrators are concerned about reopening schools safely. One administrator posed 91(!) questions on how to proceed. Considerations included:

- Who determines acceptable risk?
- What are the criteria/parameters to reopen?
- Will there be testing guidelines for staff and students? What if someone tests positive?
- Will staff and students have to wear masks? If so, who is responsible for providing PPE (personal protective equipment)?
- Will accommodations be made for families who want to keep their child home?
- Will virtual learning continue?
- How will this affect afterschool programs like childcare? Extracurricular activities?
- How will this affect transportation (e.g. social distancing)?
- How will IEPs be implemented?
- How can paraprofessionals assist students hands-on, without increasing risk?


This was later updated to 283 questions! To meet the concerns of parents and the needs of students, there may need to be legislative or regulatory changes. Additional concerns for special education students included sports, camps, and summer programs.

PHASE ONE


Downward trend of covid/flu-like symptoms over 14-days, downward trend of cases, and robust testing in place for healthcare workers.




MAINTAIN PHYSICAL DISTANCING OF 6-FEET OR MORE




AVOID GROUPS OF MORE THAN 10




AVOID NON-ESSENTIAL TRAVEL




VULNERABLE PEOPLE SHOULD SHELTER IN PLACE. THOSE LIVING WITH VULNERABLE PEOPLE SHOULD TAKE PRECAUTIONS TO AVOID BRINGING THE VIRUS HOME.



WORK FROM HOME, IF POSSIBLE. RETURN TO WORK IN PHASES.




SCHOOLS AND YOUTH ACTIVITIES REMAIN CLOSED.




LARGE VENUE GATHERINGS CAN OPERATE WITH STRICT PHYSICAL DISTANCING.

PHASE TWO


No evidence of rebound of virus




MAINTAIN PHYSICAL DISTANCING OF 6-FEET OR MORE




AVOID GROUPS OF MORE THAN 50




NON-ESSENTIAL TRAVEL IS OK




VULNERABLE PEOPLE SHOULD SHELTER IN PLACE. THOSE LIVING WITH VULNERABLE PEOPLE SHOULD TAKE PRECAUTIONS TO AVOID BRINGING THE VIRUS HOME.



WORK FROM HOME, IF POSSIBLE.




SCHOOLS AND YOUTH ACTIVITIES CAN REOPEN.




LARGE VENUE GATHERINGS CAN OPERATE WITH MODERATE PHYSICAL DISTANCING.

PHASE THREE


No evidence of rebound of virus




LOW-RISK PEOPLE SHOULD MINIMIZE TIME IN CROWDED SETTINGS.



WORKERS CAN RETURN TO THEIR JOBS UNRESTRICTED.



LARGE VENUE GATHERINGS CAN OPERATE WITH LITTLE PHYSICAL DISTANCING.



VULNERABLE PEOPLE CAN PARTICIPATE IN SOCIAL SETTINGS WHILE PRACTICING PHYSICAL DISTANCING.

Getting Back to School

Both families and school districts need to be ready to reopen as soon as it is safe, according to public health officials. But before schools can reopen, plans must be developed regarding school operations, child supports, school personnel, academics, and distance learning. Accommodations are needed for at-risk individuals, including school personnel. Students have experienced trauma due to school closures, not seeing friends, parents losing jobs, etc., and the social-emotional fallout needs to be addressed. The plans that are developed must address

the needs of all students, including those of students from low-income backgrounds, students with disabilities, and English language learners. Guidance from the American Academy of Pediatrics (AAP) stresses a holistic approach that includes everything from ensuring deep cleaning of schools to preparing for an addressing the needs of students and staff. "Schools should be attuned to the broader social and family stressors that may affect a student's ability to attend school or be ready to learn," the AAP guidance says.

Medically Fragile Students

Special consideration needs to be given to students with chronic conditions or medical complexity. The CDC guidelines have options such as remote learning, phase-in, or delayed reentry to school. Students with medical needs can have an Individual Health Plan attached to their IEP or 504 Plan. For more information on IHPs, see EP's previous article on this topic at www.ep-magazine.com/blog/children-with-special-healthcare-needs-require-individual-health-plans-in-ieps504s.

Children with disabilities are still entitled to FAPE (free, appropriate public education). Some students may need compensatory services to catch up. Students who were in their last year of eligibility for special education services are likely to need compensatory services before graduating.

If families need help with their child's school district, they can contact the Parent Center in their state or territory. Considerations of the needs of all students is important to safely reopen schools. •

ABOUT THE AUTHOR:

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

WELCOME BACK : REOPENING RESOURCES



CDC GUIDELINES

www.cdc.gov/coronavirus/2019-ncov/downloads/php/CDC-Activities-Initiatives-for-COVID-19-Response.pdf

American Academy of Pediatrics

DEDICATED TO THE HEALTH OF ALL CHILDREN™



AMERICAN ACADEMY OF PEDIATRICS GUIDANCE ON SCHOOL REOPENING

www.aapublications.org/news/2020/05/05/covid19schoolopening050520



PARENT TRAINING AND INFORMATION CENTERS

www.parentcenterhub.org/find-your-center



"I have too much to do to risk getting sick, so I'm getting vaccinated."

Every year, thousands of adults in America suffer serious health problems from diseases they could be vaccinated against like shingles, whooping cough, hepatitis A and B, flu, and pneumococcal disease. Some even die.

Talk with your healthcare professional about which vaccines are recommended to protect you and your loved ones.

Learn more at cdc.gov/vaccines/adults or call **1-800-CDC-INFO (1-800-232-4636)**.

DON'T WAIT. VACCINATE!



U.S. Department of Health and Human Services
Centers for Disease Control and Prevention

INDEPENDENCE

BY KIMBERLEE RUTAN MCCAFFERTY

My eldest son is giggling fiercely, entranced by the 3D tour of Universal Studios I've googled for him on our computer. He sees the Hagrid Motorcycle ride and gives me the briefest of glances, and I smile and acknowledge that yes, we've been on that together. The video is a good 20 minutes long, and I know that afterwards he will amuse himself with other similar fare, and doesn't need me anymore to orchestrate his entertainment. Every year he grows more and more independent, small steps away from us doing so much for him.

It is a joy to witness. Something interesting has happened during this month-long lockdown. For years I have been working on fostering independence with self-help skills and chores with Justin, and while we've made progress, it's been incremental. These last few weeks I've been seeing a subtle shift in his willingness to do more on his own. I've seen it in how he dresses himself in the morning, or bathes himself in the shower at night. It's taking less nudging for me to get him to use a fork at meals. He's putting his clothes away at night with less prompting. And I have to say, most important, he's been so compliant with me as I've put him through his paces with school, having him do chores, worksheets, and work on the computer since his school shut down.

I think the shift has to do with the world slowing down, and us being able to focus on the task at hand without having to rush off to do something else.

Justin will never be completely independent of us. This remains, and will always remain, a bitter pill for me to swallow. My boy was diagnosed with autism at the tender age of 17 months, which was quite an unusual age in 2004. I then threw myself into doing therapy with him for the next year-and-a-half because Virginia did not provide ABA

therapy or recognize an autism diagnosis at that time. My goal was for him to reside at the milder end of the autism spectrum, and ultimately to gain independence from us.

My son will never recognize either goal.

I wish I could change that about his life trajectory. I know some people would say that wish would change him fundamentally and it's wrong, but I disagree. At the core of who he is, Justin is a kind, loving soul—that would not change if his degree of autism shifted. I would prefer to leave this earth knowing my child could fend for himself when I'm gone, or was not reliant for his lifetime on individuals who won't even be born when I leave this earth.



I can't change the fact that he will remain dependent on others. But I can do all I can to help him do for himself as much as possible.

And at least during this heartbreaking month of quarantine, I can say the two of us have been able to do just that. •

ABOUT THE AUTHOR:

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

EMOTIONAL HEALTH IN ISOLATION

SUPPORTING SOMEONE WITH DISABILITIES AT HOME DURING COVID-19



BY JOHNNY PAYNE MED CPD

A study from the University of Wisconsin revealed that mothers of adolescents and adults with autism experience chronic stress comparable to combat soldiers, and struggle with frequent fatigue and work interruptions. During times of COVID19, with required isolation and social distancing, these challenges can be even greater. Many parents and caregivers may struggle to know how to care for and support an individual with a disability with whom they are isolated and sheltered when they themselves are struggling to be emotionally available.

Feda Almaliti, Vice President of the National Council on Severe Autism, recently noted in an interview with NPR, "It's the unknowing that is most difficult. We don't know when it's going to end. We don't know what's going on, and dealing with autism at home makes it even harder. The only support that I have to get through it is through fellow autism parents. We have Zoom calls, and we try to find humor in this thing. We're just trying to lean on each other to get through. Because I can't do it alone. Nobody can."

Almaliti is mother to "Mo", a 15-year-old with severe autism and limited verbal ability. She notes that Mo does not understand what is going on right now, and why he cannot go to school, one of his favorite places. "He's incredibly confused, in this time when we're all confused, but he really doesn't understand it."

Almaliti tearfully relates to isolated parents and caregivers of individuals with disabilities saying, "They're doing the best they can every day. But I don't know how to accurately convey, it's really hard. It's really hard because I almost feel like nobody hears us. Because my son doesn't really talk. And I'm supposed to be his voice. And no one's listening to what's going on for our families. You know, no one gets that we are just as vulnerable as coronavirus people".

Closely caring for and supporting an individual with disabilities during social isolation can create strain in the close, trusting relationship between caregiver and individual. Managing daily stress can lead to better outcomes of the individual being supported, as well as better work and home environments.

Exceptional Parent (EP) magazine recently interviewed Margot Schulman on the subject of managing emotional health for caregivers and parents of individuals with disabilities who are isolated with their loved ones. Schulman is a speaker and author of the acclaimed *Choose Love: A Simple Path to Healthy, Joyful Relationships*. Her expertise has been featured on TEDx, RadioMD, and Talk Healthy Today. Schulman's work offers powerful tools for caregivers and parents of individuals with disabilities as they wres-

tle to sustain their mental health. The heart of Schulman's work revolves around helping people build a foundation of trust, first for themselves, and then trust in other relationships in their lives. As people gain awareness of and begin to accept their own weaknesses and strengths, Schulman says, they may begin to recognize other's weaknesses and begin to empower their strengths.

Early on in her career, Schulman worked at a soup kitchen in upstate New York. "I fed a lot of people, and it was a really intense job. It really allowed me to take mindfulness ideas and apply them to myself." As she described this job, she noted the hardest thing was managing the volunteers, not working with those who would come through to receive food. "Dealing with the volunteers was the hardest part. Girl Scout troops, older men, churches, people from all walks of life would come to volunteer. They all came to accomplish the same task: to make food and serve it to hungry people. I found that I had to recognize that every single volunteer had something valuable to offer. It was my job to find their value and to match them with a task for which they felt proud and to make sure the job got done. It was so rewarding to recognize each person's value. That was my job."

Schulman says we can look at ourselves the same way. We all have various parts that show up in ourselves in different times and situations. "If I read something that makes me angry, my inner teenager comes out and wants to lash out at them. When I'm scared, my inner child comes out and I want to retreat. I have all these personalities in me, all these parts in me, and like the diversely gifted volunteers who come to the soup kitchen to get the same job done. My job is to recognize that each part of myself has something valuable to offer. I have to find how each could contribute towards getting the job done."

The challenges we encounter during isolation in our homes or our workplaces can bring us to our emotional and mental limits. We all want to give the best of ourselves to those we support. Schulman suggests that giving our best starts by first recognizing our own emotions and finding ways to make our emotions constructive; to help them "find a job to do." Schulman admits this can be hard to

do when we are experiencing overall high levels of stress. She notes, "I am not a mom of someone with disabilities, so I can only imagine what it may be like. Though, I do have struggles and moments of losing my connection to my children. I can imagine during more stressful, strained times, that a parent can easily lose the time and space to have a quiet and focused moment. Over time, it becomes harder and harder to come back to that inner truth, which is that I have been entrusted with the care of this unique and valuable person."

Schulman says that the more parents and caregivers can recognize and accept themselves, the more equipped they are to be their best selves for those they love and serve. "We must acknowledge ourselves first before we can really acknowledge those around us. Every day, we should say out

loud to ourselves, 'I am doing the best I can, and I forgive myself for losing focus.'"

One strategy Schulman recommends is what she refers to as a "ding", as in the sound of the Tibetan bell which is often rung to signify the beginning of the practice of meditation. In this practice, the bell presents a cue for the mind to begin working towards focus and breathing, much like the ringing bell and salvation response in the famous Pavlovian experiments. In meditation, when we hear that sound, we know that it is time to begin searching out focus and turning our attention to our breathing. Schulman recommends finding a recurring sound in your own life that is a negative trigger for anger or frustration in the relationship with the person with which you are isolated. She shares that for her, the moment of raised arguing voices between her two young children is her "ding". "That is my reminder to take a deep breath, acknowledge my emotion, and remember what I have determined I want to be."

Our strong need for relational connection is fundamental to our emotional health. Even through the difficulty of physical distancing, support and relationships with others are vital to constantly feeling refreshed.

Schulman points out a practical skill for relieving stress and maintaining relational

connections she calls "clearing". This tool allows us to hold space for each other, within a set time, and intentionally uncover stressors or other items which weigh heavily on our minds, without any judgment. It may be as simple as hosting a regularly-scheduled phone call with someone you trust and feel comfortable. During the call, you might say, "here are 20 minutes, you can clear out everything that you're feeling without any judgment, I am holding a loving space for you." Schulman notes, this might be on a

regularly-scheduled Zoom call, or a telephone call, and that a timer for the activity may be helpful. "Once the timer has started, just start talking and don't stop," she says. "Even if it feels uncomfortable. It can be 20 or so minutes without any judgment about any emotion that needs to be 'cleared out' including

frustration, anger, sadness, or loneliness."

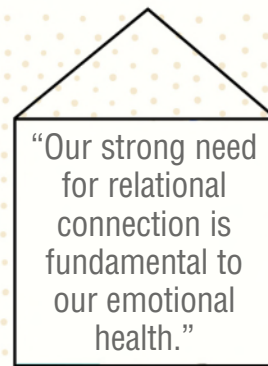
Having relationships can be difficult for many parents of individuals with disabilities. Many parents have a hard time finding common ground with others in friendships. It's hard to make that "ask" of spending meaningful time together. Parents may have many acquaintances but long for deeper and more open friendships. Asking someone with whom you wish to develop a friendship to schedule time for a regularly-scheduled "clearing" may be a great way to make a practical "ask" of developing and keeping relationships growing.

There are many resources we can tap into, including our local church community, a local autism center, support groups, or other online resources such as Parent to Parent USA.

Whatever our means to connect with others and to acknowledge our own strengths and weaknesses, it is vital that we maintain the kind of support for ourselves that we would want for those we support. Let's all begin the work of supporting others by treating ourselves a little better.

ABOUT THE AUTHOR:

Johnny Payne is the Mental Health Coordinator at the Orange Grove Center in Chattanooga TN.



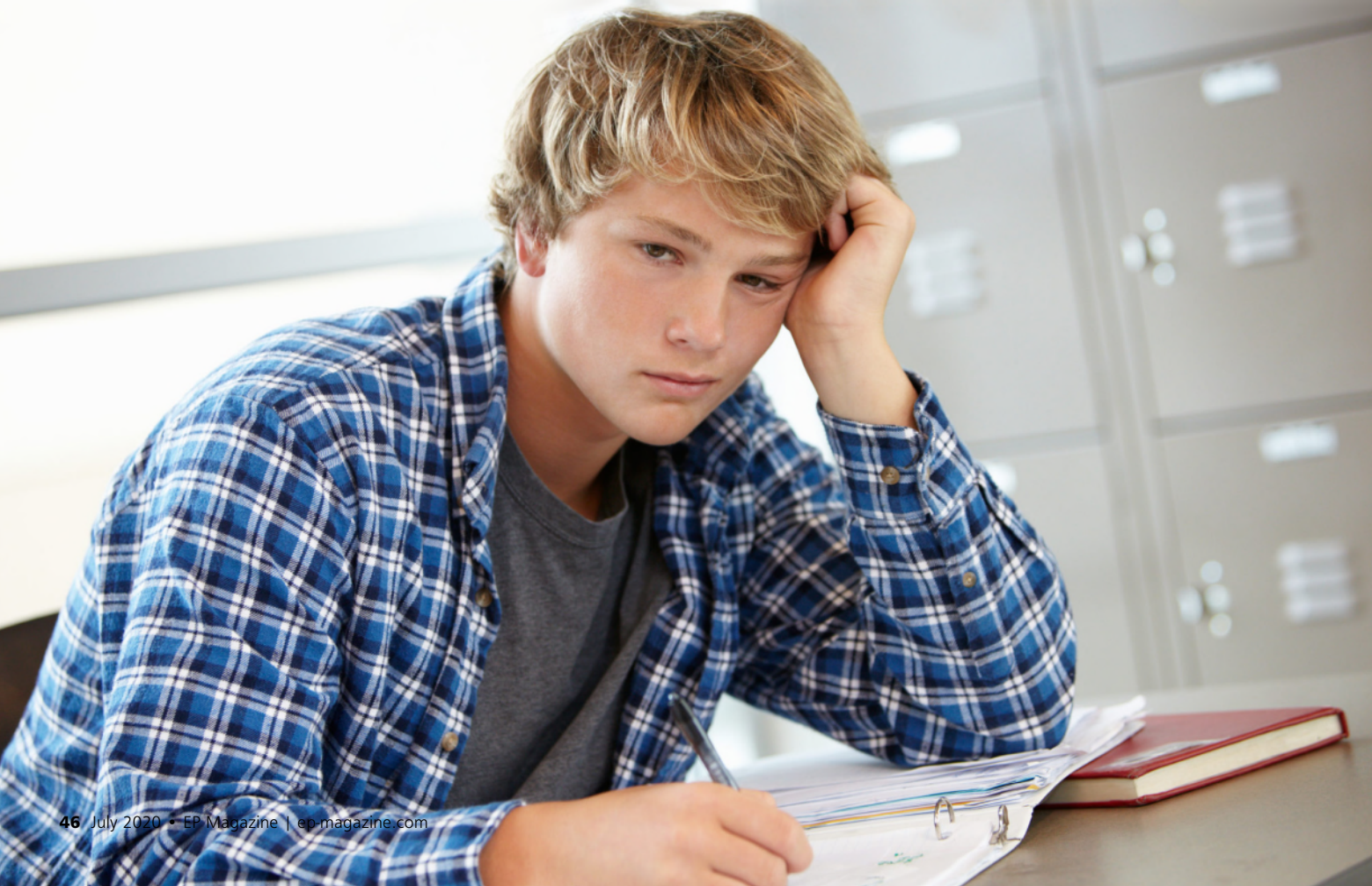
The Challenge of PANS and PANDAS

OVERCOMING IGNORANCE, EXPLORING POSSIBLE TREATMENTS

BY KARA JOLLIFF GOULD, PH.D.

The acronyms PANS (Pediatric Acute-onset Neuropsychiatric Syndrome) and its subset PANDAS (Pediatric Autoimmune Neuropsychiatric Disorders Associated with Streptococcal Infections) are relatively new terms that refer to auto-immune responses in which antibodies attack a child's brain. These attacks are believed to be a response to strep-

tococcus, Lyme, influenza or other infections. According to researchers with Stanford University's PANS program, symptoms can include sudden onset obsessive-compulsive disorder (OCD), tics, anxiety, irritability, mood swings, hyperactivity and urinary problems. Declines in cognitive and motor skills can also occur.



For parents of children and young adults diagnosed with PANS or PANDAS, everyday life can be difficult to manage. Children who are happy, healthy and functional one day can become too terrified to eat, sleep or play – often overnight. These children can become unable to engage in many of their daily activities due to sudden-onset symptoms of obsessive-compulsive disorder (OCD) or tics. They may express their frustration in a variety of ways – through disruptive behavior, withdrawal, crying or even suicidal thoughts and actions.

Parents struggle to care for these extremely distressed children. One mother writes that following a diagnosis of PANS/PANDAS, “you come to the realization that your child is gone.” The anxiety can be so all-consuming that the child’s personality seems drastically altered.

But, just as challenging as daily care is the search for doctors familiar with the syndrome who recognize it as a legitimate

disease and know how to treat it effectively. This challenge is complicated by two factors: a general unfamiliarity with PANS and PANDAS among both physicians and the public, and the lack of physician training in treating the condition.

At least one in 200 U.S. children are affected by PANS and PANDAS, according to PANDAS Network, a non-profit advocacy group. Because these children present symptoms that are similar to those associated with mental illness, many pediatricians simply refer them

to child psychiatrists. Others have taken an interest in learning more about PANS and PANDAS after encountering severe symptoms in children and questions from parents. But few are experts in treating the condition, and some still insist that PANS and PANDAS are not conditions distinct from childhood OCD and tics, despite research studies that show the effectiveness of treatments. This skepticism has

“Because children with PANS and PANDAS suffer such great distress and debilitating symptoms, the Journal of Pediatric Psychology reports that the stress families endure when caring for them is comparable to the caregiver stress associated Alzheimer’s disease.

contributed to some children struggling with symptoms for years. Yet, a study published in the Journal of Immunology confirms the effectiveness of intravenous immunoglobulin (IVIG) treatments in reducing the antibody levels that indicate auto-immune dysfunction. The establishment of the Stanford University PANS clinic has also lent further credibility to the existence of the condition and current research findings.

Newly identified medical conditions or syndromes are often met with skepticism, since it takes time for research studies to be conducted and new diseases defined and confirmed. PANDAS was first identified by pediatrician Dr. Susan Swedo and colleagues in 1998. In the early 2000s, a few doctors of various backgrounds and specialties took up the challenge of treating and raising awareness of the syndrome, which requires treatments that differ from those of conventional mental illness. The pioneers, including Swedo (now of the National Institutes for Mental Health), have developed a variety of treatments for children who present symptoms of PANS and PANDAS including steroids, antibiotics and IVIG treatment in an effort to relieve their suffering.

But the variety of specialties these doctors represent can present a dizzying array of options for parents. Each seems to offer a somewhat different approach to treating PANS and PANDAS, and while many

SEARCHING FOR SUPPORT : PANS AND PANDAS RESOURCES

There are several reputable advocacy organizations that operate websites with directories of physicians in the U.S. who treat PANS and PANDAS, often organized by state. While not comprehensive, they are a useful place to start. These websites offer other helpful resources for patients and their families as well. The most reputable include:

Beth Alison Maloney

AUTHOR BETH ALISON MALONEY

http://bethalisonmaloney.com/pandas/pans/support-groups-providers/wpbdp_category/providers



PANDAS NETWORK

<http://pandasnetwork.org/us-providers>



PANDAS PHYSICIAN NETWORK PRACTITIONER DIRECTORY

www.pandasppn.org/practitioners



THE HEARTWOOD PROGRAM FOR PANS/PANDAS

<https://pandas.theheartwoodprogram.com>

research studies support the effectiveness of some treatments, others offer treatments too new to have undergone research trials.

Parents who are desperate to try anything to help their child are left with a myriad of paths to consider. Which type of doctor should be consulted first, and which treatments should be considered? Steroids? Antibiotics? IVIG? Homeopathic remedies? Tonsillectomies and adenoidectomies are recommended to help some children. Traditional anxiety medications (SSRIs) have helped other children, often in combination with other treatments. The array of options, none of which is guaranteed to help, can be overwhelming. A parent explains, "Once your child has this diagno-

- *Psychologists*
- *Otolaryngologists (ENT)*

Some chiropractors and homeopathic physicians also offer treatment options. Treatments for PANS and PANDAS, such as IVIG, can cost thousands of dollars, as author and researcher Patricia Rice Doran of Towson University notes. Only five states mandate insurance coverage for PANS and/or PANDAS: Connecticut, Delaware, Illinois, Minnesota and New Hampshire.

Because the infections triggering the autoimmune response that attacks the brain vary, as do severity of symptoms, there is no "gold standard" of care. This presents a particular

ety or OCD coding, for example, and immunologists and neurologists can use codes related to immune disorders such as autoimmune encephalopathy.)

So how can exhausted parents find good treatment options? Some families choose care at one of the handful of PANS or PANDAS clinics that bring together several specialists into one practice to treat children with these conditions. While some such multidisciplinary clinics, such as the Stanford PANS Clinic, require that patients live nearby, others, such as the PANS Clinic at the American Family Children's Hospital in Madison, WI, and the Children's Postinfectious Autoimmune

Encephalopathy (CAPE) clinic in Tucson, AZ accept patients from around the U.S. and the world.

Because children with PANS and PANDAS suffer such great distress and debilitating symptoms, the *Journal of Pediatric Psychology* reports that the stress families endure when caring for them is comparable to the caregiver stress associated with Alzheimer's disease. Others, such as Susan Swedo, liken the experience to dealing with childhood cancer. Parents need to know that they are not alone, and that help is available. One parent describes her experience of caring for a daughter with PANS:

"Life goals and priorities change and everything centers around getting the child back to functioning in life. At the same time, you are mourning the loss of all things familiar and the child you once knew. Unlike when somebody dies, this is a continually relived grief...because just when you think you've reached a new plateau of well-being, your child can back slide. So, we live with constant PTSD and fear of what tomorrow may bring."

Without proper treatment, some children suffering from PANS and PANDAS are unable to function independently as they



FULLY FUNCTIONAL: Without proper treatment, some children suffering from PANS and PANDAS are unable to function independently as they become young adults, but when met with proper medical care many children with PANDAS and/or PANS grow into young adults who are symptom-free.

sis, life is never the same again; everything you knew about health, mental and emotional well-being, diet, and medicine in general – it all goes out the window."

The variety of medical specialists currently treating PANS and PANDAS include:

- *Developmental Pediatricians*
- *Immunologists*
- *Gastroenterologists*
- *Homeopathic Practitioners*
- *General Pediatricians*
- *Neurologists*
- *Rheumatologists*
- *Psychiatrists*

challenge for parents. A few doctors have formed informal networks in which they refer children to other specialists, but many such specialists do not accept health insurance, even in states where coverage is required. There is no current medical code in the International Classification of Diseases (ICD) for PANS or PANDAS; codes for both are not scheduled to be added until 2022, according to the World Health Organization (WHO). Physicians who work with insurance companies typically use codes that are compatible with their various specialties (psychiatrists can use anxi-

HITTING THE ROAD : PANS AND PANDAS, TRAVEL AND COVID-19

The COVID-19 pandemic presents a significant challenge to any traveler. PANDAS and PANS definitely add complexity to the situation. Many children with PANS and PANDAS have suffered from germ-related OCD before the COVID-19 crisis began, and the crisis undoubtedly makes some people's OCD worse. Some children with this condition may appreciate that other people are now expressing concern over handwashing and staying healthy, however, and find the efforts of others somewhat comforting. Regardless of how your child reacts, here are some tips that may help:

1. **Secure alcohol or other germ-killing handwipes and sanitizers before your trip.** Many stores are sold out of these items, so planning ahead is important. Let your child know you have these things on hand.
2. **Make clear which handwashing/sanitizing practices are reasonable,** and which ones you and your family will practice.
3. **Travel is an excellent way for all children to learn more about the world.** Combining the familiar (a familiar vehicle, family member, books or toys) with the unfamiliar (new countryside to see, area history to learn about) can educate children in a way that may distract them from their symptoms of anxiety and OCD.
4. **If you stay overnight in an RV, a hotel, or with friends or relatives, take precautions to guard against COVID-19,** and let concerned children know what those reasonable precautions are. You can find helpful tips online at: www.cdc.gov/coronavirus/2019-ncov/travelers/travel-in-the-us.html

Finally, keep in mind that exposure to other people with viral and bacterial infections can cause symptom "flares" in some children – even if they don't contract the particular disease to which they've been exposed. For those kids, travel outside your local area may not be advisable, unless your destination has a lower rate of illness.

(Note: these tips are not meant to serve as medical advice – always consult your physician before traveling with an ill child. Also, it is important to review the directives of local authorities in both your home and destination areas, as well as the Center for Disease Control (CDC) and/or the World Health Organization (WHO) when considering any travel away from your home region during a pandemic.)

become young adults, and a small percentage suffer irreversible cognitive damage. But when met with proper medical care, many children with PANDAS and/or PANS grow into young adults who are symptom-free.

Educating parents, teachers and pediatricians to recognize the signs and symptoms of PANS and PANDAS can help increase accurate diagnoses and bring about more awareness of the treatments that are available to help these children and their families. •

ABOUT THE AUTHOR:

Kara Jolliff Gould, Ph.D., is Assistant Professor of Journalism and Director of Undergraduate Studies at the School of Journalism and Strategic Media at the University of Arkansas. Previously, she taught for more than 20 years at colleges such as Weber State, John Brown University and Pepperdine. She has worked professionally in media in Chicago and Salt Lake City and has published scholarly work in *The Journal of Media Education*, *The Southern Communication Journal*, and *The Journal of Broadcasting and Electronic Media*. She is acquainted with the needs of students with disabilities both as a professor and as a parent.

Have you been infected by stigma?

Take a 3 question, multiple choice quiz to find out and help spread the cure.



FINANCIAL PHYSICAL...

Financial Check-up After a Crisis

BY ROB WRUBEL, CFP

My daughter with Down syndrome has her annual physical this week. It was scheduled for mid-March, just like it is every year, but this year was different. The COVID-19 crisis caused her appointment first, to be postponed, and then canceled, as the medical system reacted to the sweeping pandemic.

She runs on her high school track team and both her school and summer camp require an updated vaccination and health record each year. Like most of us, I hoped that schools, camps, sports, and her other activities would resume by the end of March and, like most of us, I was wrong.

Her physical will start with the aide taking her height and weight and asking some basic questions. The aide will then strap a flexible cuff to her arm, pump up a small balloon and listen for the blood to flow. The aide will write down numbers – 117 over 77 or 110 over 72. Taking blood pressure always seems like an odd way to start a medical exam and yet this simple test can give a doctor the information to identify heart stress and potential underlying health issues.

The COVID-19 crisis stress-tested our financial lives, and while there's no simple device to strap around our arms, there are finan-

cial measurements we can check to see how we are doing with our financial fitness. In the time leading up to the economy shutting down in March, unemployment rates were decreasing, stock market indices were increasing, and wage growth was positive. Those are usually the best times to take steps to improve your financial life. Unfortunately, more people act after a crisis highlights the weaknesses, and not when life is cruising along.

No matter what, today is a great day for a review. Take stock of these crucial measurements today.

1. **Cash reserves.** *Financial planners like me recommend that families keep three to six months of basic living expenses for times of emergency. Why? There's no way to plan for emergencies. We can plan for birthdays, camps and vacations. Emergencies are sudden and unexpected. Someone losing a job, getting into an accident, or needing to visit a sick parent still needs to pay rent, buy food, and have insurance in place. The emergency fund is there to buy time to focus on fixing problems without creating a financial disaster.*
2. **Net worth.** *Bankers and accounts love a balance sheet; real people not so much. Still, it's valuable to know what assets you own, where they are located, how much they are worth and then to list your debts. Ideally you go through this exercise annually. Put the assets list at the top of a page and the debts at the bottom. Then, subtract your assets from the liabilities – the remaining value is your net worth. You want this*

The COVID-19 crisis stress-tested our financial lives, and while there's no simple device to strap around our arms, there are financial measurements we can check to see how we are doing with our financial fitness.



number to be positive and growing each year. If it's negative, it should be getting smaller each year. Like a blood pressure reading, this simple figure measured over time is a great indicator of whether your financial life is headed in the right direction or not.

3. Debt to income ratio. *Take a look at this important financial metric. Write down your monthly household income. Then, add up your monthly debt payments – for example, the amount paid for your mortgage, credit card, car loans and student loans. Divide the debt payments by your income. Lenders look at this number for the maximum amount of loans they will offer. The reality for you is that you want this number to disappear over time and to have no debt payments. My experience tells me that you want this number to be below 25% if you want to be able to start increasing your net worth. It's hard to scrape by, let alone put money towards emergency funds, retirement accounts and to fund a trust, if your money goes to lenders and not to your own accounts.*

If you're not sure how to calculate your net worth or debt to income ratio, search the internet for apps and tools to help. Personally, I use Quicken to track my budget and the software includes a net worth review. Mint (at mint.com) and You Need a Budget (at YNAB.com) can help with budgeting and understanding your net worth. Zillow, Nerd Wallet and other sites have simple cal-

culators to check your debt to income ratio. Building emergency funds takes patience and small changes to direct money to savings. Apps like Digit and others can roundup or help redirect cash to savings, and others like Honey can help you find coupons to save money in the first place.

Winston Churchill famously said, "Don't let a good crisis go to waste." We are still in the midst of the COVID-19 crisis and with it, the uncertainty, anxiety and concerns for the future we all feel. We all have had more time at home – use some of it to review key financial measurements for an update on your financial health. Use this information to take steps immediately once restrictions to work and activities are lifted in your community.

ABOUT THE AUTHOR



Rob Wrubel is a CFP who has a daughter with Down syndrome. He is recognized as a leading expert on financial planning for families with special needs members. Wrubel has written two books about financial planning and special needs families – *Financial Freedom for Special Needs Families: 9 Building Blocks to Reduce Stress, Preserve Benefits, Create a Fulfilling Future and Protect Your Family: Life Insurance Basics For Special Needs Planning* – and he has been published recently by Law360.com and The Good Men Project. Wrubel holds the Certified Financial Planning (CFP®) designation, the Accredited Investment Fiduciary® (AIF®) designation from F360, and the Accredited Estate Planner (AEP®) designation from the National Estate Planning Council.

HELP EP, HELP YOURSELF.

EP is announcing a new program with amazing potential for its readers. In its search for new advertising partners, EP is offering its very generous commission rates to anyone helping to place ads in future issues.

Readers can help EP and help themselves simultaneously:

- Readers who connect EP's sales staff with potential advertisers are able to earn up to 20% commissions. Advertising sales of all sizes and kinds qualify for commission.
- Readers can help to ensure that EP Magazine receives the continued revenue that make it possible to educate and inform the special needs community each month.

To learn more, please contact Faye Simon
at fsimon@ep-magazine.com





SUBSTANCE ABUSE AND THE DEAF ADOLESCENT

BY J. FREEMAN KING, ED.D.

A substance abuse disorder can be defined as the continued use of any substance for mood-altering purposes, regardless of the harmful consequences that might ensue. This type of disorder is characterized by a set of symptoms that indicate an individual continues to use a substance, even though its use is causing significant problems. Substance abuse impacts both hearing and deaf adolescents.

Symptoms of substance abuse include loss of control, social impairment, risky use, and physical effects. Loss of control means the adolescent cannot keep from using the substance. He/she might use the substance in increasing amounts, or for a longer period of time than prescribed; may want to stop using, or has tried to stop, but has not been successful; may spend time trying to obtain, use, or recover from the effects of the substance; or may experience an intense craving for the substance.

When the adolescent faces social consequences connected to substance abuse, this is referred to as social impairment. Examples of this are: 1) a repeated neglect, such as not meeting responsibilities at school, work, or home; 2) a continued use of

substances even though the use causes arguments or getting into trouble with others; 3) and/or giving up or minimizing involvement in activities that used to be considered important.

It is risky use when he/she insists on using the substance, even in dangerous situations, and puts themselves at physical risk, i.e., drinking while driving, or may keep using the substance even though they are aware that abuse can cause physical or mental health problems.

A physical effect occurs when the substance abuse impacts the adolescent's body in predictable ways. Often it requires a greater amount of the substance to get the same high or even leads to experiencing withdrawal. Regardless of these physical symptoms being unpleasant, the adolescent uses the substance repeatedly in order to stop withdrawal symptoms.

Much research has been conducted on substance abuse among adolescents who are hearing, but few studies have been conducted on those who are deaf. There appears to be a number of reasons that contribute to the lack of prevalence data on deaf adolescents and substance abuse: 1) a scarcity of assessments that have been translated into American Sign Language (ASL); 2) a variety of communication preferences among the deaf population; 3) the availability of qualified, certified interpreters for substance abuse concepts; 4) the risk and fear among participants regarding the loss of confidentiality; and, 5) cultural difference (hearing vs. deaf) resulting in a distrust of researchers.

The data that does exist for deaf adolescents involved in substance abuse often relies on deduction or comparative evidence on small, restricted, or non-representative samples. It is possible that those who have more social interaction with hearing peers in order to "fit in," may use substances more frequently than do those with less interaction.

The situation is further complicated in that substance abuse disorders among hearing adolescents in the general population typically occur concurrently with mental health problems, i.e., conduct disorder, antisocial personality, major depression, and post-traumatic stress. Few studies include information on co-occurring disorders among deaf adolescents, although those that do, indicate similar to

higher rates compared with their hearing peers. The recognition and understanding of substance abuse within the Deaf community tends to lag behind that of the hearing community.

Getting treatment and beginning a program of recovery can present many problems for deaf adolescents. These problems are associated with assessment, treatment, and post-diagnosis care. There appears to be a negative stigma, resulting in the denial of the use of alcohol and other drugs within the Deaf community. Some of the barriers that exist include the treatment agencies' and providers' inadequate knowledge regarding the unique linguistic and cultural needs of deaf adolescents, lack of specialized treatment programs, lack of qualified/certified treatment settings, inaccessible video and print materials, and assessment tools that are in English rather than American Sign Language (ASL).

When a deaf adolescent is referred for treatment, the referral most appropriate would be to a specialized program designed specifically for deaf people, a program that is sensitive to cultural, linguistic, and communication issues that includes staff fluent in ASL and knowledgeable about Deaf culture. Deaf adolescents will typically feel most comfortable in a specialized treatment facility where they can communicate visually using American Sign Language (ASL). Assessments that are used are often administered via speech by an interviewer, or self-administered in written English. For many deaf adolescents, English is not their most accessible language. Therefore, administering a written English instrument to them is often not valid or reliable.

If a deaf adolescent is referred for treatment, the referral will most likely be to an integrated program (hearing and deaf individuals are blended into a program that is designed for the hearing population), as opposed to a specialized program that is designed specifically for deaf people. Deaf

individuals will naturally feel more comfortable in a facility where they can communicate deeply and meaningfully and have access to other deaf people during recovery.

Regarding communication during treatment, it is instructive to realize the difference between the interpreted message (the utilization of an interpreter to facilitate communication) and direct, one-on-one communication in sign language. With limited communication among peers, deaf adolescents have minimal opportunities to benefit from peer

support and to develop trust or rapport with the professionals who work on staff.

Substance abuse disorders and the provision of culturally sensitive treatment for deaf people is often vaguely reported, and resources are often under-reported. This causes a dilemma for parents of deaf adolescents who are seeking assistance for their child.

Despite the lack of reliable research information, the consensus among those involved in services for and education of the deaf adolescent, there appears to be a problem that approximates the number of hearing adolescents with a substance abuse problem. It is apparent that efforts more seriously focused on substance abuse among deaf adolescents needs to be addressed.

ABOUT THE AUTHOR:

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

"Substance abuse disorders and the provision of culturally sensitive treatment for deaf people is often vaguely reported, and resources are often under-reported. This causes a dilemma for parents of deaf adolescents who are seeking assistance for their child."



INTRODUCING THE ALL-NEW WWW.EP-MAGAZINE.COM



EP's Innovative New Digital Strategy

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

www.ep-magazine.com now features a bold new design and intuitive site-wide navigation system with improved menu functionality that directs you to the information most relevant to you. It is also fully responsive with mobile devices, making it easy to navigate on a wide range of web browsers and portable devices.

We've introduced a range of new content to the website, including In This Issue that highlights selected content from our latest issue, and

From Our Contributors, which features the most recent offerings from regulars such as Genetic Alliance and the AADMD.

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

We're really proud of the new website and feel it will create the experience you're looking for when you pay us a visit. Check it out here:

www.ep-magazine.com



ADVERTISERS: Reach a growing audience on EP's all-new website and strategically target your consumers. Our competitive advertising rates offer top-quality results for an excellent value. Our team of designers and developers are ready to create digital marketing campaigns that effectively communicate your brand's message to our dedicated online audience.

CONTACT: Faye Simon at fsimon@ep-magazine.com

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

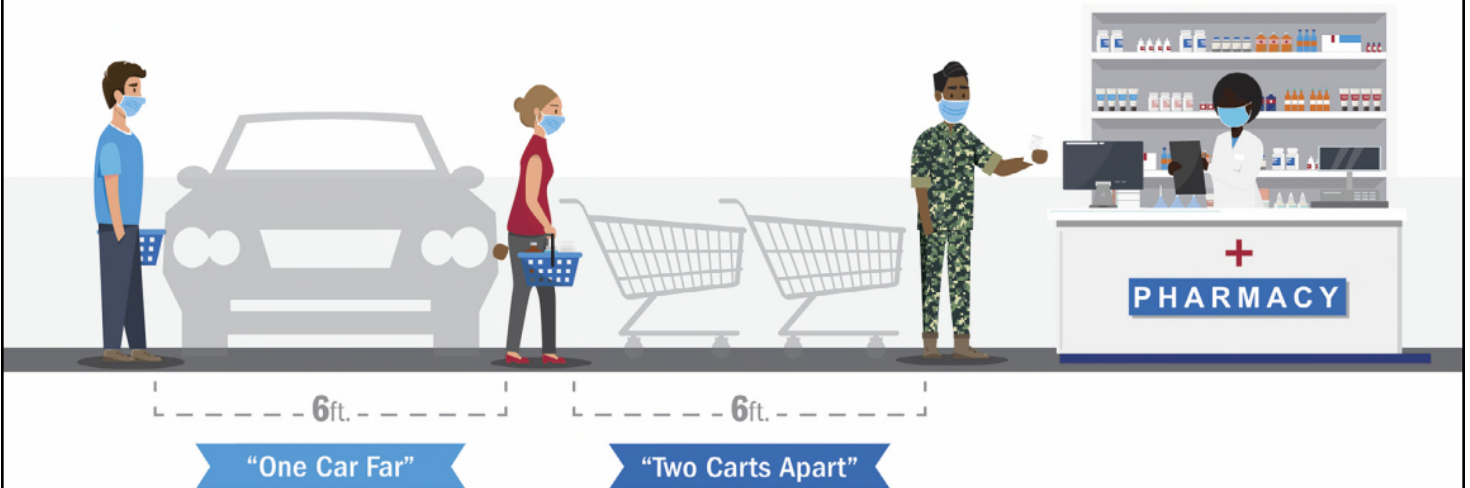
Coronavirus Disease 2019

COVID-19

What you need to know to keep your family safe and healthy.

How Do You Practice Social Distancing?

According to the CDC, the virus is thought to spread mainly from person-to-person. It's important to stay "two carts apart" or "one car far" from others when in public areas to reduce the spread of COVID-19.



To learn more about TRICARE and COVID-19, visit:

www.tricare.mil/coronavirus





FROM OUR FAMILIES... TO YOUR FAMILIES

MILITARY SECTION

MILITARY LIFE

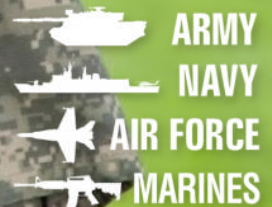
58 TOP 10 WAYS TO PRACTICE RESILIENCE SKILLS DURING CHALLENGING TIMES

60 MOVING WITH PETS

PUZZLES & CAMO

62 LEVEL 3

By Shelly Huhtanen





MILITARY LIFE

This is an incredibly challenging time, but you have tools and resources to help you stay strong.



TOP 10 WAYS TO PRACTICE RESILIENCE SKILLS DURING CHALLENGING TIMES

Uncertain times like these can present incredible challenges. Normal life has turned upside down because of coronavirus disease 2019 (www.cdc.gov/coronavirus/2019-ncov), and no one knows when things will be settled again. Military families are used to uncertainty and challenges and already have skills needed to remain resilient in challenging times. The current COVID-19 situation can be an opportunity to practice your resilience skills and share them with others.

Change and uncertainty can increase stress and anxiety. A healthy dose of concern can help solve problems, but paying too much attention to things we can't change can leave us feeling powerless and more stressed. Here are 10 things you can do to practice staying strong and build resilience skills to help yourself, your partner, your children and other loved ones:

- **Recognize the situation and validate your feelings.** It is normal to feel stressed and worried right now. There is a saying in psychology that "what we resist, persists," so the best way to begin to address an issue is to face it. Acknowledge that things are uncertain now and know that is OK. If you are not worried or anxious, that's fine too. Everyone deals with stress in different ways, and the most important thing is to validate whatever you are feeling.

The Centers for Disease Control and Prevention offers information on managing stress during the outbreak at www.cdc.gov/coronavirus/2019-ncov/daily-life-coping/managing-stress-anxiety.html If you want to talk to a professional, free, confidential non-medical counseling is available through Military OneSource at www.militaryonesource.mil/leaders-service-providers/sp-1-confidential-help/confidential-non-medical-counseling-provides-support

- **Talk to your children.** It's especially important to talk to children now, because even if they aren't saying anything, they may have questions and concerns they don't know how to voice. Talk to them in an age-appropriate manner (www.dodea.edu/upload/HowtoTalktoYourKidsAbouttheCoronavirusBranded_3_3_20.pdf) about COVID-19 and make sure to acknowledge their feelings.

PARENTING RESOURCES DURING COVID-19

Try this updated list of extensive parenting resources featuring new ideas for managing children at home during the pandemic.

www.militaryonesource.mil/more-parenting-resources-for-managing-at-home-during-covid-19

- **Follow accurate information about the virus.** Make sure you are doing the things you can to stay safe and healthy while staying at home (www.militaryonesource.mil/family-relationships/family-life/preventing-abuse-neglect) and explain those things to your family. Continue to check the Coronavirus Information for Our Military Community page (www.militaryonesource.mil/coronavirus) for updates.
- **Try to view the current social situation as a challenge rather than an insurmountable problem.** Yes, times are difficult right now, but things will get better again. The situation in China has already improved, and with time, will improve in the rest of the world.
- **Maintain routines as much as possible.** Paying attention to things you can control helps to decrease anxiety and increase a sense of personal effectiveness.
- **Limit media exposure.** Stay updated on health and safety measures, but try not to tune in 24/7. Constant media viewing can increase stress and anxiety. Choose one or two reliable news sources and schedule regular times to check updates. Make time for positive input as well. Try searching online for good things that have come out of the current social situation. You might be surprised at what you find.
- **Stay connected.** Talk to your spouse, your children and extended family. Military spouses (www.militaryonesource.mil/family-relationships/spouse/military-life-for-spouses/military-spouse-support) usually have a strong, established virtual support network. This could be a time where you help others develop similar connections.
- **Practice positive thinking.** When you find yourself dwelling on negative thoughts or worrying excessively, stop and count 10 things that make you feel grateful. Starting a gratitude journal can be a powerful daily practice, and is also something that is easy to do with children to get them to practice positive thinking skills. For more ideas, check out these resilience resources (www.militaryonesource.mil/confidential-help/interactive-tools-services/resilience

[tools/resilience-tools-the-essentials](http://www.militaryonesource.mil/resilience-tools-the-essentials)) from Military OneSource.

- **Help others.** Research shows that helping others decreases anxiety and builds resiliency. Search online for things people are doing during COVID-19 to help others. Have your kids draw pictures and text them to grandparents. Bring groceries to an elderly neighbor who can't get out. Have your teenager organize a video dance party or put together a playlist for family dance time. You can also search online for organizations that are helping deployed service members and veterans, and find some way to get involved.
- **Take care of yourself and seek help if you need it.** Make sure you are practicing good self-care, and addressing all five pillars of wellness (www.militaryonesource.mil/national-guard/psychological-health-program/the-pillars-of-wellness). Turn off the TV. Listen to music. Get outside and take a walk. Check out these other tips for managing stress (www.militaryonesource.mil/health-wellness/healthy-living/managing-stress/follow-these-stress-relief-tips). Everyone needs

a hand now and then, and the Department of Defense offers a variety of programs and services to keep service members and their families healthy and strong.

Help for an unsafe or abusive relationship is available at www.thehotline.org. The military community has resources to support you if your partner's behavior makes you feel uncomfortable or anxious, and you are seeking ways to maintain your boundaries at home, or make a plan for safety. Call 911 if you are in immediate danger, or if your partner or spouse has threatened you, your children or someone you know. If you are on a military installation, call your military law enforcement office. Connect

KEEP CALM WITH COVID COACH

This app can help you cope with pandemic-related stress. It's free, secure and recommended by the Department of Defense.

www.militaryonesource.mil/health-wellness/recommended-wellness-apps

24/7 with an advocate at the National Domestic Violence Hotline by calling 800-799-7233, or chat online at thehotline.org.

Parenting help (www.militaryonesource.mil/family-relationships/parenting-and-children/parenting-infants-and-toddlers) is available, and you can tap MilParent Power year-round at www.militaryonesource.mil/family-relationships/parenting-and-children/parenting-infants-and-toddlers/milparent-power

If you have financial stresses as a result of COVID-19, contact your military service relief organizations at www.militaryonesource.mil/financial-legal/personal-finance/protecting-your-finances, or tap other financial resources at www.militaryonesource.mil/financial-legal/personal-finance/protecting-your-finances/support-for-financial-stresses-caused-by-covid-19.

Free, confidential non-medical counseling (www.militaryonesource.mil/leaders-service-providers/sp-1-confidential-help/confidential-non-medical-counseling-provides-support) is available for eligible individuals, and for immediate help you can call the Military Crisis Line at www.veteranscrisisline.net/get-help/military-crisis-line

This is an incredibly challenging time, but you have tools and resources to help you stay strong. Understanding of COVID-19 is rapidly changing. For updates and information specific to your location, visit your installation's official website. You can also follow your installation's Facebook, Twitter or Instagram platforms. For

Department of Defense updates for the military community, visit Defense.gov, follow Military OneSource's Facebook, Twitter and Instagram platforms, and continue to check the Coronavirus Information for Our Military Community page for updates.

– Military One Source

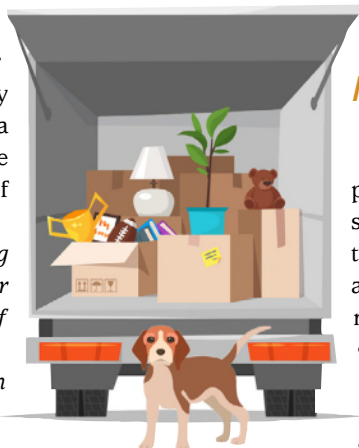
MOVING WITH PETS

When you're preparing for a military move, having a pet can add another layer of complexity, particularly if you're moving overseas. But you know the drill: spend some upfront time planning and preparing, and you can ease some of the stress of relocating for both you and your pet.

PET MOVING TIPS

Before your move, make sure you bring your pet to the vet. Making sure your pet is healthy and has updated immunizations can make a domestic or overseas move go smoother. Before moving, consider some tips for keeping track of your pet in unfamiliar territory:

- Give your pet an identification tag. The tag should display the name of your pet, your cellphone number and the phone number of an emergency contact.
- Take a picture of your pet so that you can show people what it looks like should it get lost during the move.
- Consider having your veterinarian insert an identification microchip under your pet's skin.



TRAVELING IN THE CAR

Make the move easier on your pet. Spend time with your pet in the vehicle. Introduce it well beforehand to the crate that you intend to use during the move. Show your pet that traveling can be fun. Try the following tips:

- Offer your pet a reward whenever it gets into the vehicle.
- Take your dog, for example, on short drives to the park so that it associates car travel with a happy destination.
- Put the pet's crate you plan to use inside your home or backyard, leave the door open and put a treat inside the crate.
- Teach your dog to respond to a bathroom command such as "go potty" or "go outside." Make sure you give your cat access to a litter box.

MOVING TO ANOTHER STATE

- Visit the U.S. Department of Agriculture's Animal and Plant Health Inspection Service's website (www.aphis.usda.gov/aphis/pet-travel) to see if there are rules for bringing animals into the state to which you have been assigned.
- There may be a limit to the number of pets that you can have on a military installation. Look up the regulations for your installation before you start to pack.
- Call a friend and ask if he or she can watch your pet on moving day.

- Seek out pet-friendly hotels along your travel route before moving day.
- Don't forget to take your pet's health certificate and proof that it has current vaccinations.
- Put your pet's food, water, bowls, leash, toys, bedding, plastic bags and medication in one bag.
- Feed your pet three to four hours before the trip and give it a light meal when you stop for the night.
- Stop at rest areas and give your pet some water as well as a chance to run around. Give your cat access to a litter box.

MOVING TO ANOTHER COUNTRY

Prepare to move your pet in advance of an overseas trip. You can save yourself and your pet a lot of hassle and potential heartache by understanding the ins and outs of rules of your destination country. Different nations have different rules and quarantine requirements associated with the relocation of cats, dogs and other types of pets.

- Contact the consulate or embassy in the country to which you were assigned to learn about the rules for bringing in pets.
- Many overseas destinations require that pets have microchips with a number that matches the number on the health certificate.
- Check the airline travel requirements for pet crates before buying a crate.
- Write your name, your pet's name and your destination address on the crate. If your pet is unfriendly, then put a warning on the crate.
- Ask your airline if you need to reserve a space on the flight for your pet.
- Some countries may require your pet to be quarantined for an extended amount of time before it can live with you. The cost associated with that quarantine can be pricey. The Department of Defense may reimburse you for up to \$550 (www.defensetravel.dod.mil/site/faqpet.cfm) if you are an active-duty member moving to a country where the quarantine period is mandatory.
- The Department of Defense will not reimburse you for the relocation cost associated with moving your pet from one country to another.

Help ease the stress your family and pet might experience during a major move by knowing what to expect before you begin to pack. Various transportation rules and health regulations could impact you and your pet, and you will want to be prepared to deal with them when they arise. Each installation has its own rules regarding pets. Contact your new installation (<https://installations.militaryonesource.mil>) to get specific information before your move.

— Military One Source



[Coronavirus.org](https://www.coronavirus.org)

Artwork by Shepard Fairey | Amplifier.org



Level 3

The girl's father told me that he was retired, but his spouse was still active duty. "When you have a special needs kid, it's so hard to get services so we are stretching this post out. My wife is on her third year here."

It was the third time I had read the same page in a novel I kept in my purse. The book I chose started out slow and I was hoping the story would start to pull me in to become an enjoyable read. I was sitting in a salon waiting room while my mother got her haircut. I figured between the book and my phone, I would have plenty to occupy my time. It was only going to be about 45 minutes.

I looked up from my book when I heard the front door of the salon open. It was a man carrying an Army backpack, pushing a girl in a special needs stroller. To avoid staring, I quickly looked down at my book to continue reading after noticing him choose a seat next to me. My eyes kept leaving the page as I watched her in her stroller. She was nonverbal and was reaching out to him. He grabbed several things to appease her, but you could tell that she was not content with the choices he gave her. I smiled and said, "I don't think she wants those pretzels. She wants your phone." He looked over at me. "She's not getting my phone. She destroys everything she gets her hands on." He showed me his phone with a crack in it.

Watching her mannerisms, I noticed similarities to my son, Broden. It was evident that she had multiple diagnoses, but I was curious if autism was one of them. After getting a closer look at his backpack, I knew he had to be Army. I asked,

"Do you live at Jackson or do you live off post?" He was surprised I asked the question so matter of fact and told me that they chose to live off post this time. I told him that we decided to live on post this time around. He told me that he was retired, but his spouse was still active duty. "When you have a special needs kid, it's so hard to get services so we are stretching this post out. My wife is on her third year here." He was waiting on her while she was getting her hair done. I then looked over and saw his wife with wet hair walk over to make sure he was doing ok. He nodded to her, encouraging her to continue with her hair appointment.



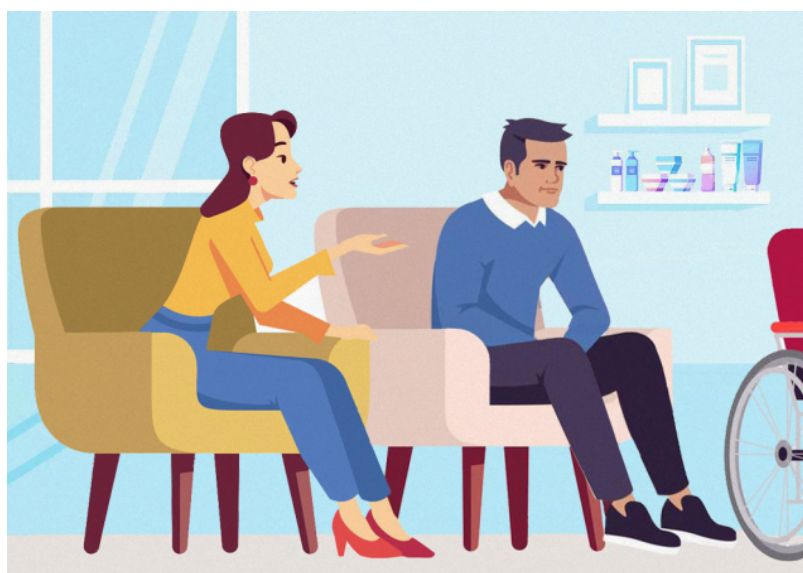
son with autism. It's really hard." He leaned in and said, "Really? Well my daughter is a level 3. What's your son?" I knew exactly what he was trying to figure out. How hard did I have it? Level 1 is high functioning autism. Level 2 is moderate,

and level 3 is a different story. Level 3 autism is severe. I looked over and responded, "My son is a level 3."

Once I said, "level 3", his eyes opened wide and he shifted his body towards me. "Your son is a level 3? Is he verbal? Does he have SIB (self-injurious behavior)?" I started to answer his questions. He began to open up about how life-changing it was to raise his daughter, including the effort involved when his spouse works such long hours. All I could do was nod in agreement. I got it. He didn't need to prove anything to me. The more I listened to him, the more I admired him.

I opened up a little bit to validate his frustrations and recalled a time at Leavenworth, Kansas when an ER doctor threatened to turn me in to social services because he thought I was hurting our son, only for him to be diagnosed a week later with severe

autism. His face lit up after I told him the story and said, "Me too! They came to my house! My daughter has SIB and they thought I was hurting our daughter. My



LEVEL BEST: "He grew emotional and started to raise his voice, "Nobody loves my daughter like I do! I have fought for her when doctors wouldn't do anything for her!" He apologized, but I reassured him that he had every right to be upset and it was okay.

We continued talking and he started to open up about how difficult it was serving in the Army with a special needs kid. I nodded and said, "Yea, I get it. I have a

wife was sent back from deployment because they thought I was hurting our daughter.”

My heart ached for him. I responded, “I feel like I have OCD with my son’s food and care now. Even though it wasn’t my fault when that ER doctor threatened me, I still feel like I have to prove to everyone that I love and care for my son enough.” He grew emotional and started to raise his voice, “Nobody loves my daughter like I do! I have fought for her when doctors wouldn’t do anything for her! How could they accuse me of that?” He started to wipe away a tear.

I sat in the chair quietly and nodded in agreement. I believed him. No one loved her like he did. He apologized for getting emotional, but I reassured him that he had every right to be upset and it was okay. I kept telling him that he had every right to be upset. The more he talked, I felt like a hole had been poked in his chest, hot steam would shoot out and burn the side of

the salon. After sharing stories of Broden and listening to more stories of his child, I looked up and realized that my mother was done and ready to leave

“We both realized it was time for me to go. All I got was a first name. We weren’t done. He still had more of his story to tell and I needed to still sit next to him and listen.”

the salon. I wish I would have asked for an email or phone number. All I got was a first name. We weren’t done. He still had more of his story to tell and I needed to still sit next to him and listen.

We both realized it was time for me to go. I looked at his daughter and smiled. He was a true father warrior and I

couldn’t find the words to express my admiration for his determination to care for his daughter and the loyalty he had to his family. He cares for their daughter so his wife can put on her uniform every day.

As I walked towards the salon door I said, “I will be thinking about you. Thank you for sharing your story with me.” He smiled and said goodbye. I don’t know if I’ll ever see him again, but I will never forget his story. •

PUZZLES & CAMO

Shelly Huhtanen is an Army wife stationed at Fort Benning, GA who has a child with autism. She enjoys sharing her experiences of day-to-day life caring for her son with autism while serving as an Army spouse. She authored “*Giving a Voice to the Silent Many*” that encompasses many stories of raising a child with autism in the military. Shelly is passionate about autism advocacy for our military and works to bring awareness to our local legislators and command about providing better support for our military autism community, such as better health care and education.



#Be There
for Veterans and Servicemembers

 **Veterans
Crisis Line**
1-800-273-8255 **PRESS 1**

PRODUCTS AND SERVICES

ADAPTIVE/SPECIAL NEEDS BEDS

KAYSERBETTEN

P: 800-574-7880

E: ruthann@kayserbettenus.com

W: www.kayserbettenus.com

KayserBetten beds ensure special needs children are in a safe secure adaptive health care special needs bed.

AUTONOMOUS DRONE SOLUTIONS

DRONE USA INC.

www.droneusainc.com

Drone product reseller, distributor, and service provider to police, firemen, industry and the U.S. government.

FINANCIAL PLANNING/ ESTATE PLANNING/ INSURANCE

MASS MUTUAL SPECIALCARE

www.massmutual.com/specialcare

Financial planning products and services by a company that cares.

FINANCIAL PLANNING EDUCATION

THE AMERICAN COLLEGE OF FINANCIAL SERVICES

www.theamericancollege.edu

A private college focused on professional training for financial practitioners

NON-PROFIT

IRENE AND ERIC SIMON BRAIN RESEARCH FOUNDATION

www.iesbrainresearch.org

Helping to further research and find answers to addiction, pain and other brain diseases and disorders.



HOME ADAPTATION/DESIGN

LJS ELECTRIC

www.ljselectric.com

Home automation products and devices professionally installed.

SCHOOLS/CAMPS/RESIDENCES

CAMP LEE MAR

P: 215-658-1708

E: ari@leemar.com

W: www.leemar.com

Private 7 Week Summer Camp For Children With Special Needs, Founded In 1953.

Unique Curriculum. Comfortable & Secure.

THRESHOLD PROGRAM AT LESLEY UNIVERSITY

Cambridge, MD

W: www.Lesley.edu/threshold

P: 800-999-1959 ext. 8181; or 617-349-8181

E: threshold@lesley.edu

A two-year, on-campus college experience for students with diverse learning challenges.

A PROVEN WINNER!

ADVERTISE IN EP MAGAZINE

Exceptional Parent is an award-winning publishing and communications company that has provided practical advice, emotional support and the most up-to-date educational information for families of children and adults with disabilities and special healthcare for over 49 years.

Advertising in EP Magazine is an effective form of communicating both brand and product-specific messages to our targeted and motivated audience. EP's specific demographic guarantees that you reach your intended customers.

For information, contact:
Faye Simon
 Sales & Marketing Manager
 (800) 372-7368 ext 234
 fsimon@ep-magazine.com

COMING NEXT MONTH IN EP: THE ANNUAL HEALTHCARE ISSUE



TO LEARN MORE
ABOUT ADVERTISING
OPPORTUNITIES

CALL 800-372-7368 EXT 234
OR EMAIL FSIMON@EP-MAGAZINE.COM

IS YOUR FAMILY CYBERFIT?



Protect your family. Protect your country.
Teach your kids online safety.
TRICARE.mil/CyberFit



Special needs require *Special Care.*

When you're ready, we're here to help. MassMutual's *Special Care* program provides access to information, specialists and financial products and services to help families facing the financial responsibilities of raising a child with a disability or other special needs. To learn more about how a financial professional can help your family, visit [MassMutual.com/SpecialCare](https://www.massmutual.com/SpecialCare)

Insurance. Retirement. Investments.

 **MassMutual**

SpecialCare
a special needs program developed by MassMutual