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EXCEPTIONAL PARENT
MAGAZINE
JULY 2018
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INSIDE THIS ISSUE:

EXPAND THE LIMITS *of* YOUR HOME

EP's ANNUAL ACCESSIBLE HOMES ISSUE:

PET SPACE DESIGN

+ ANIMAL THERAPY

AND:

CREATING ACCESSIBLE HOME BATHROOMS *for* KIDS

PLUS:

PROJECT FREEDOM *and* INDEPENDENT LIVING

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TRAVEL *and* AUTISM WITHOUT FEAR

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ON OUR COVER

Pets and assistance animals bring pure happiness and joy. By making pet spaces useable and functional, youngsters with special needs will be more empowered to participate in the care of their pets. Learn about pet spaces and much more in our Annual Accessible Homes Issue.
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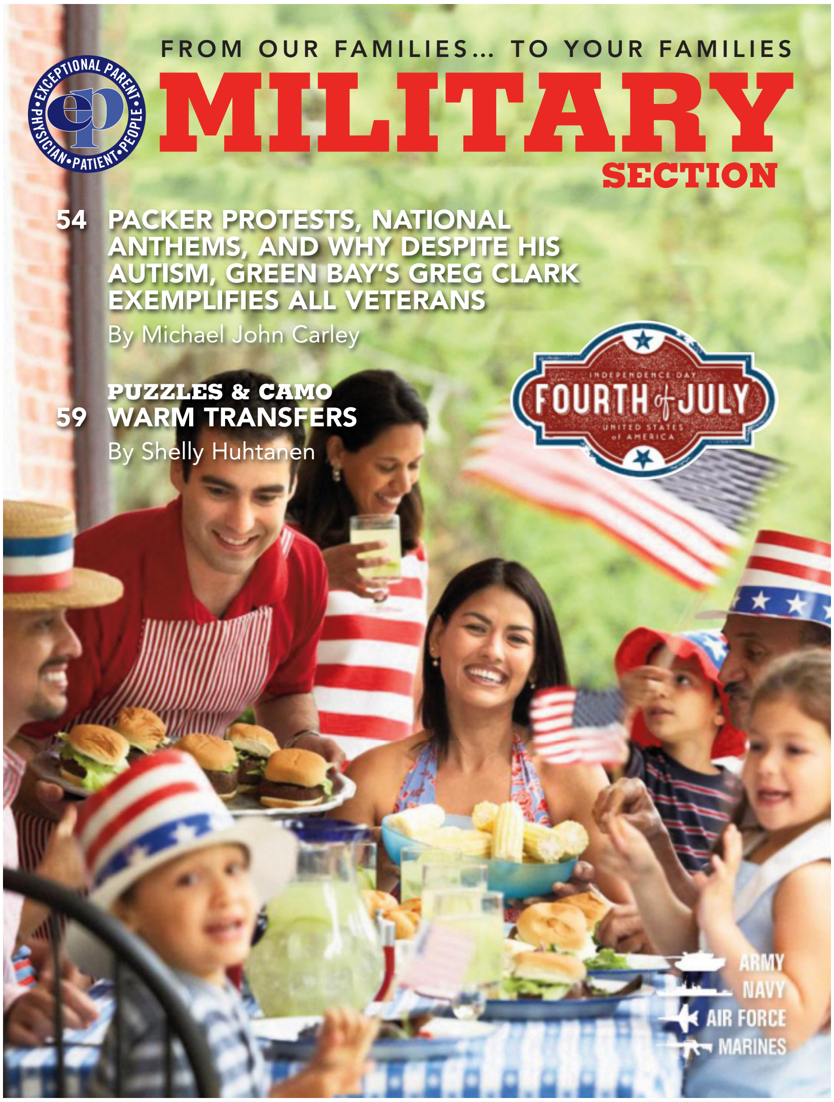

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Information and Support for the Special Needs Community

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— Rick Rader, MD

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

ANCORA IMPARO RICK RADER, MD ■ EDITOR-IN-CHIEF

A Breath of Fresh Air

The idea that odor might be a key in disease determination is not new. Almost 2,000 years ago, one of the originators of ancient Hindu medicine stated, "by the sense of smell we can recognize the peculiar perspiration of many diseases, which has an important bearing on their identification."

One of my fondest memories of being a medical student in London was the weekly Liver Rounds conducted by one of our professors at a pub called The Faltering Fullback. I have always been fascinated by the creative names of British pubs and the images they conjured up. Take the Bucket of Blood, The Jolly Taxpayer, Bunch of Carrots, The Cat and Custard Pot, The Hung Drawn and Quartered and, of course, the I Am the Only Running Footman. With names like those, the ales and lagers could almost be an afterthought. Those names were far more impressive than the lame The Swan or The Black Mare.

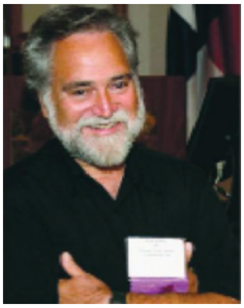
Some American watering holes were not to be outclassed by the Brits. We have had our own versions of imaginative names for watering holes. There is Psycho Suzi's Motor Lounge and Tiki Garden, Hard Times and Misery, The Fainting Goat, Otto's Shrunken Head and The Fat Angel. One of my favorites, simply based on the name, is Hog's Breath Saloon. One didn't really need to have ever been close enough to a hog to smell its breath to get the picture. The name was a siren when it first opened up in Ft. Walton Beach, Florida in 1976, and it was so successful it led to several locations with the same name. The actor Clint "Make my day" Eastwood owned the one in Carmel, California. The tag line of the saloon was also unforgettable: "Hog's breath is better than no breath at all."

And, of course, there is some truth to that slogan. No breath equals death, and if the key to life was smelling like a hog, well it's certainly a viable option.

The impact of odors was best described by Patrick Suskind, "Odors have a power of persuasion stronger than that of words, appearances, emotions, or will. The persuasive power of an odor cannot be fended off, it enters into us like breath into our lungs, it fills us up, imbues us totally. There is no remedy for it."

Odors can not only be seductive, they can be diagnostic as well. Kids for instance. Unusual breath odors are common in kids. Take the following list of odor-based diagnostic clues and the related diseases or disorders they might reveal.

Acetone (fruity smell) diabetes or acetone, alcohol, phenol, or salicylate ingestion. Ammonia might be some type of urinary tract infection or kidney failure. Bitter almonds suggest cyanide poisoning. Cat's urine could be, get ready for this one, "beta-methyl-crotonyl-CoA-carboxylase deficiency," (don't expect the Minute Clinic at your local CVS to make that connection). Dead fish is a dead ringer for trimethylamine oxidase deficiency, garlic could be arsenic poisoning, horse-like (often described as mouse-like or musty) could be phenylketonuria, rancid butter is likely hypermethionemia and hypertryrsinemia. And of course the diagnostic give-away of the odor of sweaty socks would be reflective of Isovalryl CoA dehydrogenase deficiency.



HIGH ON THE HOG: The Hog's Breath Saloon sign and beer coaster. "There is some truth to that slogan. No breath equals death, and if the key to life was smelling like a hog, well it's certainly a viable option."

These tell-tale pediatric disorder-linked odors are reason enough for parents to climb into bed each night to read to their children. They will never suspect that you are really doing a scratch and sniff test.

In the not too distant future, the responsibility of smelling your children will not be something that parents will be required to perform. Thanks to Artificial Intelligence (AI), machines will be able to decipher the chemical compounds in breath samples. According to a recent article in Neuroscience News, "Mathematical models inspired by the brain, called deep learning networks, were specifically engineered to read the traces of compounds left by odors. A team of physicians, nurses, radiographers and medical physicists from the Edinburgh Cancer Center collected breath samples from participants undergoing cancer treatment." The team analyzed the samples and converted them to data points that would be recognized by accelerated computation techniques. Rather than try to describe the mechanics of "deep learning networks," let's just say that the technology makes the robotic vacuum cleaner look like a pitch-

IMAGES COURTESY WWW.HOGSBREATH.COM/HISTORY fork. The use of AI will be capable of identifying volatile compounds in breath odors to a set of disorders related to a variety of pathogens and other organic culprits that could suggest disease states, long before the symptoms and deficits announce themselves. The odors would be the equivalent of fingerprints, unique and novel to each disease or pathology.

The idea that odor might be a key in disease determination is not new. Almost 2,000 years ago, Sushruta Samhita, one of the originators of ancient Hindu medicine, stated, "by the sense of smell we can recognize the peculiar perspiration of many diseases, which has an important bearing on their identification."

Parents of children with special healthcare needs also have an array of distinguishing odors. From the moment one of them enters the examination room with their child, the astute clinician can tell an "exceptional parent" has crossed the threshold. Odors have historically been described as wispy, rancid, airy, musty, stale, fresh, putrid, faint, light, floral and acrid. None of them describe the fragrance of determination, commitment, strength, focus, perseverance, stamina and resourcefulness.

It's safe to say that the vast array of the characteristic odors needed and displayed by exceptional parents would confuse the most sophisticated attempts of any device fueled by artificial intelligence. The most advanced deep-learning networks would be stymied and derailed by the infinite combinations of odors given off by exceptional parents.

I have no doubt it would result in seeing a bus load of AI engineers, scratching their heads and heading towards the nearest "Hog's Breath Saloon" to start over again. •

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

Introducing Our All-New Website WWW.EP-MAGAZINE.COM

Exceptional Parent Magazine is announcing 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 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.

PLEASE NOTE
that our previous web address, eparent.com, is no longer associated with our magazine.

WHAT'S HAPPENING

AUTISM SPEAKS AND DNASTACK COLLABORATION

Accelerating Scientific Discovery on One of the World's Largest Autism Genome Databases

DNAstack, a software company that develops a cloud-based platform to manage, analyze and search genomic datasets, and Autism Speaks recently announced a collaboration to enhance the Autism Speaks MSSNG research portal, designed to facilitate research to understand the complexities of autism spectrum disorder. Through this collaboration, DNAstack will organize one of the largest collections of autism genomes in the world, making them more accessible and analyzable, accelerating the pace at which researchers can use the resource to make discoveries.

The Autism Speaks MSSNG project will help researchers answer the many remaining questions about the genetic underpinnings of autism by sequencing the DNA of more than 10,000 families affected by autism. The omitted letters in MSSNG (pronounced "missing") represent the missing information about autism that the research program seeks to deliver. Through the MSSNG Database for Autism Researchers, the project provides open access to de-identified whole genome sequences as well as tools for analysis, with the aim of advancing personalized treatments by deepening understanding of the many subtypes that make up the autism spectrum.

"Sharing data in the MSSNG database and making it easy for researchers to analyze is crucial to our goal of understanding autism and accelerating discoveries," said Dr. Dean Hartley, Autism Speaks senior director of discovery and translational science. "We are excited about how our relationship with DNAstack will help us move the needle on open science. Their technology will bring this resource to a new level by empowering researchers to more efficiently investigate genomic data." Dr. Hartley adds that this collaboration will also increase accessibility by building on global standards developed through the Global Alliance for Genomics and Health (GA4GH).

Despite decades of research, there is much more to be done to understand the genetic variations that lead to differences on the spectrum, and to develop more personalized and effective treatments and support services. Working with Autism Speaks, DNAstack will build new features that will make it easier than ever before for autism researchers to use the data within the MSSNG resource, including:

GAINING THE UPPER HAND: Research using the MSSNG genomic database has identified 61 genetic variations which could lead to earlier diagnosis and potential personalized treatments for autism.

- *A data discovery portal that allows researchers to find datasets of interest based on genomics and clinical features, and create custom collection;*
- *A bioinformatics workflow integration allowing researchers to run custom and best-in-class analyses in order to, for example, find new variants or do case/control studies;*
- *A data-sharing beacon enabling researchers worldwide to identify autism-specific information about genomic variants of interest.*

"The genetics of autism is complex, but we've made great progress because the research community can access genomic information," said Dr. Stephen Scherer, research director of MSSNG, and director of the Centre for Applied Genomics at Toronto's Hospital for Sick Children (SickKids) and the McLaughlin Centre at the University of Toronto. "MSSNG is a powerful resource to identify new subtypes of autism and study their underlying genetics and biology. Enhancing research capabilities and improving collaboration will further advance scientific discovery in autism."

"We believe that sharing data is one of the most important things we can do to accelerate discovery and the realization of precision medicine, not just in autism but in other conditions as well," said Dr. Marc Fiume, CEO of DNAstack and co-chair of the Discovery Work Stream for the GA4GH. "By sharing data on the cloud, MSSNG has set an important precedent in open science. DNAstack is excited to help further Autism Speaks' mission in making this resource even more accessible to the research community and impactful than ever before."

DNASTACK

DNAStack develops a cloud-based platform for genomics data analysis and sharing. DNAstack provides push-button access to state-of-the-art technologies to help researchers, clinical laboratories, and pharmaceutical companies more quickly and cost-effectively make sense of the world's exponentially accumulating genomics data and break down barriers to data sharing.

AUTISM SPEAKS
It's time to listen.

Autism Speaks is dedicated to promoting solutions, across the spectrum and throughout the life span, for the needs of individuals with autism and their families. We do this through advocacy and support; increasing understanding and acceptance of people with autism spectrum disorder; and advancing research into causes and better interventions for autism spectrum disorder and related conditions. To find resources, join a fundraising walk or make a donation, go to www.AutismSpeaks.org

PHOTO COURTESY BLOG.DNASTACK.COM

WHAT'S HAPPENING

The Arc Responds to the Department of Education's Rescinding of Affirmative Action Guidance

The Trump administration, in June, rescinded guidance the Department of Education provides to colleges, universities and K-12 schools on how they can use race and ethnic background in admissions decisions to promote diversity.

EDUCATION SECRETARY BETSY DEVOS: The departments of Justice and Education announced that they have retracted documents that advised schools on how they could legally consider race in admissions and other decisions.

The Arc has released the following statement in response to the Trump Administration's actions:

This is the latest of a series of moves that shows this Administration's intentions to chip away at the instruments that have been put in place to increase equity and access to quality education for our country's most vulnerable populations.

"Two weeks ago, The Department of Education and the Department of Justice delayed by two years a regulation intended to prevent race-based imbalances in pre-school and K-12 education for students with disabilities, a regulation whose delay was opposed by the vast majority of parents, students and administrators who submitted public comments.

"Earlier this year, the Administration also indicated its intent to rescind a guidance package to prevent racial disproportionality in public school discipline. While guidance documents are non-binding practical tools that help school systems follow the law, the Trump Administration's collective actions make clear that it is scaling back efforts made by previous administrations to encourage diversity in our schools. This is a troubling trend in policymaking that may lead to poorer education outcomes for many Americans with and without disabilities," said Marty Ford, Senior Executive Officer of Public Policy, The Arc.

WALGREENS RECEIVES TOP-SCORE ON THE 2018 DISABILITY EQUALITY INDEX

Walgreens recently received the top-score of 100 percent on the 2018 Disability Equality Index

The Disability Equality Index® (DEI) is a national benchmarking survey and report on corporate policies and practices related to disability inclusion and workplace equality, administered by the American Association of People with Disabilities (AAPD) and the U.S. Business Leadership Network (USLBN). This marks the second consecutive year Walgreens has earned a 100 percent score from the DEI and named one of the DEI Best Places to Work for Disability Inclusion.

"Walgreens is proud to foster a disability inclusive culture through two programs to train and hire people with disabilities in our stores and distribution centers, where our team members work side-by-side to perform the same jobs for the same pay," said Carlos Cubia, vice president and global chief diversity officer of Walgreens Boots Alliance, Inc.

"It's an honor to be acknowledged by the Disability Equality Index for our commitment to a diverse and inclusive workforce that aligns with our purpose to champion the health and well-being of every community in America."

The DEI is a national, transparent benchmarking tool that offers businesses an opportunity to receive a score on a scale of zero (0) to 100, on their disability inclusion policies and practices. It is a joint initiative of the American Association of People with Disabilities (AAPD) and the U.S. Business Leadership Network (USBLN), developed by the DEI Advisory Committee, a diverse group of business leaders, policy experts, and disability advocates.

Walgreens joins the ranks of 126 U.S. businesses, which also earned the designation this year. •

PHOTOS COURTESY GAGE SKIDMORE; WWW.DISABILITYEQUALITYINDEX.ORG

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From leading devices to expert advice to the opportunity to network with others in the community, Abilities Expo has everything you need, all under one roof!

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Los Angeles	**Feb 22-24, 2019**
Toronto	**April 5-7, 2019**
NY Metro	**May 3-5, 2019**
Chicago	**June 21-23, 2019**

Abilities EXPO | The event for the disability community

www.abilities.com/expos

Register online today to bridge the gap between ability and disability. Come for the products, stay for the fun!

NEW PRODUCTS TOUCHY SUBJECTS

GEL FLOOR TILES

These Gel Floor Tiles are designed for children with sensory processing or integration disorder, ADHD, or autism to encourage sensory integration and stimulation, visual processing, and gross motor skills. They feature bright cosmic liquid colors that flow and ooze as children push, jump, or dance on their surface. No installation required. Use with soft shoes or no shoes to avoid scratching the tiles. Each tile is 20 inches x 20 inches. Colors include Pink, Blue, Purple, Green, Red/Blue and Orange.

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CLATTERPILLAR

The Clatterpillar is a therapeutic musical toy for children ages 3 and up to help young children with disabilities develop rhythmic movement, coordination, and improve upper extremity motor skills. Features smooth, handle-like ends for easy gripping. As the child raises one hand and lowers the other the Clatterpillar come to life with exciting clattering sounds. The Clatterpillar can encourage a child's interest in music, help them develop their coordination and motor skills, and develop rhythmic movement.

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GRABEASE UTENSILS

Grabease are ergonomic utensils designed for infants and toddlers to encourage self-feeding and independence when eating. They are easy to grasp and pick up, giving children the opportunity to eat independently. The individual sets include one pair of utensils (spoon and fork). The set comes in an individual box set with a travel EVA pouch and stickers. Made of BPA-free and Phthalates-free, non-toxic plastic. Wash before use. Dishwasher safe.

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ABLEDATA

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

NEW PRODUCTS

BATH BUDDY MITT

The Bath Buddy Mitt is designed for children with sensory disabilities to provide proprioceptive feedback to improve grip. The mitts can be used as a puppet for children who need to increase finger flexibility. They can be also be used as a "helper" while feeding, or by children who enjoy toys in the bath. They are made of a 100% cotton exterior with a thin layer of foam and nylon interior. Mitts maintains their shape. Machine wash on gentle cycle or hand wash using detergent. Use warm or cold water to maintain color brightness. Lay flat to dry or tumble dry in dryer on low heat. Options include Duck or Hippo.

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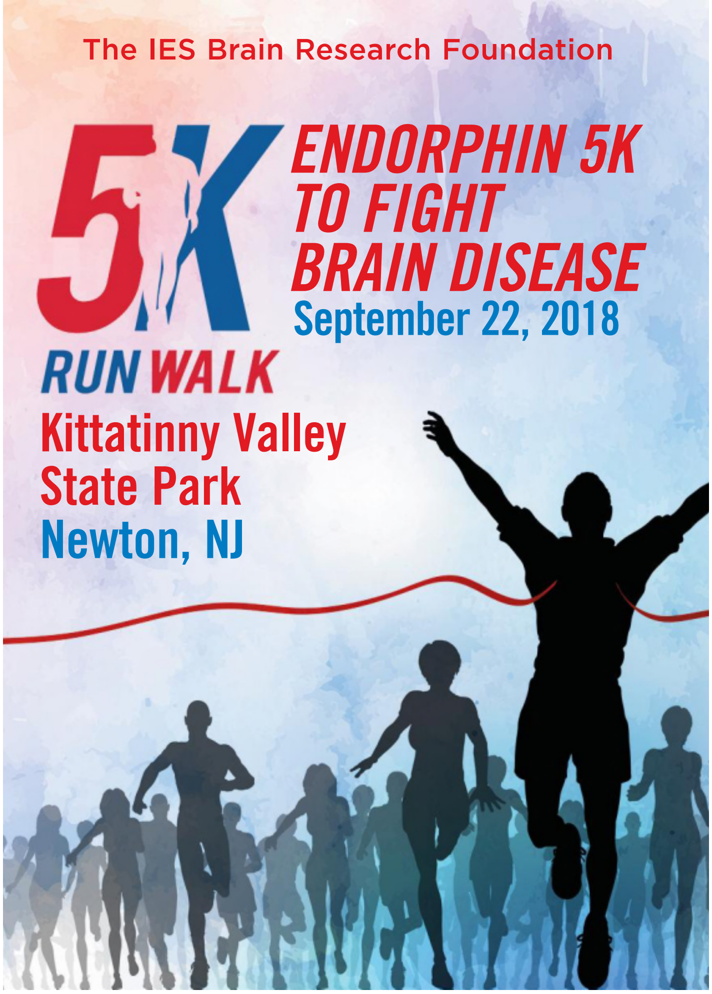

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Track 17 and Individuals with Disabilities

Track 17 and so many other memorials remind us how easy it is for us to forget the individuals and their families who are affected by indifference to the struggles of others.

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

There are untold numbers of memorials that detail the horrors associated with World War II. The millions who died in the holocaust that consumed individuals of all ages, gender, races, religions, ethnicities and ability to work (particularly in slavery) are detailed in the libraries of documents produced by the perpetrators of these inhuman actions.

As decades have passed, the reminders of these acts are relegated to black and white films, and stories by fewer and fewer survivors who relate their experiences to the next generations for whom current events overshadow the unfathomable numbers in the tens of millions of who were lost. The reality of these senseless events are relegated to the world of history books.

One strange memorial in the suburbs of Berlin, Germany tells the story in a most subtle and understandable manner – the impact on small numbers of people and families at a time. Track 17 looks like any railroad station. Ribbons of steel lead into the distance – **However…**

Next to each rail are plaques which detail the daily numbers of individuals who were torn from their families on particular dates – shipped to some nameless location where they were encouraged to believe that they were being sent to begin life anew. – They were never to be seen again. (For example).

10. 1. 1944 – 353 Juden (Jews)

10. 3. 1944 – 190 Juden – Berlin to Auschwitz

We learned that these particular individuals and unbelievable numbers of others of the many religions, races, ethnicities and *individuals with disabilities* who couldn't work were murdered immediately. (Auschwitz was primarily a slave work camp with some gas chambers; the associated location, Birkenau, was a death camp.)

TODAY'S WORLD

We have made considerable advances during the following decades in the care of individuals with disabilities. They are no longer confined to institutions or the back rooms of homes. Dependent upon the degree of disability, they live and work in our communities. Nevertheless, all too many with capabilities for employment are faced with limited opportunities, lack of educations and the unwillingness by employers to provide needed placements.

LABOR FORCE CHARACTERISTICS

In 2016, 11.9% of U.S. individuals (16 years and older) with a disability, compared to 65.3% individuals with no disabilities were employed.

- *For all age educational attainment groups, jobless rates for persons with a disability were higher than those for persons without a disability. Persons with a disability are less likely to have completed bachelor's degrees or higher than those with no disability*

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.

- *34% of persons with a disability, compared to 16% of persons with no disability, were employed part-time.*
- *Employed persons with a disability were more likely to be self-employed than those with no disabilities.*
- *Persons with a disability, were more concentrated in service occupations than those with no disabilities.* [1]

However, labor employment statistics are not uniform throughout the country. For example, in 2015, among non-institutionalized working age **(ages 21-64 years)** people with disabilities, 35.2% were employed, compared to 78.3% of people without disabilities. Major variations in employment rates among the states for working age individuals with disabilities ranged from:

Less than 30%: Alabama, Kentucky, Maine, Mississippi, Puerto Rico, South Carolina; with the lowest rate of 25.8% in West Virginia

Greater than 45%: Iowa, Minnesota and Wyoming

Greater than 50%: South Dakota and the highest rate of 59.9% in Wyoming

Among individuals **without disabilities,** employment rates ranged from 56.4% in Puerto Rico and 72.5% in West Virginia, to 85.1% and 85.3% in New Hampshire, North Carolina and Nebraska.

GHASTLY FIGURES: In the suburbs of Berlin, plaques near the railroad station detail the daily numbers of individuals who were torn from their family on particular dates; never to be seen again.

In Maine and Kentucky, the proportion of individuals without disabilities who were employed was **three times** the rate for individuals with disabilities; respectively, 82.5% vs 27.5% and 76.7 vs 26.9%.[2]

SOME QUESTIONS: WHY ARE THERE MARKED DIFFERENCES?

- Are the marked variations of employment proportions a reflection of differences in regional industrial characteristics; e.g. agricultural vs. manufacturing?
- Are there limited educational opportunities to prepare individuals with disabilities for employment in some regions?
- Are there limitations in transportation for individuals with disabilities in local areas?
- What polices are in place to encourage the employment of individuals with disabilities?
- Are local government agencies working to improve the employment status of individuals with disabilities?
- How active are families in the development of necessary avenues to prepare their communities to ensure the employment of youngsters and older individuals with disabilities?

PLANNING FOR THE FUTURE

Preparing a child with a disability for adulthood involves multiple issues beyond those faced by all children. The added burden is to ensure that, to the limit of his/her capabilities, they are able to function in all areas of activities – even including the arena of employment.

> ***"Job. J-O-B. That word has music and beauty to me. It is not just about money. It is knowing your kid will have a place in the world."*** [3]

It may seem premature. Nevertheless, testing and directive efforts can provide a foundation for the development of training and experiences leading to areas of employment. For example, summer and holiday programs for youngsters with disabilities could lead to employment opportunities; as potential employers can recognize their potential abilities for future consideration.

Track 17 and so many other memorials remind us how easy it is for us to forget the individuals and their families who have been and are affected by indifference to the struggles of others. Youngsters with disabilities must be prepared to overcome these realities if they are to succeed to the limits of their difficulties; even in the employment arena.

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References

1. Bureau of Labor Statistics. Persons with a disability: labor force characteristics survey. Available from: https://www.bls.gov/newsrelease/disabl/nr0.htm. Accessed September 20, 2017.

2. Cornell University. 2015 Disability Status Report United States. Available from: http://www.disabilitystatistics.org/StatusReports/2015-PDF/2015-StatusReport_US.pdf?CFID=1938350&CFTOKEN=d9671429e6557443-3E7D34C3-EF9D-DA98-E2FAF11577349851 Accessed September 20, 2017.

3. Newman J. Opening doors for my autistic son. Reader's Digest 2017;22(76):88-98.

While it may seem like many are against the use of service and support animals due to frequent abuse of their titles, legitimate cases are protected by the ADA and Air Carrier Access Act. It is also important to remember that service and support animals are indeed working animals – those vests may be adorable, but what they represent is no joke.

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PHOTO COURTESY AFP/GETTYIMAGES/

YAY or NEIGH

The Ins and Outs of Alternative Service Animals

BY ANNE ABRAHAM

"Working Dog, Do Not Pet": something many of us have read at least once, embroidered onto the vest worn by an obedient (and oftentimes, adorable) service dog. However, how many of us can say they've encountered "Do Not Touch, Service Animal On Duty" emblazoned across the vest of a... mini horse?

Within the last decade, mini horses have steadily grown in popularity as an alternative service animal option for the blind community. In 1999, the Guide Horse Foundation was created to train and supply mini horses as service animals. At first glance, the appeal of a guide horse, as opposed to a traditional guide dog, may not be explicitly clear. However, according to the Guide Horse Foundation, there are many advantages to a guide horse. Mini horses have a lifespan of more than 30 years, which is significantly longer than that of a dog, and therefore makes guide horses a more long-term, cost-effective option. Additionally, a longer lifespan means the potential for a deeper relationship between guide horse and handler. Mini horses also tend to be more mild-mannered than dogs, have exceptional memory and eyesight, and are reportedly very clean and can be housebroken.[1] Of course, owning a guide horse is very different from owning a guide dog – mini horses consume a specialized diet of hay and oats, require a large outdoor space, and need to relieve themselves more often than dogs.

HORSE SENSE: *(Opposite page)* Mona Ramouni came from a devout Muslim household and could not own a guide dog. A guide horse was the best option for her.

Other than practicalities, people may choose a guide horse for many reasons, including simple personal preference, a dog allergy, or even religion. In 2010, *Today* told the story of Mona Ramouni, a young blind woman from Michigan who could not own a guide dog.[2] Mona came from a devout Muslim household that did not allow the keeping of dogs in the house. Therefore, a guide horse was the best option for Mona. Mini-horses are highly intelligent and make exceptional service animals, a concept that many do not realize until seeing them in action, working with their handlers.

There are many accounts of the use of alternative service animals. In 2008, the *New York Times* told the story of Jim Eggers and his "assistance parrot," Sadie.[3] Jim has bipolar disorder with frequent psychotic tendencies including homicidal feelings. He describes living with this condition "like when the Incredible Hulk changes from man to monster." However, he notes that Sadie quells his outbursts and allows him to function in society. Jim recalls that before he adopted Sadie, he would frequently talk out loud to calm himself down, though it rarely worked, and he often landed in court for his outbursts. After adopting Sadie, she began mimicking his words in these situations – "calm down, Jim, it's okay, Jim" – and according to Jim, Sadie's calming words worked better than his own. Since having Sadie, Jim has not had a single public episode, and credits her with "keeping [him] from snapping." Sadie is also trained to alert Jim to knocks on the door, fire alarms, etc., as Jim's antipsychotic medications often leave him in a "mental fog."[3] Despite a parrot being a seemingly unusual choice, Jim and Sadie's relationship truly works.

Though there is evidence to show the benefit of incorporating trained animals into the lives of those with health needs, in recent years there has been growing unrest and resentment toward the world of service animals. The Americans with Disabilities Act, otherwise known as the ADA, initially defined "service animal" as "[any animal] individually trained to provide assistance to an individual with a disability...are considered service animals."[4] With such a broad definition, many people started to abuse the rule by falsely claiming their dogs, cats, snakes, birds, etc. as "service animals" or "emotional support animals" and unlawfully bringing them into public establishments. In some cases, this resulted in injury to other people and even to actual service animals, and also frequently posed a health risk in restaurants. Of course, not all of these cases involved "fraud" service animals – there are many alternative service animals out there (like the cases of Mona or Jim and Sadie) that shock people and sometimes make them uncomfortable. For example, parrots and snakes are often used as "psychiatric support animals," and capuchin monkeys are frequently trained to help quadra- or paraplegics perform a variety of day-to-day tasks.[3]

"Service and support animals are major monetary and emotional investments, and their quality of life is just as important as a person's treatment."

Due to this controversy of fraudulent service animals, the ADA's definition of service animals was revised to only include dogs and expressly forbade other species of animals "whether wild or domestic, trained or untrained."[5] However, because of the growth in popularity and proven success of guide horses, a clause was added to the ADA to recognize guide horses as an exception and granted them the same "rights" as guide dogs, with a few additional regulations regarding mini horse's size and whether or not it is housebroken.[5]

But what about the more "exotic" service animals? While these "alternative" service animals are incredibly helpful for those that have them, since the ADA does not recognize or approve them, they are not allowed in public places like restaurants or grocery stores with their handlers like guide dogs or horses. Due to this, those who suffer from psychiatric disorders or paralysis who could benefit from an alternative service animals help must find other solutions. This means that now, Sadie may not be allowed in public settings with Jim, which could possibly endanger himself and others, as well as put a limit on what he can do and where he can go on his own.

Additionally, the ADA does not recognize emotional or psychiatric support animals in its definition of "service animal." This means that, although support animals may be a medically prescribed part of a treatment plan for mental health conditions like depression, anxiety, or loneliness, they are not protected by the ADA and businesses can deny them and their handlers entry.[5] Despite this, the Air Carrier Access Act issued by the U.S. Department of Transportation in May 2018 ensures that travel with most emotional and psychiatric support animals is just as accessible as travel with ADA-protected service animals. The act states "the Department [of Transportation] considers a service animal to be any animal that is individually trained to assist a person with a disability, or an animal that is necessary for the emotional well-being of a passenger." The act does further state that airlines have the right to refuse any support animals they suspect to be illegitimate. Therefore, proof of the animal's status as an emotional or psychiatric aid is necessary to ensure no problems arise during travel, though that proof can sometimes be as simple as a doctor's note.[6]

So, why does this matter to you as a parent? If your child lives with a special healthcare need and could benefit from the assistance of a service or support animal, you may want to consider alternative options. For children with dog allergies, a guide horse may make a great service animal, should your home and lifestyle fit a mini horse's needs. If your child could benefit from the introduction of an emotional or psychiatric support animal, a reptile or bird may also be a great option to avoid allergies, or if your home lacks the necessary space or amenities to care for a larger animal like a dog. Though the former two are not perhaps the easiest pets to care for or travel with, their presence may greatly improve your child's well-being.

As cute and sensational as a mini-horse may be, service and support animals are major monetary and emotional investments, and their quality of life is just as important as a person's treatment. It's wise to only consider purchasing an alternative service or support animal if your lifestyle and living situation are suited to caring for them. If you wish to pursue the idea of a service or support animal, alternative or not, speak to your health professional team and/or an advocacy organization that supports those with your child's condition for information on the considerations and process of acquiring a service or support animal.

While it may seem like many are against the use of service and support animals due to frequent abuse of their titles, legitimate cases are protected by the ADA and Air Carrier Access Act. It is also important to remember that service and support animals are indeed working animals – those vests may be adorable, but what they represent is no joke. "Man's best friend" may come in many forms, and it is important to find the best service or support animal option for your family. Whether they bark, neigh, or chirp, introducing a service or support animal into your or your child's life could dramatically change it for the better.•

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References

1. "Miniature Horse Facts." Guide Horse Foundation - Miniature Horses for the Blind. Accessed June 05, 2018. http://www.guide-horse.com/faq_horses.htm.
2. The Today Show. "Miniature Guide Horse Opens Doors for Blind Student." TODAY.com. November 15, 2010. Accessed June 05, 2018. MSNBC.
3. Skloot, Rebecca. "Creature Comforts - Assistance Animals Now Come in All Shapes and Sizes." The New York Times. December 31, 2008. Accessed June 5, 2018. www.nytimes.com/2009/01/04/magazine/04Creatures-t.html.
4. "Commonly Asked Questions About Service Animals in Places of Business." ADA.gov. December 1, 2008. Accessed June 05, 2018. http://www.ada.gov/archive/animal.htm.
5. "New ADA Service Animal Definition July 23, 2010." International Association of Assistance Dog Partners. Accessed June 05, 2018. http://www.iaadp.org/doj-def-comments-Title-II-III-SA.html.
6. "Nondiscrimination on the Basis of Disability in Air Travel." Regulations.gov. May 9, 2018. Accessed June 05, 2018. http://www.regulations.gov/document?D=DOT-OST-2018-0067-0019.

Webinar Education for Direct Support Professionals

BY JOHN RAFFAELE, MSW

Direct support professionals desire meaningful educational opportunities. The sad reality is that throughout North America, most direct support training is driven and designed by compliance and regulation versus education and development. Furthermore, most direct support professional training happens in a classroom setting. The National Alliance for Direct Support Professionals (NADSP) has addressed this issue and over the past 10 years and has created a myriad of robust and exciting educational and learning programs for direct support staff for the classroom and well beyond.

Validated and research-based materials are the basis for all our material. For instance, The National Alliance for Direct Support Professionals (NADSP) with the University of Minnesota has created a validated competency set for direct support workers in the United States. The NADSP competency areas are identified by the U.S. Department of Labor's Employment and Training Administration's Competency Model for Long-Term Care Supports and Services as providing industry sector technical competencies – the first and only set of LTSS competencies to receive such approval by the United States Department of Labor. The competencies are embedded in all our training curricula and are the primary focus of NADSP's in person and web-based teaching programs. The NADSP also provides other training products based on; The NADSP Code of Ethics, The National Frontline Supervisor Competencies and other research-based material.

The importance of direct support education and development cannot be understated. The NADSP mission is to spread the knowledge, skills and values of direct support practice through all our products. Direct support professionals are highly mobile, often working in remote locations and invariably non-traditional hours and settings. We need to ensure that we meet them where they are. One of the most popular and growing educational tools in higher education, professional development and business is the utilization of webinars. Virtual learning is now a standard method in our high-tech society and we have recognized that. We captured this at the NADSP and webinars allow for busy direct support staff to take advantage of incredibly rich and engaging sessions anywhere/anytime. We are continually creating informative, educational and topical learning sessions that will focus on the needs of direct support professionals and expanding with whom we collaborate to ensure excellence in what we offer direct support professionals.

Each month, the NADSP offers several engaging and informative webinars that are built to expand the knowledge and skill sets of the direct support and frontline supervisory workforces. These are not your typical webinars, they're lively discussions that pull from some of North America's best minds in contemporary topics to support people with disabilities in community-based settings and lead to improving direct support practice standards. Webinars are convenient for direct support professionals in that they can be viewed anywhere and at any time if one has a computer or smart phone and has a connection to the internet. The NADSP has two types of webinars: the NADSP Learning Annex and "Let's Talk": A Webinar Series in Partnership with The International Journal of Direct Support and author, educator and speaker, Dave Hingsburger.

> *The NADSP knows that webinars allow for busy direct support staff to take advantage of incredibly engaging sessions anywhere/anytime.*

The NADSP Learning Annex Webinar series features industry experts and thought leaders, as well as our numerous NADSP teaching faculty, as they explore many topics relevant to the daily practice of direct support. These subjects include ethics, working with families, stress reduction, grief and loss and many other topics that embrace best practices for direct support. The "Let's Talk" series is a monthly collaboration between NADSP and The International Journal of Direct Support. The journal is a monthly publication edited and published by Dave Hingsburger and Vita Community Living in Toronto, Ontario, Canada. The webinars dig deeper into journal articles and feature lively conversations with the authors featured from the journal. Dave Hingsburger acts as a moderator for these sessions. The topics covered include sexuality, abuse and neglect, working with people who have Prader-Willi syndrome, respectful language, guardianship and the list goes on.

The NADSP believes education for direct support professionals needs to be modern and needs to be synchronized with how adult professionals learn most effectively. Webinars cater to many learning styles. They are visual and auditory and, most notably, they are concise and portable. Direct support professionals have a limited amount of time for significant and meaningful educational experiences. Therefore, through utilizing one-hour webinar viewings that focus beyond typical regulation and compliance topics, NADSP believes that those who participate can acquire much needed education and professional development in a manner and method which resonates with their busy lifestyles.

We invite the reader to learn more about the National Alliance for Direct Support Professionals (NADSP) and visit our website. **www.nadsp.org** We archive all past webinars in our members only library. If you have interest in learning more about our robust webinar library or any of our products and please visit the website. •

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Project Freedom's housing is specifically designed for people with disabilities who use wheelchairs or have mobility impairments.

PROJECT FREEDOM

A MODEL FOR INDEPENDENT LIVING IN THE COMMUNITY

BY LAUREN AGORATUS, M.A.

The complexes look as ordinary as any newly built condos or townhouses. They are well kept, freshly painted, spacious, and appealing. It is only on a closer look that certain aspects stand out, indicating something is different. The extra cut outs in the sidewalks and the numerous, so-called "handicapped parking" spots are also telling signs to an observant visitor. Yet, that same visitor may also jump to an erroneous conclusion about what these complexes are designed to be.

Located in several towns across New Jersey, the unique housing complexes described above are part of Project Freedom. Co-founded by Norman Smith, Project Freedom is a nonprofit organization that develops and operates barrier-free housing in order to enable individuals with disabilities to live independently.

"We've had many people drive by Project Freedom housing without actually exploring it. All they see is the housing, and the housing doesn't fit their concept of housing designed for people with disabilities. That's the way we want it," said Norman, who has cerebral palsy and lives in one of the complexes with his wife Shirley and son Joshua.

Project Freedom's housing is specifically designed for people with disabilities who use wheelchairs or have mobility impairments. This means that many items, such as lowered light switches and kitchen cabinets, are standard for each apartment. There

PHOTO COURTESY PROJECT FREEDOM

also larger features, such as a roll-in shower, in nearly every apartment to meet the physical needs of many people with disabilities so they can live independently.

An observant person may detect the outward signs of housing designed for people in wheelchairs. "Seeing ten people scooting around in motorized wheelchairs is a dead giveaway," he said with a wry smile. He utilizes a power wheelchair himself. Seeing people in wheelchairs may lead to another erroneous conclusion about this type of housing.

"The first erroneous conclusion is that housing designed for people with disabilities looks like institutions. The second erroneous conclusion is that our housing complexes are institutions. Both are totally wrong, but the second causes everybody here the most problems," he said.

He should know. As the associate executive director of the 34-year-old non-profit agency, Norman describes himself as "chief cook and bottle washer" of Project Freedom because he handles so many tasks during one week. One day he may be giving advice to the staff about Low Income Housing Tax Credits, the next day he is inputting data into Project Freedom's database, and the next day he is commenting on emergency preparedness issues for people with disabilities.

LET FREEDOM RING: Norman Smith *(left)* says "People assume that people with disabilities cannot live on their own, so they conclude that our housing is some type of institution with nursing staff, rules, curfews, and supervision. That's totally wrong."

Project Freedom's corporate history started in 1984, but Norman started feeling the need for an alternative to living with his parents soon after returning home. His father, Richard, started having chest pains when he drove Norman around to his various activities. Norman was torn between continuing to be active in the community or staying home to save his parents work, trouble, and pain.

"My parents were both in their 60s at this point, and I was just becoming active in both recreation and advocacy. The disability community loves to meet, and sometimes I had three evening meetings and then horseback riding in one week. This is fine if you're not depending on someone you love for transportation and dressing and that person is tired or in pain," relayed Norman. "It puts a young person in a very difficult position."

Desperately wanting to be able to live independently and give others the same opportunity, he partnered with local disability advocates as well as members of the Nottingham Recreation Center for the Physically Limited to establish Project Freedom.

Nearly 35 years later, Project Freedom Inc. has seven apartment complexes located in four counties New Jersey and three more are scheduled to be built next few years.

"People with disabilities like having Project Freedom because there is not enough barrier-free and affordable housing," he said.

"Unfortunately, many people assume that people with disabilities cannot live on their own in the community, so they conclude wrongly that our housing is some type of institution with nursing staff, rules, curfews, and supervision. That's totally wrong," said Norman.

"It's unfortunate because thinking that way robs people of their dignity," he continued. "Once people assume you are incapable, you are automatically in a different category, separated from other people and treated differently. It is a hard box to fight your way out of."

Norman has struggled with that himself since cerebral palsy is a life-long developmental disability that has affected much of his daily life. Because of it, he needs assistance with bathing, dressing, eating, and going to the bathroom. His speech is also affected to a point where some people may not understand him. He has been put in that box many times and has often had to fight for respect.

"The wheelchair, the speech, and the involuntary muscles spasms – they all put me at a disadvantage in professional settings. I'm judged before I speak, and I'm judged after I speak," he stated.

Being involved in every aspect of the housing industry, he often finds himself the lone person in the room with a visible disability. This is especially true in the development, construction, and management phases.

"Sometimes I'm pleased to be in that situation so I can open people's minds to the capabilities of people with disabilities. Other times I'm frustrated that more people with disabilities are not involved in the actual production or management of housing," stated Norman.

Building housing is not what he envisioned himself doing in 1979 when he graduated summa cum laude from Long Island University with a degree in Journalism and a degree in Political Science. "I wish that I had taken business courses," he sometimes laments when discussing his college years. "I wanted to change society through journalism, not building apartments."

However, he credits his college experience for putting him on his current path. He set off to the Brooklyn Center of Long Island University (LIU) in 1976, needing assistance with nearly everything, but was grateful that LIU had a support program where fellow students provided exactly that. It was unique to LIU in the 70s, and he found a place where he thrived and excelled academically and socially.

"College was a freeing experience for me. It was really my first time on my own completely in charge of what I did," said Norman. "This freedom is what I craved for when I graduated and returned to my parent's home. Our name is no coincidence."

As part of his advocacy for independent living, Noman serves on the board of the Progressive Center for Independent Living, which is his local Center for Independent Living (CIL). CILs help people with disabilities gain independent living skills. The Core Services of CILs include:

- *information and referral*
- *independent living skills training*
- *individual and systems advocacy*
- *peer counseling*
- *transition from institutional care, avoiding institutional placement*
- *transition of youth to postsecondary education*

CILs can help individuals with disabilities maintain independence to live and prosper in their communities.

Although Project Freedom is one type of model, this may not be the answer for everyone as people with disabilities and their families are advocating to make housing in all communities more accessible.•

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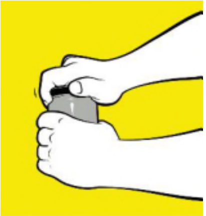
"A SENSE OF COMMUNITY"

When Mary Edmondson moved into Project Freedom in Robbinsville in 1991, she moved from a senior building with her 11-month-old son, DeManuel. It had not been the best place to raise a child, and the management was pressuring her to move. But senior housing was the only place for young people with disabilities who needed wheelchair accessible apartments to live, and those apartments had very limited accessible features. Non-senior housing did not have wheelchair units at all in 1991.



HELPING HANDS: "We look out for one another. You don't get that sense of community everywhere – especially if you have a disability."

"I had nowhere else to go until Project Freedom came along," said Edmondson. Mary uses a wheelchair after being hit by a car in 1985 while crossing a major highway. The accessibility of Project Freedom's apartments provided her greater physical freedom and made it easier to raise her child. It also brought Mary a feeling of community. "There is a sense of community here," said Edmondson. "We look out for one another and help each other. If someone needs a can opened, a neighbor will open the can. You don't get that sense of community everywhere – especially if you have a disability."

Mary says that Project Freedom influenced her son's life too. Growing up with people with disabilities as neighbors gave DeManuel a different view of people. When he was in middle school, "DeMan" had a best friend that he talked about all the time for months. Mary finally met him at the school and was surprised to see the friend had a disability that DeMan never mentioned.

"DeMan never saw his friend's disability. It was natural to him," said Edmonson with pride. He is now attending Monmouth University majoring in both psychology and criminology after being in the first graduating class at Robbinsville High School.

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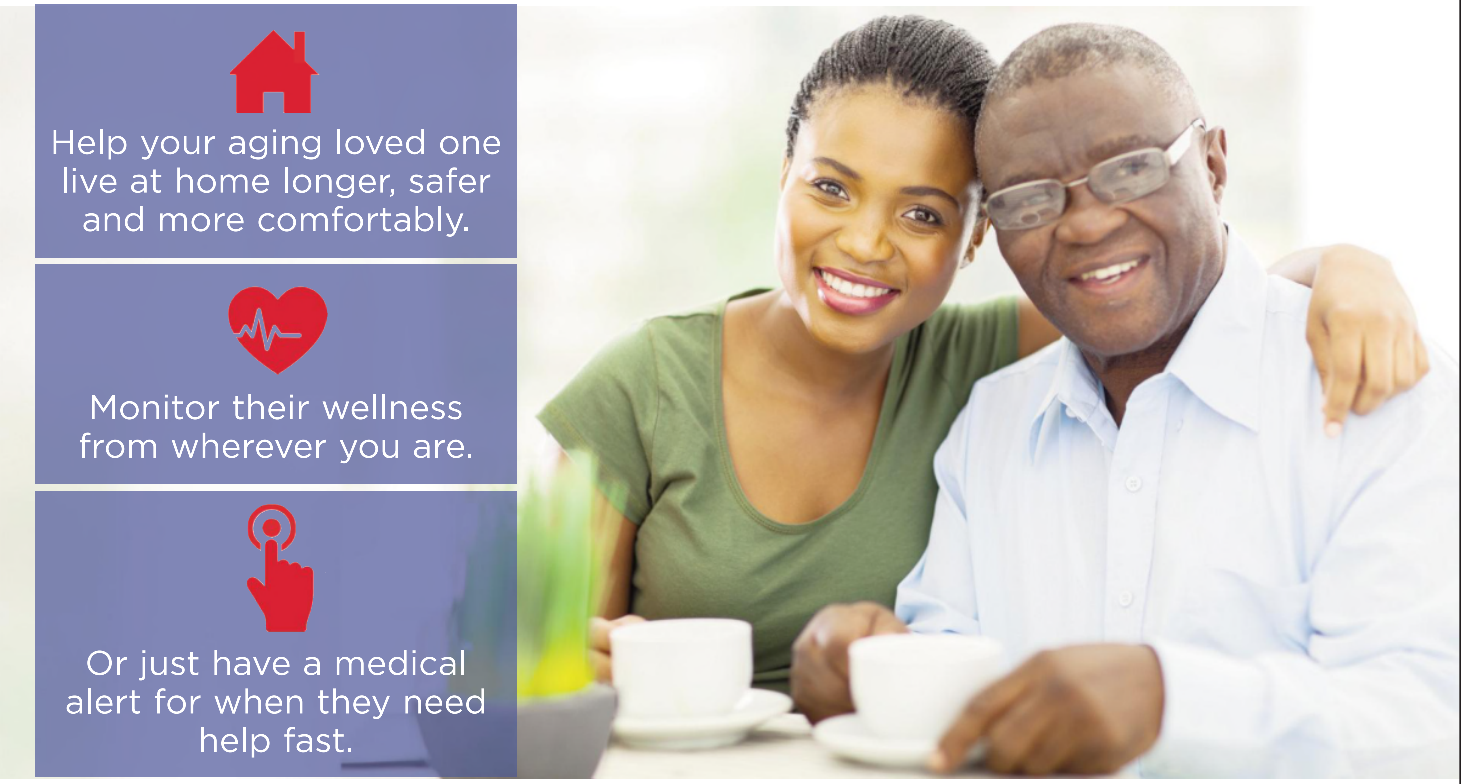

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EXPAND THE LIMITS OF YOUR HOME

Planning Home Adaptations that Make Your Existing Space Work for You

BY MICHELE ROSNER

Our family loves our home. It's a modest ranch house, right in the heart of a small town in the Midwest and just blocks from where I went to high school. My husband Matt and I have lived in this home since we were married, and our four children have spent their childhoods here. Just weeks ago, our oldest son graduated from that same high school I did. We have planted deep roots in this community and this home.

As our family has grown, the demands we have put on our living space have also grown. We have continued to adapt our home to meet our family's changing needs, adding bedrooms as we added kids and updating our kitchen as appetites grew. But the greatest demands on the space have come from our 16-year-old daughter Julia, who has multiple disabilities and complex medical challenges.

Our house was not built with accessibility in mind— the hallways are narrow and the bathrooms are small. As Julia has grown, her care needs have become more involved and complicated. She relies on caregivers for one hundred percent assistance with her daily care needs, and she is no longer a small child who can easily be carried throughout our home.

Whether it is because of financial constraints, emotional attachment, personal choice or lack of accessible homes on the market, many families who have children with special needs find themselves wanting to make adaptations to their existing home rather than moving or building a new home.

Through trial and error, we have developed a structured, yet creative thought process that has helped us maximize our available space to accommodate Julia's needs. Here is the process we have found to be effective:

1. Determine the greatest challenge(s): Many people's budget and sanity are more suited to a series of smaller projects

PHOTOS PROVIDED BY MICHELE ROSNER

implemented over time, rather than a single all-encompassing remodel. This also allows you to focus on the challenges that are currently, or will soon be, creating the biggest complications and the most frustration.

Our first big challenge as Julia grew was bathing, changing and dressing her. We were manually lifting her in and out of a bath chair, and she was becoming too heavy for that to be safe. While the fold-down changing table in our bathroom that Matt designed and installed worked wonderfully when Julia was smaller, her body had grown longer than the table.

> **“Many families who have children with special needs find themselves wanting to make adaptations to their existing home rather than moving or building a new home.”**

2. Define needs and wants for the home adaptation: Create your list of priorities: those things that you must have because they are critical to mobility or accessibility; or they impact safety. Also include your wants: things that would make your life easier, but you could live without. Think about what your needs are now, and as much as possible, also try to project future needs.

In many cases, the space being modified will also be used by other family members and/or guests. It is important to consider their current and future needs as well.

The more clearly you can articulate what is *not* working as well as what you need and want for better accessibility, the easier it will be to see whether or not proposed adaptations will be able to deliver the results you are trying to achieve.

To resolve the challenges with bathing and changing Julia, as well as providing bathroom facilities for the rest of the family and guests, our list of needs and wants looked like this:

NEEDS

- ***Ability to give Julia a bath:*** *Julia loves soaking in the bathtub, and we wanted to make sure we did not take away that pleasure. In addition, sprays of water can startle her and trigger a seizure, so a roll-in shower would not work for her. Based on those factors, our main priority was finding a way to get her in and out of a bathtub safely.*
- ***Showering for other family members:*** *Since this bathroom also serves as the primary bathroom for Julia’s three siblings, it had to have a shower.*
- ***A safe, convenient area for changing and dressing Julia:*** *We needed to have a changing table that was at the right height for caregivers as well as the right length to accommodate our growing girl.*

WANTS

- ***Temperature control:*** *Julia struggles with managing her body temperature, so we wanted to make sure we had the ability to keep her warm during bathing and changing.*
- ***Storage:*** *We wanted at least as much storage space as the current space, but with easier access.*

3. Explore alternatives and choose the best option: Now is the time to be creative. Make a list of every possible idea that might be able to meet your needs and wants. As you are brainstorming, try not to let your ideas be limited by how you are doing things now. Write down every idea! Do not rule out options that seem completely impossible, too expensive or over-the-top outrageous. Those ‘crazy’ ideas might become the foundation of an amazing out-of-the-box solution.

TIME FOR A CHANGE

(Left) Prior to the redesign, this flip-down changing table was too small to accommodate Julia’s growth, and much of the cabinet storage was not accessible when the changing table was in use. *(Right)* We needed to have a changing table that was at the right height for caregivers as well as the right length to accommodate our growing girl. The new changing table was a collaborative effort between Matt and the cabinet maker. The simple, yet ingenious design allows maximum use of a small space.

Bring in others who can help with idea generation and evaluation. Talk with friends and professionals with construction and remodeling experience, such as architects, builders, engineers, electricians and plumbers. Members of your child's medical and therapy team might be able to provide suggestions. Consult with companies that specialize in accessibility and mobility for people with disabilities. Keep in mind that the more conversations you have, the more ideas you will generate, increasing the likelihood of a lightbulb moment.

Talk with parents with kids who have similar needs to yours. Request pictures of their care spaces and run downs on how well the space works for their family. There are also online options for researching home adaptation ideas on Pinterest and Facebook. The "Home Hospital NOT Hospital Home" Facebook group has been a valued resource for our family.

> ***"Now is the time to be creative. Write down every idea! Do not rule out options that seem completely impossible, too expensive or over-the-top outrageous."***

After you have developed a list of possible options, think through if and how the adaptations will be able to accommodate your needs and wants. Take the time to review every step of the activities that will happen in the space and every aspect of the space usage. This is the best time to spot potential challenges, giving you the chance to resolve them before construction begins and adaptative equipment is purchased.

To meet Julia's bathing and changing needs, here are some of the options we considered and how we determined which would best meet our needs:

1. Convert existing laundry room and bedroom into an adapted bathroom: convert garage space into a new bedroom for Julia: With our laundry room, a small bedroom and the garage adjacent to one another, we knew this was an area where we could do a home adaptation and expansion. The biggest appeal was the ability to design a fully adaptive bedroom and bathroom from scratch, and we let our imaginations run loose. We talked about building a bathtub that was raised up on a platform, putting Julia at counter height for bathing – a dream for the caregiver giving her a bath. Taking it a step further, we talked about raising the ceiling above the bathtub to create headspace for a tub/shower combo, making it more usable for others in our family.

However, this option was not the best choice for us. We would lose valuable garage space, and it would be an extensive, costly project. In addition, the raised bathtub was a highly specialized modification that could negatively impact our home's resale value.

2. Use a bath chair lift and transfer to bedroom: This was the option provided by the accessibility consultant. She suggested using a bath chair lift to raise Julia up about 18" above the tub bot-

LIFT ME UP

(Left) When not in use, the changing table slides under the countertop, making the space usable for other family members and guests. A mat placed on the slide-out table makes it level with the countertop, doubling the length of usable space.
(Right) A ceiling lift and sling enable safe transfers in and out of the bathtub. Our lesson learned here was to make sure that we evaluated every option thoroughly ourselves. Having clearly defined priorities ensured that we did not end up with an adaptation that did not meet our specific needs.

tom, and then manually transferring Julia to her wheelchair and moving her to her bedroom to use her bed for dressing. This suggestion did not meet our top priority of eliminating the difficult and dangerous manual lift out of the tub. It also added additional manual transfers to the process and required moving a chilled, wet child to another room. Our lesson learned here was to make sure that we evaluated every option thoroughly ourselves. Having clearly defined priorities ensured that we did not end up with an adaptation that did not meet our specific needs.

3. Adapt existing guest bathroom with ceiling lift and changing table: This option was the most straightforward in addressing our top priorities: installation of a ceiling lift to enable safe transfers in and out of the bathtub, a longer changing table to accommodate Julia's growth, maintaining a tub/shower combo so that the space could also be used by other family members and reconfiguration of the cabinets for more accessible storage. While straightforward, the space does not lack for creative solutions. The changing table pulls out from under a countertop, doubling the length of the changing area and enabling it to disappear when it is not in use. The drawers under the changing area were designed specifically to provide perfect storage for all of Julia's personal care supplies. And, an oversized ceiling heater keeps the space toasty warm for her.

> ***"Approaching home adaptations with a spirit of creativity and thoughtfulness can lay the foundation for accessibility that makes day-to-day life easier."***

Raising a child with special needs presents physical, emotional and financial challenges. You want your home to be a safe haven in that storm of complexities. Adapting your living space to accommodate the accessibility and mobility needs of your child is a critical part of creating that haven for yourself, your child and your entire family.

Approaching home adaptations with a spirit of creativity and thoughtfulness can lay the foundation for creating accessibility that makes day-to-day life easier. Being fully invested in the process while still taking into account the expertise of professionals and others who have faced similar challenges provides the greatest likelihood of home adaptations that are a perfect fit for your family's unique situation.•

ABOUT THE AUTHOR:

Michele Rosner is the mother of four children, including a daughter with multiple disabilities and complex medical challenges. With a desire to help others overcome adversity and find more joy in the journey of raising a child with disabilities, she launched Different Kind of Special (www.differentkindofspecial.com). This online community provides resources and support for families who have a child with special needs.

SMALL ADAPTATION, PERFECT TIMING, HUGE IMPACT

Changing the angle of this hallway corner from 90 degrees to 45 degrees has been a game changer, providing the clearance needed to move large equipment to and from Julia's bedroom.

As we were doing the bathroom remodel, I was talking about a mobility challenge with my cousin, who is a general contractor. Julia's room is at the end of a hallway that had a right turn, and it was difficult to move equipment, such as a stander or wheelchair, to and from Julia's room. My cousin suggested turning the 90-degree angle of the wall into a 45-degree angle instead. Because we were in the midst of the bathroom remodel, with the drywaller and plumber already onsite, this was a simple and cost-effective project. Now, getting Julia and her equipment up and down the hallway is much easier.

GETTING HELP FROM ACCESSIBILITY EXPERTS

With more and more senior citizens desiring to 'age in place' and stay in their homes longer, more attention is being given to home accessibility. Take advantage of this trend and tap into ideas from accessibility consultants. These experts can be found by talking to your child's case manager or doing an internet search of your state and 'accessibility consultant' or a similar search term. As with any consultant, be sure to carefully vet their background. Also, be sure they listen to your needs and understand your situation so their suggestions help you address your unique circumstances.

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.

PHOTOS PROVIDED BY BECKY WRIGHT

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 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.

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."

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.

AHEAD OF THE CURVE

A child using a wheelchair may need to have open access under the sink to accommodate a wheelchair. Some sinks offer curved fronts that will allow a child (or adult) using a wheelchair to get closer to the faucet. There are also sinks with hand pulls in the front (a grab bar that is part of the sink) that allow an individual using a wheelchair to maneuver more easily.

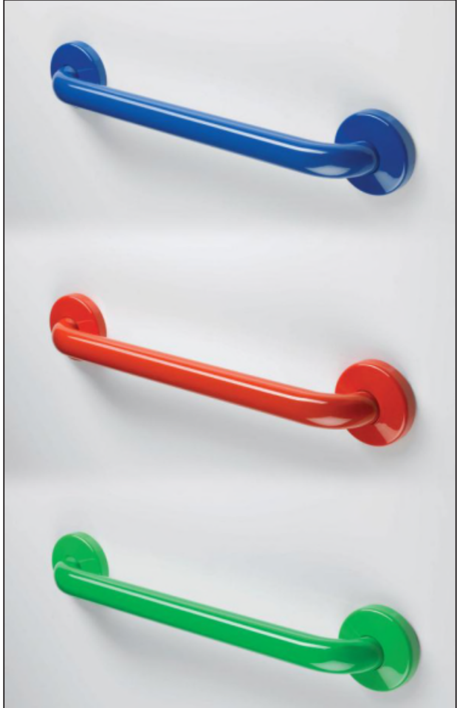
Another bathroom safety product that can be adapted for children is the shower seat. The shower seat is usually mounted at the same height as the toilet seat, so for adults that would be most comfortable in the 15 to 19 inch range. For children the recommended height would be 10 to 15 inches, keeping 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.



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 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."

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.

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.

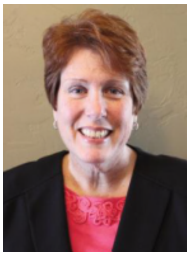
When doing a home remodel it is not necessary to follow the guidelines of the Americans with Disabilities Act (ADA) which was signed into law in 1990. The law was enacted to insure the civil rights of individuals with disabilities and established guidelines for creating a barrier-free environment for 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 the elevated toilet seat, which can be added to any toilet adding 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.*•

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@PonteGiulio USA.com

We explore how to size and design a dog den (doghouse) or pet space, as well as spaces that will encourage youth participation in the routine and pet activities required by the animal on a daily basis.

Pet Space Design + Animal Therapy = A Happy Youngster And A Cool Pet Pad

BY CHARLES M. SCHWAB ARCHITECT

Have you ever wondered if a service dog or assistance animal could benefit your child and family? Has your youngster asked you if he or she could have a pet? A better question may be, when was the last time they did? Chances are, you have answered affirmatively to one of those questions. Maybe your family has already discovered the many pleasures that furry friends can bring to any household.

In this article, we explore how to size and design a dog den (doghouse) or pet space, as well as spaces that will encourage youth participation in the routine and pet activities required by the animal on a daily basis. Pets and assistance animals have the ability to bring pure happiness and joy. They can be of assistance in many ways, performing specific tasks and providing emotional support at the same time. A dog can truly be a kid's best friend.

The hypothesis here is that your child or youth with impairment will be more likely be able to carry out pet care routines when they *actively take part in the design of the pet care & living spaces.* By making the dog room or pet space useable and functional for the youngster and the animal, the youngster will be more empowered (and more willing) to participate in many of the pet care activities that having a pet requires.

Estimates are that 78 million dogs and 85.5 million cats are family owned in the USA. Approximately 44% of all households in the United States have a dog and 35% have a cat. That accounts for over half of all families living with pets. The percentages in Canada and Mexico are similar. North Americans love their pets!

WHAT DO SERVICE AND ASSISTANCE DOGS DO?

Before we think about animal space, let us look at the various ways dogs in particular can assist people with disabilities. The possibilities and real-life examples are endless; here are but a few:

- *Mobility Assistance Dogs assist and are trained to complete everyday tasks and can assist with transportation (in the case of a mini horse), by pulling a person along in their wheelchair. They can fetch and perform other tasks.*
- *Guide Dogs lead a person who is blind or visually impaired.*
- *Autism Assistance Dogs are trained companions for children with autism and can provide emotional support by helping them cope with unfamiliar and difficult situations.*
- *Diabetes Assistance Dogs help type 1 diabetics by detecting low blood sugar with the scent of the person's breath. They help fetch food or get help if needed.*
- *Seizure Alert Dogs assist people who suffer from seizures. Seizure alert dogs know when to warn their owners of the possibility of a near seizure, even before it occurs.*
- *Hearing dogs are trained to help hard of hearing and deaf people when to be aware of and react to sounds such as alarms or ringing phones, just to name a few of their talents.*
- *Veteran Service Dogs help those with PTSD by being "buddy dogs" while providing comfort and therapeutic support.*
- *Rescue Dogs are a valuable asset in wilderness tracking for lost people, natural disasters, and in locating missing people after major disasters. Dogs save lives!*

Those are just a few of the helpful tasks assistance dogs can provide. A number of other animal species serve as assistance animals, and of course all kinds of critters can be fun companions, even when they are not specifically trained to perform tasks. Most people have fond memories of their childhood pets.

CARING FOR EACHOTHER: Designing the pets' environment will help the young person think through how to feed, clean and exercise the animal within its habitat. When your youngster assists in designing the animal's habitat, it helps nurture healthy emotions toward all living things.

TAKE YOUR TIME, DO ANIMAL AND HEALTH HOMEWORK FIRST

Before we go any further, perhaps it makes sense to consider how realistic it is for your child with a disability and family to care for and manage an animal's life and care, let alone an energetic and active dog. Simply put, there is a lot of work and time involved when caring for a pet.

Children with disabilities will have different abilities to cope with and perform the tasks of caring for a pet or assistance animal. Parents with a youngster with specific needs will likely need to consider additional safety measures before deciding if a pet or dog is a good fit for them and the family. For example, a rambunctious dog, not well-tempered or trained as an assistance animal, may knock over a fragile child using a mobility aid, stand aid or another device. A barking dog or screeching bird may scare or cause sensory stressors for some children. It will be best to choose a pet that comforts and also may be comforting for the neighborhood kids.

Always discuss the pros and cons of having assistance animals and pets of any kind with your youth's Pediatrician, Occupational or Physical Therapist, Animal Therapy Advocate, and perhaps an animal shelter representative that has experience with connecting similar animal companions with families like yours.

The American with Disabilities Act (ADA) allows a person with disabilities to escort them into public places when they are trained to do so. There are very specific laws in the USA and this is a hot and evolving topic.

Think big picture space and place design first: consider where you live, will live and plans for your families' future. Will you be moving often? Do you live in a small apartment or house? Housing and Urban Development (HUD) guidelines for reasonable accommodation and section 504 of the Fair Housing Act also provide you rights to accommodate assistance animals in an apartment complex with four units or more. *(See the references links below)*

Be sure to be aware of your rights and discuss this with the landlord if you are an apartment owner before you spend a lot of effort designing a perfect space for Fido. If you are adopting a pet from an animal shelter, ask if you can bring the animal home for a few days before you adopt it permanently. In the case of an assistance animal, there will most likely be paperwork and a waiting period before you design the animal shelter or room space.

CARE GUIDELINES FOR FAMILIES CARING FOR ANIMALS

Professional advice from child psychiatrists shares children's abilities to care for animals. The list is created for ambulating and typically healthy children as it does not reference kids with disabilities. Readers here are probably aware that disabilities are as unique as the youngsters' personalities, and so you as parents will perhaps know best when your child or youth is ready for an animal companion. Remember to consult with your child's health professionals first. The following list is adapted from the American Academy of Child and Adolescent Psychiatry (AACAP):

- *Children under the age of 10 are typically unable to care for a large animal on their own.*
- *Very young children (under the age of 4) should be monitored at all times when in the presence of pets. Children at these early ages do not have the maturity to control their aggressive and angry impulses.*
- *Parents should always oversee care activities to make sure the*

pet is properly cared for, even when they believe the youngster is old enough to care for the pet successfully.

- *Parents need to be prepared to care for the pet and take full responsibility if their youngster slacks off or becomes ill and no longer performs daily pet care.*
- *Remind the youngster on a regular basis and in a gentle manner, that animals are like people: need food, water, exercise and they need to go potty too. Someone needs to let them out (if it is a dog).*
- *Be prepared to find a new home for the pet if your youngster continues to neglect the pet. Make this clear prior to bringing the pet into your home.*
- *AACAP reminds us that parents are role models for their youngsters and they will adopt responsible pet behavior by watching their parent's actions.*

Remember, there is also the cost of pet food, maybe cat litter, as well as finding the time to walk a dog, groom it and clean up after it does its business. There are pet health care needs and everything else that comes with all living critters.

In some cases, the best approach may be to start with a bug or small animals such as a gerbil, turtle, lizard or a small bird if that is your pleasure. The idea is to experiment by starting with a small pet and see how your child or youth is able to assist with the pet chores. All pets can have emotional and therapeutic benefits. The last thing you want to do is create more stress on the family and the neighbors too.

One more thing: recent research suggests that raising a young child in the presence of animals may actually reduce the likelihood of developing allergies from pets by building up the child's immunity to them. Dogs and cats have fur while monkeys have hair and are usually not a nuisance to people of all ages with allergies. Consider the health pros and cons of the entire family.

CHILD + PARENT = PET SPACE DESIGNERS

Okay, after you have done your homework and are up to the task of designing the animal haven, dog den, or birdhouse, now what? It is time for the fun animal space design. Have you ever thought your youngster can play an active role in designing the pooch's own space? Inviting your youngster to participate in the design of the animal's physical environment can instill responsible pet care behavior. It may even motivate them more when it is time for the daily pet care chores. When the child helps create a routine that works well for them too, the task becomes more pleasurable.

Since kids and pets both respond well and are comforted through a consistent routine, teaching a child how to design for the pet's daily care – with a regular lifestyle that is in harmony with their own – can be a valuable experience. For all children and youth, the responsibilities that come with pet care can be an avenue toward independence and increased self-esteem, among a myriad of other health and social benefits.

Designing the pet's environment will help the young person think through how to feed, clean and exercise the animal within its habitat. When your youngster assists in designing the animal's habitat, it helps nurture healthy emotions toward all living critters. These feelings may stay with your kid, creating lifetime positive memories of their early years. What more could you ask for?

BESTIES: Pets and assistance animals have the ability to bring pure happiness and joy. They can be of assistance in many ways, performing specific tasks and providing emotional support at the same time. A dog can truly be a kid's best friend.

As mentioned earlier, this experience can lead to a stronger bond with the animal and increased independence for the youngster.

Our goal is also to make pet care accessible for the youngster encouraging empowerment not frustration. I hope that by now, you have conferred with the pediatrician or therapist and you are well aware of youngster's abilities. If your dog is a service animal, it is important to first consult the service dog trainer before designing the most appropriate dog den space. There may be strict boarding requirements and the concept of interaction with the shelter design may not be advisable.

All living things need space to live and move. When dogs feel stressed they like to have a cover over their bodies for cozy protection. Dogs are den animals meaning they like a defined space that will become their own territory. The den helps relieve Fido's stress.

MEASURE THE DOG FIRST BEFORE YOU SIZE THE DOG SHELTER

Ok, let's start and get your youngster involved, if possible. That's the whole idea here. Animal Welfare Act Regulations require that a primary enclosure for an adult dog (in the following example that will be a dog house or den) without nursing puppies, must have enough space to stand, sit and move about freely. It must be able to lie comfortably and walk in a normal manner.

Space must also be high enough therefore the primary shelter/enclosure must be 6 inches higher than the dog. Following is an example of how to calculate the dog's minimum space needs for either an outdoor doghouse or indoor shelter (inside cage, under steps, under a cabinet etc.)

Dog Houses: Minimum Space Requirements

Dog Length inch (IN.)	Square Feet. Needed	Dog Length inch (IN.)	Square Feet. Needed	Dog Length inch (IN.)	Square Feet. Needed
7 IN.	1.17	19 IN.	4.34	31 IN.	9.51
8	1.36	20	4.69	32	10.03
9	1.56	21	5.06	33	10.56
10	1.78	22	5.44	34	11.11
11	2.01	23	5.84	36	12.25
12	2.25	24	6.25	38	13.44
13	2.51	25	6.67	40	14.69
14	2.78	26	7.11	42	16.00
15	3.06	27	7.56	44	17.36
16	3.36	28	8.03	46	18.78
17	3.67	29	8.51	48	20.25
18	4.0	30	9.00	50	21.78

Chart design © 2018 Charles M. Schwab Architect

The above chart is adopted from Animal Welfare Act Regulations. (9 CFR 3.6 (c)(1)(i). For further reference refer to the latest 2017 USDA Bluebook, Animal Welfare Act and Animal Welfare Regulations. www.aphis.usda.goc/animal_welfare

1. *Measure the dog height from the floor to the top of the dog's head in inches, then add 6 inches to that. This number is the ceiling height of pooch's pet pad. Write the height down.*
2. *Now measure the dog's length. With the dog in a normal standing position, or when lying down flat on his side, measure the dog along a straight line from the tip of his nose to the base of the tail, not the end of the tail. Then also add 6 inches to this number.*
3. *Let us presume your dog is 30 inches from the tip of his nose to the base of his tail, then add 6 inches to that for a total of 36 inches.*
4. *This is simple. The square foot minimum is then 36 inches x 36 inches = 1296 square inches.*
5. *Since there are 144 inches in a square foot, we divide 1296 divided by 144 = 9 square feet. 36 inches = 3 feet. So simple, 3 feet x 3 feet = 9 feet.*

(See the table as a guide to help you determine your dog's space needs based on his body length.)

Based on a 30-inch dog, he needs a 3-foot square space so he could turn around comfortably. If it was 2 feet wide by 4 feet 6 inches it would still amount to 9 square feet total, but since it is not square, the dog could not turn around and be cozy.

We all know how animals can be particular about finding the "just right" position to lay down and relax. The dog simply needs space enough to turn around within his dog house, turning left or right as he gets cozy. Pet space should have no sharp edges to cut the pooch's paws and sensitive snout, the floor should be accessible to be cleaned.

Explain to your youngster (if he or she uses a wheelchair) that dogs can turn around in circles in much the same way that a mechanical wheelchair revolves around its center, more or less. I say this so you can make an analogy with your child's mobility device, showing how the dog needs space to turn around, just like the child does in his own room.

Keep in mind this is for one dog only. There are calculations for dogs nursing puppies as well. This may seem like too much information, but the point is that all animals are required to have safe and sufficient space to move about a place. Your youngster has now had their first DIY home design lesson!

DESIGN SPACE WITH YOUNGSTER FOR DOG / PET CARE!

Cleaning: This can be tricky. I have designed open grates 30 x 30 inches (or larger) in garages or outside the door near a hose bib. This area can then serve as a wheelchair wheel-wash and a dog-wash station. I include cellulose free "glass-matt" wallboard on the garage walls three feet up so it does not get wet or moldy. Some people have "pet spas" with ramps for the dog to walk up into a shallow tub. Pet spas are becoming popular in multi-family housing complexes.

When the dog wash is inside, of course a flexible hand hose is a fine faucet fixture. The dog room or space may in the mudroom where the pet's paws can be cleaned of yard muck before entering into the main house. A separate space adjacent to a mudroom can be decorated and made special by your son or daughter. The biggest trick is to make it enjoyable for your young designer, accessible and safe for the entire family.

Eating: It may be difficult for your youngster to reach into a bag with a scoop or reach down to the floor to fill Fido's bowl. This is an opportunity for a fixer-upper person to design a dog feeding station with the youngster. Have you ever seen at the store where they put grains and nuts in a bin with a funnel that empties when it is pushed? Maybe create a dog food shute-drop that slides its food down a slide to a dog bowl: think Hot Wheels ramp.

Exercise: Automatic pet door openers are very popular for this very reason: to let the pooch out to do his business when he wants. Think about security and how that will work. There is a link to an article I wrote about automatic people and pet doors below. An article titled "Wag More: A Tale for Healthy Living" (www.harvard-health.com) gives the following advice (I have tweaked it for service dogs and youngsters using a wheelchair):

1. *Chart your strolling (both walking and rolling) path ahead of time. Make sure it's accessible and stable for the wheelchair and there are clear sight lines.*
2. *Set a goal; dogs need to exercise at least once a day. The article says a good rule of thumb is to walk a dog two blocks a day for every 10 lbs. of the dogs body weight.*
3. *Design the exercise regimen for the dog. Make sure the youngster can participate, if not, be there for support.*
4. *Teach your dog to heal on a leash. There are all kinds of wheelchair dog walking devices. Lastly, have cool water prepared when you return or bring it with you.*

Decorate the dog pad! Why not try it and see how much your child is really interested in design and art? It becomes art when your child takes part in decorating the doghouse or painting it and making the end project an extension of himself. Maybe even embellish it with a few kid stickers that can be removed over time and made new again over time.

Give your youngster all the benefits and happy memories that the dog can offer. Pets are considered part of the family, so why not treat them as such from the start and by getting your youngster involved in designing their space? The benefits may be even more profound than you could ever imagine. •

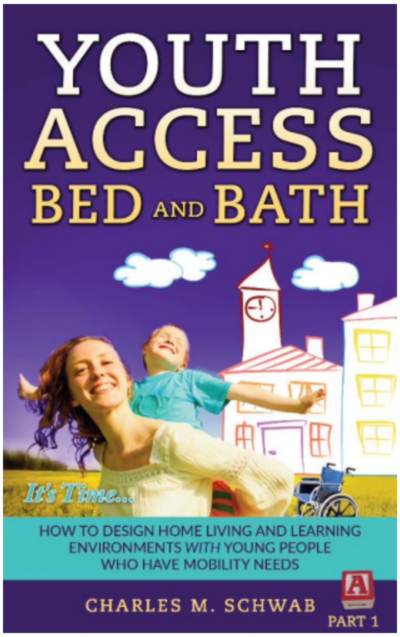
Please let me know how your child participates in the animal space design and send pictures so I can post them on my Pinterest page of service and assistance animals. Contact me anytime at charlesschwab@universaldesignonline

References

1. Complete references for this article are available at https://accessiblehealthhome.com/?p=620
2. You can view a free animal shelter webinar, and read about other kinds of assistance animals the ADA and HUD, Fair Housing Act at my blog post at https://accessiblehealthhome.com/?p=624
3. The Automatic Door Openers for Pets and People post is https://accessiblehealthhome.com/?p=630

ABOUT THE AUTHOR:

Charles M. Schwab is a licensed Architect and Author of Universal Designed Smart Homes for the 21st Century, 102 home plans you can order and build. He has contributed to *EP Magazine* since 2005 and has written over 50 home design articles about design for all. He is a Certified Aging-in-Place professional (CAPS), Certified Green Professional (CGP), Universal Design Certified Professional (UDCP). He has designed hundreds of accessible and healthy homes utilizing the systems approach of "universal design-ing."



Have you ever wondered how to design your son or daughter's home environments with their participation so it works best for them, you, the entire family and helpers too? Schwab's new book series titled *Youth Access Bed and Bath: How to Design Living and Learning Environments with Young People Who Have Mobility Needs, Part 1* starts with the bedroom and bathroom and guides you through the process.

Originally titled *Child Access Bed and Bath*, the expanded book series takes a holistic approach to accessible and healthy home design that is fun, yet serious enough with specifications, and educational too. It encourages parents to involve their youngsters in "universal design-ing" their own home environment for health and wellness. Another goal is to eliminate fear of the unknown for new and adopting parents by offering awareness and a pro-active, U-Designing approach.
The series is scheduled to finally be available on Amazon Kindle in early August. Those who signed up for a copy last year will receive theirs. Visit www.AccessibleHealthHome.com to learn more. Or contact CharlesSchwab@UniversalDesignOnline.com

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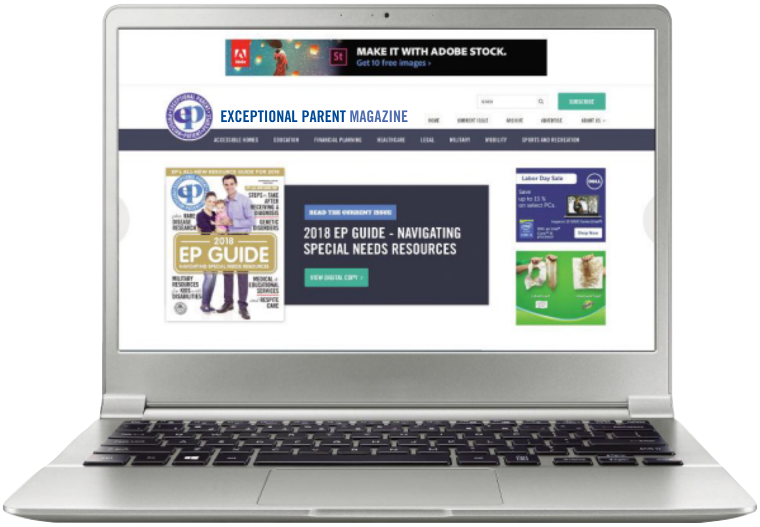

EP's Innovative New Digital Strategy

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

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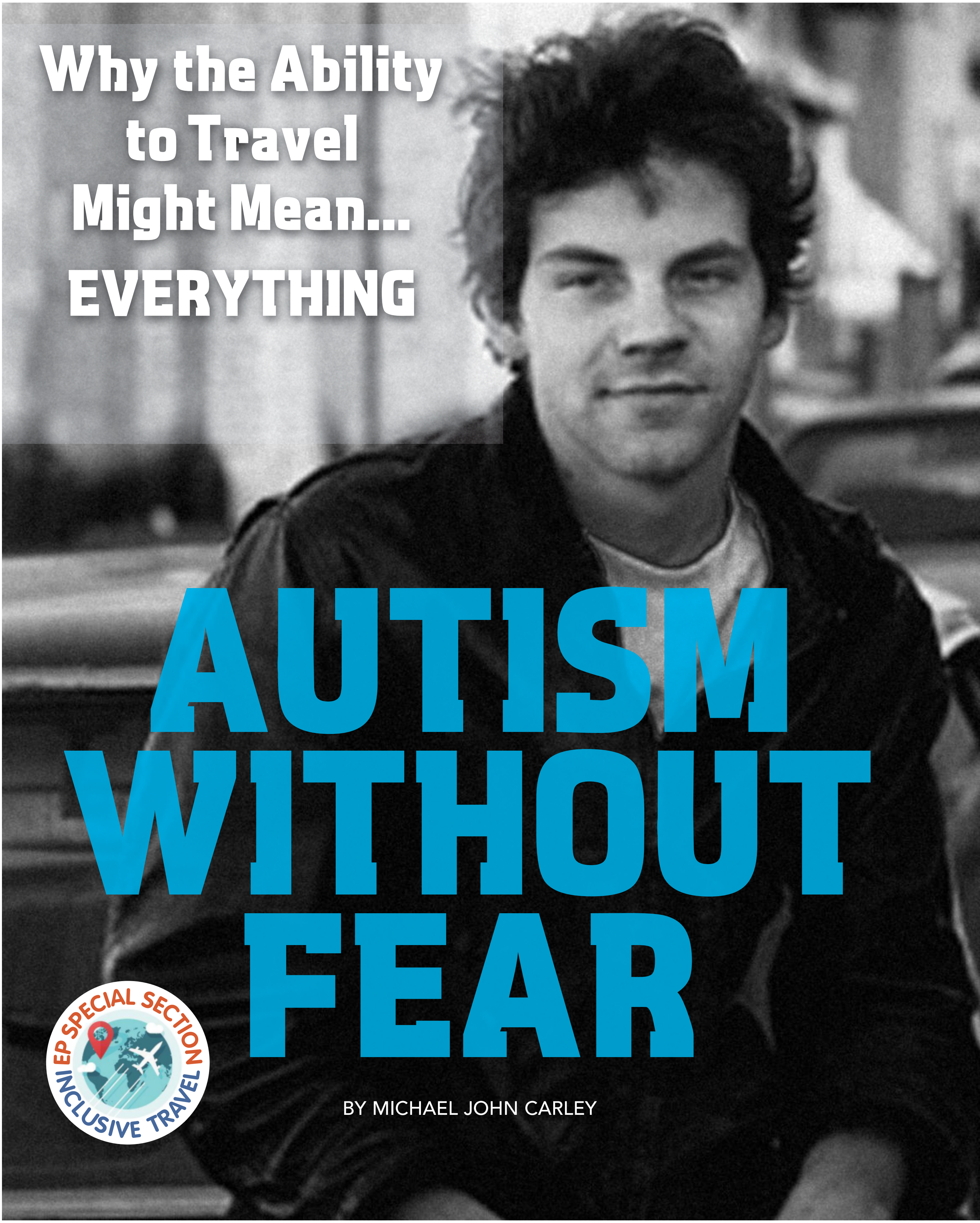

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Why the Ability to Travel Might Mean... EVERYTHING

AUTISM WITHOUT FEAR

EP SPECIAL SECTION
INCLUSIVE TRAVEL

BY MICHAEL JOHN CARLEY

SOJOURNER: Michael John Carley during his months inside Eastern Europe, 1986. "In travel, our successes in behavior modification come quicker because others unknowingly give us a superior chance to learn."

> *"Security is a superstition.*
> *It does not exist in nature.*
> *Life is either a daring adventure, or nothing."*
> *~ Helen Keller*

The principle idea behind meteorologist Edward Lorenz's "Chaos Theory" speculates that the brief flutter of a butterfly's wings can evolve into air currents capable of creating a hurricane 10,000 miles away.

Well, if you can believe it, her name really was "Fifi." She was 12 years old, just like me; and I thought she was beautiful.

Fifi... and Secrets

Years ago, my maternal grandparents swapped residences for a month with friends who lived on a small Greek island. Consequently, all involved parties enjoyed cheap, yet memorable vacations. The Hellenic friends got a cozy, three-story house in New England, while our family – grandparents, my mother and I, an aunt, an uncle, and two cousins – stayed at a minimalist, yet spacious former pistachio farm.

I was bored and driven a little nuts by so many family members who were also bored. But as the undiagnosed kid on the spectrum who was enduring typical school pains back home, I also felt liberated, and grateful for such a dramatic change in scenery.

Fifi worked at the ticket window of her family's small movie theatre. And when I would walk or bike the two miles along the coast into town, Fifi could be seen on my right from the dirt road as it opened up onto the whole port. In the frame of my vision she existed as a bored, motionless oddity amidst a sea of activity; forced to sit in her tiny shed, surrounded by commerce – the unloading of small fishing boats, fast hands and loud voices in the open market, and on certain days, the sound of waves falling on the docks to my left.

Her English was broken, but good enough, and I set about my plan to ask her out on a date. In front of our bathroom mirror, I repeatedly tried to replicate the facial expressions Harrison Ford produced in the first Star Wars movie – contortions of the skin and muscles that magically elicited sounds of approval from the girls in the audience (…all *twelve times* I saw the movie). I'd never asked someone out before, but if I failed here, no one would know, so why not try?

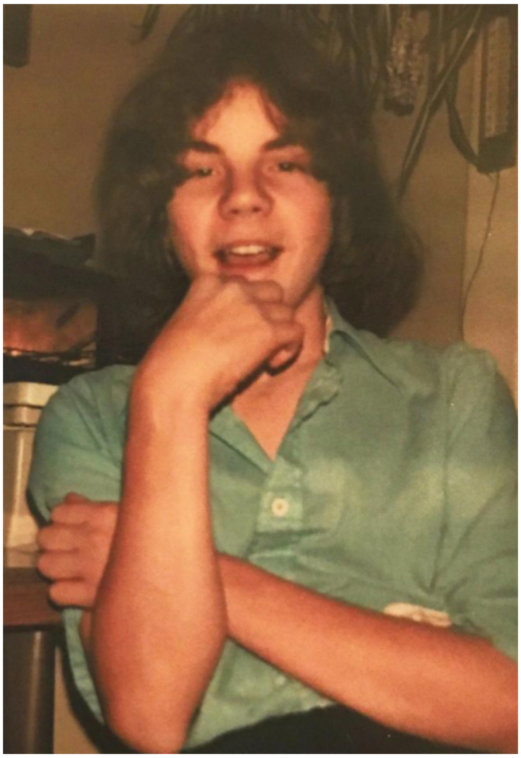
When I arrived at the movie theatre, ready to ask, her much older brothers were doing some work in the back of the ticket booth. Clearly, it wasn't the perfect opportunity. *"Eh,"* I thought, impatiently, *"Big whup,"* and I went for it anyway.

"Oh no," she blushed, smiling happily, *"I am not supposed to go out with boys."*

Halfway home on that dirt road her brothers ambushed me. They'd been running alongside, unseen by the foliage that shielded the ocean from the road's view, and so I never saw them until it was too late. They roughed me up a little, found a high point off land's end, and then as trees to my hammock swinging in the wind, they counted 1-2-3 and threw me into the sea.

Walking home, soaked, but drying quickly in Greek summer heat, I was so happy. No, it hadn't been traumatic. Fighting was a way of life back then, and when I saw how deep the water was, I knew they had no intention to really hurt me. And no, it wasn't a happiness steeped in cultural pluralism by learning that Greek rules for dating were different – Please… the new rules sucked! And lastly no, I wasn't happy because I'd gotten nobly whipped up for a girl: while beautiful, Fifi wasn't worth this kind of trouble.

I was happy because of the marvelous discovery I'd made. I had just been humiliated, and yet I had the opportunity to keep it a secret. Had I suffered the same degradation back home, people would talk, word would get to friends, maybe family too, and I'd have to endure social repercussions for my failures until others got tired of teasing me. I might even be hearing taunts about it



CHARTING A COURSE: *(Above left)* The author at the age of 12 or 13, around the time of "Fifi." *(Above right)* Later, as a teenager; learning to read maps and look afar.

today!

But because I was traveling, and having this experience amongst strangers, no one would know unless I decided to tell them. Far from home, in travel, there really was infinitely less punishment for screwing up. Herein, amongst strangers, risk, was relatively safe.

Risk, and the Entire Spectrum

Now if you're reading this and thinking, *"Well, my child's place on the spectrum is much more challenged, so this article isn't really relevant to me,"* – you're making a huge mistake. For at its core, this story is about having a clean slate to try out new things, and this applies to the entire spectrum. My experiences are from my end of the spectrum (wherever you deem that to be) but the values are universal, and with modification can become adaptable to the entire spectrum.

When at home, everybody knows about the blowup you had last week, the issue you had in the produce aisle. Any time they want, caregivers can bring up the suspension you got from school two years ago. You're just waiting for them to do it, you know they know, and they know you know they know. You can't escape!

And if you make a mistake and get a lecture about it, this usually convinces you not to try again. Even if the lecture is deserved, why do people think that you'll have the social confidence to want to give it another shot? Where's the incentive? Is it to please your lecturers? Or to learn the lesson? Sociologist Terri Apter states that it takes five words of praise to erode the damage done by one word of blame. So those lectures, those emotional reactions from loved ones, only increase the humiliation.

But in travel, if you fall on your face in disgrace…who cares? You'll probably never see those people again! Just go to the next (town, street, or store) and try again; only this time armed with more information with which to modify the social experiment.

As a school consultant, I know that when districts travel train the more challenged kids so that they can go learn how to buy a slice of pizza on their own…that on a developmental level this exchange is the victorious equal to someone like me learning to slow down movements and vocal patterns in the deep south so as to emulate locals (and have them accept me more).

But despite the wide-spread autism awareness we've all built over the last 20 years, our ability herein has actually decreased due to our urgency to monitor so much. Unless the individual is still learning not to inappropriately touch others, or doesn't understand street safety (i.e. that cars can kill you), I say they're ready for these independent lessons of travel. I'll be the first to tell you that we were way too reckless in my day. But I'll also counter that we've since gone *way* too far into the opposite extreme of over-protection, having bypassed an emotionally-healthy middle ground to the point where finding opportunities to develop confidence and strength, wherein you are truly unmonitored, have become far harder than they need to be.

We also often teach independence by…increasing their dependence on us as caregivers? And we wonder why it's not working?

Independence, outside of cooking, cleaning, and how to manage a bank balance, is often best taught by independence itself.

Our over-protection has humanist origins. Spectrum realities such as pool drownings, assaults of every kind, and a sickening overuse of the sex offender registry have so riled up caregivers that spectrum kids are often raised in a fear-based atmosphere that resembles a lockdown. But I believe that we, as spectrumfolk, process failures better than

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people think. I think caregivers refrain from providing true opportunities at independence often because of *their* inability – not ours – to process the failures. It's a snowball effect, leading to spectrumfolk being denied the opportunities to fail, which then makes for *true* inabilities to process failure because failure itself is now so much more intimidating. Under these circumstances it can even transform into trauma. Our kids leaving home successfully means relying on us as parents less, not more (and as I wrote in my first book, nervous parents usually end up raising nervous kids).

The degree of independence will always be relative to one's place on the spectrum. But if we all digest these ideas, then we might do a better job of looking for those proportionally-appropriate situations amongst "strangers" – You know them… those fellow earthlings that we've been condemning as too dangerous to interact with?

My mother and grandparents did not monitor me when I went into town on that dirt road, or when I'd be gone for hours. Therefore, my capacity for adventure, and my confidence in risk-taking, was comparatively through the roof. All my attention could now be directed at the world, rather than apportioning off attention to the amenable, or unwanted companion that most kids on the spectrum are stuck with when they're out amongst the community.

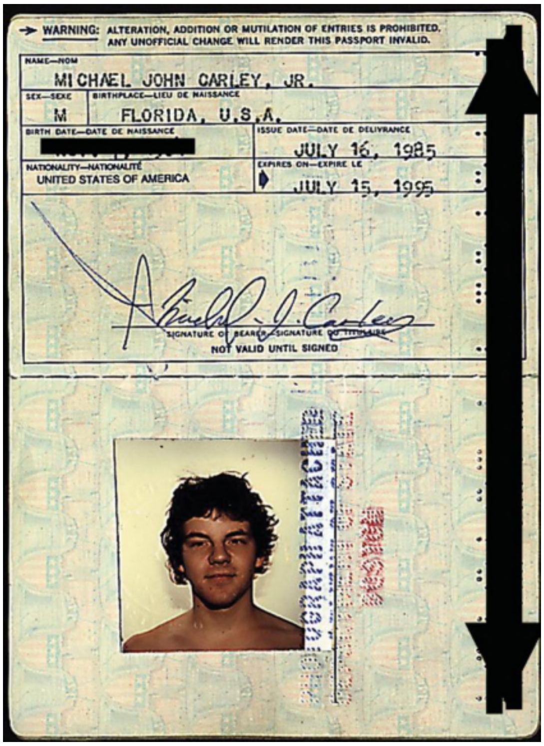
What we *can* do as parents is to let go of control, not try to assume more of it as is our instinct – to be the *catalysts* of independence, not the architects. If we can't stop ourselves as parents from monitoring, we could at least convince kids of the giant lie that we are completely unaware of whatever transpired.

Is there more risk? Yes.

Is it worth it? When you consider the true cost of doing otherwise? (the absence of confidence? Or Independence?) Absolutely.

Becoming That Pluralist

Another benefit of travel for especially the literal-minded spectrumite, is that you become a pluralist; one who gets it into their head that there is never one way to do anything. And immersing yourself in different customs and traditions is incredibly helpful because as spectrumites, we often *desire* the narrow-minded simplicity of one culture; we often *don't* want more than one option, as we don't trust our ability to choose! (It's like trying to shop at a large supermarket when you're really hungry). Issues *without* context are easier to count on, and therein become safety valves to those of us who find ourselves in a very strange world.



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JULY 16, 1985

NATIONALITY—NATIONALITÉ
UNITED STATES OF AMERICA

EXPIRES ON—EXPIRE LE
JULY 15, 1995

Michael J. Carley
SIGNATURE OF BEARER—SIGNATURE DU TITULAIRE
NOT VALID UNTIL SIGNED

QUICK PIC: The author was washing pots at a kitchen job one summer when he realized he had only one hour to get a picture taken and mail in an application for a new passport. Needless to say, this provided many border agents with a good laugh.

Oddly enough, many economically-challenged children learn this lesson much faster than more-privileged folks, and here's how. When we grow up, our parents convey their values to us, usually in the context that this is the way to live life on planet Earth. Most of the time we comply and emulate them – until later on when we realize that our generation is rejecting or reshaping those values… into new standards that the younger generation can call its own.

But often, poorer children get partially or even fully raised by grandparents, who have different values than the parents. And not only do those kids therein learn early that there is a different way of thinking than that of their parents, it opens up the opportunity to sense that there could be *multiple ways* of thinking. When my father left for Vietnam, my mother and I moved in with my grandparents so that my mother could try to get her degree. After my father's death, we continued to live with them, and even after getting our own place, they were a mile away, and always retained a major influence. I *clearly* saw differences in the values of my 1960s-era mother vs. the more Victorian mores of my grandparents.

Travel exposes you to what those different modes of thinking, interpreting, behaving, and feeling…really are. And this gives you options, starting with the choice to embrace those elements that you like about the culture you grew up in, and to reject the ones that you don't.

"Oh, He's Just Weird Because He's a Foreigner."

Where travel *does* discriminate between the entire autism spectrum is that some of us have varied abilities to conceal our diagnoses, and some of us have none.

Still, more of us have that ability abroad than we do at home. For when you are a foreigner, you are *expected* to be different. A little struggle with eye contact won't be noticed that heavily, and in countries that speak a different language, a unique and monotone manner of speech will rarely be of concern. Even the occasional inappropriate comment can often be misinterpreted as having been translated awkwardly.

Where you may *not* be ready for travel is if you are so infused with the spectrum tendency to be self-involved. For everyone wants to be heard, and any natural interest in that other culture will go a long way towards their embracing you. But be forewarned: real attention to other people and their stories is almost impossible to fake.

If you can show that true interest in their culture, then not only will this increase your chances for acceptance abroad, there is the additional benefit that it could make you more attractive *at home* to foreigners in your country.

As the relatively "weird" person in our surroundings, our sense of alienation from our peers will often be noticed by others. And to visitors and immigrants who are also trying to figure things out, this then presents as a potential bonding mechanism. They're more prone to share their sense of estrangement if they see that the majorities are alienating you (however unconsciously),

PHOTO COURTESY OF THE CARLEY FAMILY

and they do so in the hope that you might understand what they're going through. For instance, when I was in college, all of my longer-term relationships were with girls from France, Sweden…etc. Fellow spectrumite author, Stephen Shore, married a woman who is originally from China. The "not belonging" factor can make for kindred spirits that metamorphasize into…belonging.

I didn't marry a foreigner but my wife and I met in Iraq, and I wonder if she would have fallen for me under domestic circumstances. Over there, I know that I was at my passionate best, and that others more universally respected me. I wasn't the eccentric guy in Iraq, I was the guy saving lives.

SARAJEVSKA HRONIKA STRANA 7

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Pomoć američkih veterana

Veterani za mir iz New Yorka upoznaće američki Kongres i Bijelu kuću sa problemima ratnih vojnih invalida iz BiH

Predstavnici organizacije *Veterani za mir* iz New Yorka došli su u Sarajevo kako bi ovih dana stupili u kontakt i iznašli mogućnosti najefikasnije pomoći ratnim vojnim invalidima Bosne i Hercegovine, kazao nam je predstavnik njujorških veterana **Michael John Carley**. Organizacija u kojoj djeluje, prema njegovim riječima, do sada je omogućila liječenje 25 bh. državljana u SAD, uključujući i djecu. Sada, kako smo saznali, rade na projektu izgradnje bolnice za ratne vojne invalide u Sarajevu i animiranju sponzora za ovu akciju.

"Našu organizaciju nedavno je posjetio **Muhamed Šaćirbegović,** ambasador i stalni predstavnik BiH pri UN i zamolio nas da dođemo ovdje, upoznamo probleme veterana, a nakon toga nešto i poduzmemo", rekao je Carley, naglasivši da se već uvjerio kako je pomoć invalidima neophodna. Za dolazak *Veterana za mir* u BiH, dodao je dalje, zaslužan je i njihov šef i zvanični predstavnik pri UN **Benjamin Weintraub**.

Carley, na osnovu iskustava iz američkih ratova, ukazuje da su psihološki problemi dominantni te da na površinu isplivaju nakon rata. "U Bosni i Hercegovini ti problemi nisu još izraženi", istakao je, uz napomenu da za to postoji mogućnost te da će američki veterani priskočiti ukoliko zatreba.

"Po povratku u SAD, izvještaj ćemo prezentirati američkom Kongresu, Bijeloj kući i ambasadorima zemalja članica UN. Kako znamo da se mnogo toga obećavalo, a nije ostvarivalo, potrudićemo se da ono što obećamo zaista bude realizovano", završio je Michel John Carley.

M. R.

Michael John Carley

READ ALL ABOUT IT: A 1996 Sarajevo newspaper article details the author's work with veterans in Bosnia.

And if you fall deeply in love with being far from "home," well…many spectrumfolk also live happily abroad.

"What *Doesn't* Travel Accomplish for People on the Spectrum?"

While the following is an admittedly superficial and paraphrased rendering (I'd bore you otherwise), the criteria for an autism diagnosis under the DSM-5 comprises three major points:

1. **Deficits in social communication**
   In travel: *People care less*.
2. **Repetitive patterns of behavior**
   In travel: *People care less.*
3. **Symptoms must present in early childhood**
   In travel: *People care less. And no one knew you then anyway.*

If one is young and has a speech delay, therein perhaps avoid travel to a country where English is not well known, as learning new words could hamper the development of your first language. But if you're secure in your native tongue, travel. And remember that the less they speak your language, the more you will learn of theirs.

If you have potentially alienating issues, such as with hygiene… that you do not address because you want to be liked for who you are, try to at least accept that others have the right not to want to spend time with you, and that maybe you too are not ready for travel abroad.

We are a part of a minority that cannot yet "just be ourselves" and be accepted. In order not to slip through the cracks we have to make ourselves into somebody that others will take interest in. This can mean working hard at a talent, like a musical instrument, or a language, or *any* ability that will cause others to notice us. But in the end, everyone (including neurotypicals) has to become someone that others will want to befriend, date, or hire. Nobody can just really "be" unless they are ok with limiting their potential friends and partners to others who also just want to "be," or to not developing.

Go Ahead… Hit Me with Your Excuses

Actually, don't. Because the only legitimate excuses are a medical inability to leave home (which is probably insurmountable), or a lack of money.

On the latter, let's think…

One golden rule to remember is that the more exotic your destination, the more likely the exchange rate will dramatically work in your favor as an American. That right there is an economic win-win.

If you're a parent, try the house swap as my grandparents did, and save perhaps thousands of dollars in hotels. Such swaps, thanks to the internet, shouldn't be that difficult.

Some Examples from Bygone Days

In 1986, I spent months behind the Iron Curtain. Finishing my undergrad work at Hampshire College, I had become a rather junior scholar of a World War II-era playwright named Bertolt Brecht; and with the help of a college advisor got permission from the East German government to do some work in the Brecht Archives in East Berlin. Well, thanks to the exchange rate, I lived in a land that no Americans were traveling to on less than $5 a day. I had saved money from my job in the school cafeteria and took off for, not just East Germany, but also Poland, Czechoslovakia, and Hungary.

My graduate writing thesis for Columbia University required that I live out of my car for the summer of 1988. While I needed starter money to figure out how to get work to pay for food and gas (and beer), I soon got the hang of it using a CB radio, and by inquiring at truck stops. I worked every job imaginable; road crews, open-pit mining, car mechanic, dish washing, unloading trucks, I was always paid at the end of the day, and in cash. In sticking with small towns (where you will always be noticed), I frequently cut deals for free beer by playing guitar in bars. Compared to what my needs were as a 23-year old (such as $5 per night or less to pitch my tent), I was actually rolling in money. On that trip, I accrued independence and job skills that went far beyond the provincial lessons experienced by my neurotypical peers. The rules have probably changed, but… go learn the new rules!

Any chance I could, whether it was with family, a group of friends (for some strange reason I had a lot of buddies who were well-known combat photojournalists), I left, to adventure with them. And while I never made much money, I could sometimes get my expenses paid by writing about the experience, such as when I covered the Jamaican elections in 1989. If a big event is happening that's worthy of global news coverage, there will at least be foreign media representatives there that you can solicit.

And if you can dream of getting so lucky, your adventures might become of value to someone, and become a job. Unlike my friends

PHOTO COURTESY OF THE CARLEY FAMILY

THIRST FOR ADVENTURE: With neighborhood children in Iraq at the restored Labbani water treatment center in 2001.

and wife, I did not become a proper journalist. But as the United Nations Representative to a veterans group, I conducted work in Cuba, Bosnia, and was the Director of the Iraq Water Project (IWP) an endeavor that brought clean water to 81,000 people in the Basrah area during the Saddam years. In those days, when I said something inappropriate to a boss, I got away with it so much more than I would have in an office job because the work was somewhat imperative. Getting the job done in that line of work was a lot more important than *how* it got done.

My advice for the adventurers of today (whose spectrum "juice" resembles mine) would be to scale back on some of the risks I took, like… avoid bullets. And maybe avoid countries that harbor the Al Quaedas, the Talibans, and the Boko Harems. Avoid North Korea too. I know they're in the news a lot, but given their monitoring system, you'll unfortunately learn very little. Think instead of places like Belarus, all the other countries in Africa, spend a month or six in India, Bolivia, China, or better yet… Iran!

Tabula Rasa

Far away from home, no one was expecting "weird," "smart," or "rude" Michael John to say or do something out of the ordinary. Our home life, after all, is dependent on how others interpret our past behaviors – how our words and deeds become the building blocks of our reputations. Our happiness at home relies much on other people's opinions. We are treated differently because of earlier actions – sometimes suffering, sometimes benefiting from the consequences.

But not so when we are strangers with no history. With unfamiliar people we start from scratch. Amidst unknown territory, the treatment towards us is clearly different. Herein freed, we can conduct tests, trying out different mannerisms, or different ways of carrying and presenting ourselves without fear of reprimand or ridicule, because no one besides us knows that we are faking something. In travel, our successes in behavior modification come quicker because others unknowingly give us a superior chance to learn.

Sometimes the risks are painful. When I arrived in East Berlin at the end of my 1986 trip, I was not well. Having run afoul of authorities who wanted me to sleep in expensive hotels rather than youth hostels, I'd spent an awful lot of nights running from cops, sleeping in train stations or park bushes (a night in jail) – and I'd recently been violently sick with one of those 24 hour illnesses. After months in the other countries I was near tears as I would plead with officials for the "Eastern-Europeans-only" hostels that to my surprise barred Westerners (the other communist countries had no issue with my staying in their hostels). I begged them to let me in… just to have a bath even… until finally, one succumbed. I rejoiced like never before, and may have cried some from relief. My long shower preceded a 14 hour sleep. And so happy, I did something in waking that in today's context won't be viewed so favorably – I passionately kissed the maid; though not because I wanted anything else to transpire. I did it to show "Anja" how grateful I was to everyone there. (After doing it I of course wondered if I had gone too far, but she eased my conscience by demanding my address in the U.S., and yes, I got a few letters later on).

And two years later, in living out of my car in the states I was cathartically confronting the land that I felt hated me, and that had stolen my father. Still three years away from quitting drinking, there were a lot of bar fights – most of which I lost. But herein I was just as much the prized foreigner as anywhere else. That trip taught me that most of my country was surprisingly just as, if not more eccentric than me, and that it was home, whether I liked it or not.

I could go on… But the real mystery was as follows: That for as long as I can remember within these fantastical travels, that I've had an intangible, remarkably overblown sense of purpose; a narcotic illusion of destiny egged on by the ideas I studied – theoretics foretelling me (and others, as this is a very spectrumlike tendency) that great heroism was in store; even as it told others, rather accurately, that great comedy was a lot more likely.

PHOTO BY KATHRYN HERZOG (SOON TO BE CARLEY)

But that's what makes it so much fun. That's why travel teaches you to take yourself less seriously, not more. That's why, at my age now, these experiences are money in the bank; withdrawals, rich with interest, that I can extract at any time, whenever I need a voice telling me how lucky I am.

Midwesterners Have No Sea to Look At

When I went downstairs at the East German hostel, there were four women waiting behind the check-in desk. Dressed in their hostel employee uniforms that included (surprisingly) stylish red coats, they beamed at me and erupted into laughter.

"You kissed Anja, yes?", one asked. Embarrassed, I smiled, laughed also, and nodded. Gesturing to her colleagues, who all smiled at me, she said, *"Then you have to kiss all of us."*

I know, I know… in this day and age that may not be the best story to tell. But given that informed consent was loud and clear, I share it.

It is also a moment that still resonates with intense, shared joy. I can only speak for myself, but I'd wager that none of us had sex on the brain at all. As I did indeed kiss all four of them, warmly amidst a sea of blushing and laughter, I knew that we were enjoying the kind of moment you can only have with someone that you will never see again.

The word is "abandon." We have forgotten that it also has a positive use.

My mother only put her foot down with me twice. The first time was in my senior year of high school when I wanted to go to Oberlin music school. She refused, saying I was going to a liberal arts school. The second time came at the end of my cross-country trip, when I was fully intoxicated with a confidence I was sure no one else had ever known. I could get work anywhere, and I could meet new people for as long as I wanted. In a phone call, as I regaled her with a monologue depicting my superiority over the rest of the world, she surprised me by interrupting.

"You need to come home."

It was like the snapping of fingers that releases you from the grip of hypnosis.

Eventually back in Chairman Howard Stein's office, I feared serious reprimand. I was supposed to have arrived at Columbia to begin my thesis year on September 1st. It was now October 3rd.

"Michael, did you seriously entertain not coming back?"

I remained silent.

"You were thinking of staying out there, and living like that…?"

I nodded, and I wasn't smiling.

But he was.

Where I come from, even the poorest of the poor are encouraged to dream about the faraway places they hope to visit.

But we recently moved to the predominantly white, northern Midwest to take care of in-laws. Because we did so for family, we'll never regret it. But it's been really hard – and not just because of the contrast that 28 years of prior New York City living would indicate. The Midwest is now an incubator of insecurity, resentment, and low-productivity. Whereas it once enjoyed a rich, educational history, thriving industry, and a dedication to community and toughness (both mental and physical), it has slipped into an Emperor with no clothes – one that cannot face its lack of an economic or spiritual future. Forget diversity – real critical thinking is also rejected at the first, subconscious sign (too intimidating). White values herein are such presumed universal values that locals can't understand why people of color aren't flocking to adopt them. Here, the good folks refuse to stand up to the bad folks, which puts into question how good they really are. Perhaps all are threatened by our coastal standards (including the pressure to travel), as they seem to demand that we stop judging them in reference to our snooty selves. With apologies to the ones I care about, they insist on their right to what I have termed "the license to suck (at whatever they do)," and will not stop whining until we give it to them.

And so, within this region, feeling as rejected as I was in middle school for my behavioral differences (and corresponding big mouth), I remember stories like those I've described in this article more vividly because it has become critical to do so; not to combat Midwesterners' accusations of elitism, or their cultural reluctance to venture outside their own skin – but instead for me to make sure that I continue to share with them, even if it's in the disrespectful spirit of colonialism. They too often seem indignant that others have stories to tell, choosing to believe that the only reason people tell them is to make others feel inferior. Their lack of confidence is heartbreaking, but their dedication to isolationism is sickening.

So every time I venture back East, I rush into the love of friends; figuratively bathing in both their approval and the absence of behavioral bigotry. But I also reserve one morning to stand on a beach.

I imagine what lies afar – not because I can visualize it, thanks to the travels that shaped me; but instead because the conjuring act serves as a challenging, albeit beatific reminder that at heart, we are not free; not one bit. The bitterness of Midwesterners is a poker tell; it's a dead giveaway. Somewhere inside, they know what they're missing. Unless we all expand with our fellow man, and grow past our surroundings, we are prisoners.

When you're that kid on the spectrum, diagnosed or not, you get it – that others don't get *you*. I knew, walking home on that Greek dirt road, that if I were to tell my family the story of Fifi and her brothers, that they would come up with inaccurate assessments and irrational, unthought-out takeaways; all of which they'd of course have to "share." Trust me, there would be plenty in my life that I would not share with them. We'd all been down *this* road many times before.

But their forever-unconditional love always more than made up for the confusion, *and* said love felt strong that day. So I told them what had happened. It was my choice. And I am still hearing jokes about Fifi to this day.

It has never bothered me.•

ABOUT THE AUTHOR:

Michael John Carley is the Founder of GRASP, a School Consultant, and the author of *Asperger's From the Inside-Out* (Penguin/Perigee 2008), *Unemployed on the Autism Spectrum*, (Jessica Kingsley Publishers 2016), the upcoming *Book of Happy, Positive, and Confident Sex for Adults on the Autism Spectrum…and Beyond!*, and the column, "Autism Without Fear," which for four years ran with the Huffington Post and will soon be transferred to Sinkhole at https://sinkholemag.com/ For more information on Michael John, or to subscribe to his updates, you can go to www.michaeljohncarley.com

Our daughter seemed to "wake-up" after our vacation. She saw more of the world.
Stopped running toward tractors and running face-first into trees. . .
Maybe she needed to be in a new surrounding or needed a break too.
I don't know. But I do know that you don't know until you try.

YO HO, YO HO! TRAVEL LIKE THE EXCEPTIONAL PARENTS YOU ARE!

BY JACKIE SCHWABE

No, travel is not easy for exceptional parents. However, it is not impossible either. We have to do what we always have to do! We have to figure out what we are fearing, make a plan for addressing the issue, find the resources we need, and then just do it. It was 17 years without a vacation until we finally took the plunge in 2017.
Here's how we did it!

RUNNING TOWARD TRACTORS AND C FOR CHOCOLATE

I am not going to lie, I was scared to death. We had never taken a family vacation before and there were solid reasons for that. We have four children. At the time of the trip, February 2017, they were 3, 5, 7, and 11. I was more worried about the five-year-old than the three-year-old. Why? Well, our five-year-old has an autism diagnosis.

If you are wondering why that would be reason for concern, well, then you most likely do not have a water-seeking child that cannot swim but loves to jump in any (and I mean any stinky, smelly, or nasty) water she can find. Chances are also good that your child does not run toward tractors that are scaring her, or into the street and in front of a vehicle to get away from cars. (Yes, you did read that correctly, I wrote *toward*).

It is also possible that your child isn't sensitive to sound or terrified of loud noises or petrified of crowds. Perhaps you also don't have a child who only eats things that start with the letter P: pizza, popcorn, peanuts, pepperoni, and on occasion, what we sometimes think might be poop and hope like heck we are wrong. Our hope, she has finally ventured into a new letter like C (for chocolate).

Yet, alas, we have been married since the year 2000 and had not taken a honeymoon. We are practical. We knew that we could go on vacations once we had a family and our kids were older. Well, we never went anywhere on vacation, after having children, that was more than an hour or less drive away; you know, we had to have an easy way to abandon our fun and return home without much fuss.

ENTER: MAGIC KINGDOM

Go big or go home, I guess. We didn't start out small when we decided to go on our first vacation – ever. Nope, not the

A WHOLE NEW WORLD: Disney will make special accommodations based on a child's needs. We were able to go to the front of the line at our designated time on rides our child went on. It may not seem like much to you, but to us – it was magical.

Schwabe family. We decided we were going to go to the Greatest Place on Earth, the Magical Kingdom. What were we thinking?

Well, what we were thinking is the wife of a college friend of mine was a travel agent for Disney. She contacted us a few times and we always politely said, "No, thank you." We didn't really say why we never went anywhere. I guess we didn't want to say the words out loud and make it seem like our dear daughter was the cause of our near-hermit type lifestyle. I mean, she wasn't to blame really, we were just uninformed, scared, and overwhelmed by the thought of the whole thing.

I am not a secretive person and I had been sharing more and more on social media about the adventures of being a working mom of four with an extra side of communication challenges (not quite as great as an extra side of fries). Thank heavens Jennifer Terruso of Magic Travel watched a few of the videos and didn't let me off the hook so easily the next time she reached out.

TRAVEL AGENTS RULE!

Turns out that there are services for parents like us, trying to make memories, and not just the types of memories that involve a mop and a bucket.

Jennifer told us that we could pre-board with Southwest Airlines to allow our daughter to get settled before the flight. Not only that, but she told us that all we had to do was call ahead and let them know, and then again when we checked into our flight. I was less than convinced it would be that easy, so our pediatrician gave us documentation indicating her diagnosis. Why? Well, it turns out, children with disabilities often look just like children without them. Armed with our paperwork and a mom on a mission, check-in went… smoothly. Oh, and the folks at Southwest were pretty darn amazing too.

> "Turns out that there are services for parents like us, trying to make memories, and not just the types of memories that involve a mop and a bucket."

While check-in went smoothly, Zoe was not as thrilled with boarding. I thought I had it made, but as soon as all the noise of the airport went away, and we entered the plane – before everyone else – she dropped to her knees and screamed her head off. I sure was glad that we got on before everyone else. Zoe got settled with a video and her stuffed animal, Little Rock, and the rest of the flight wasn't as momentous.

One success under our belt! Jennifer also told us that she would contact the resort and let them know about our unique circumstances. Turns out, Disney will make special accommodations based on a child's needs. We were able to go to the front of the line at our designated time on rides our child went on. It may not seem like much to you, but to us – it was magical.

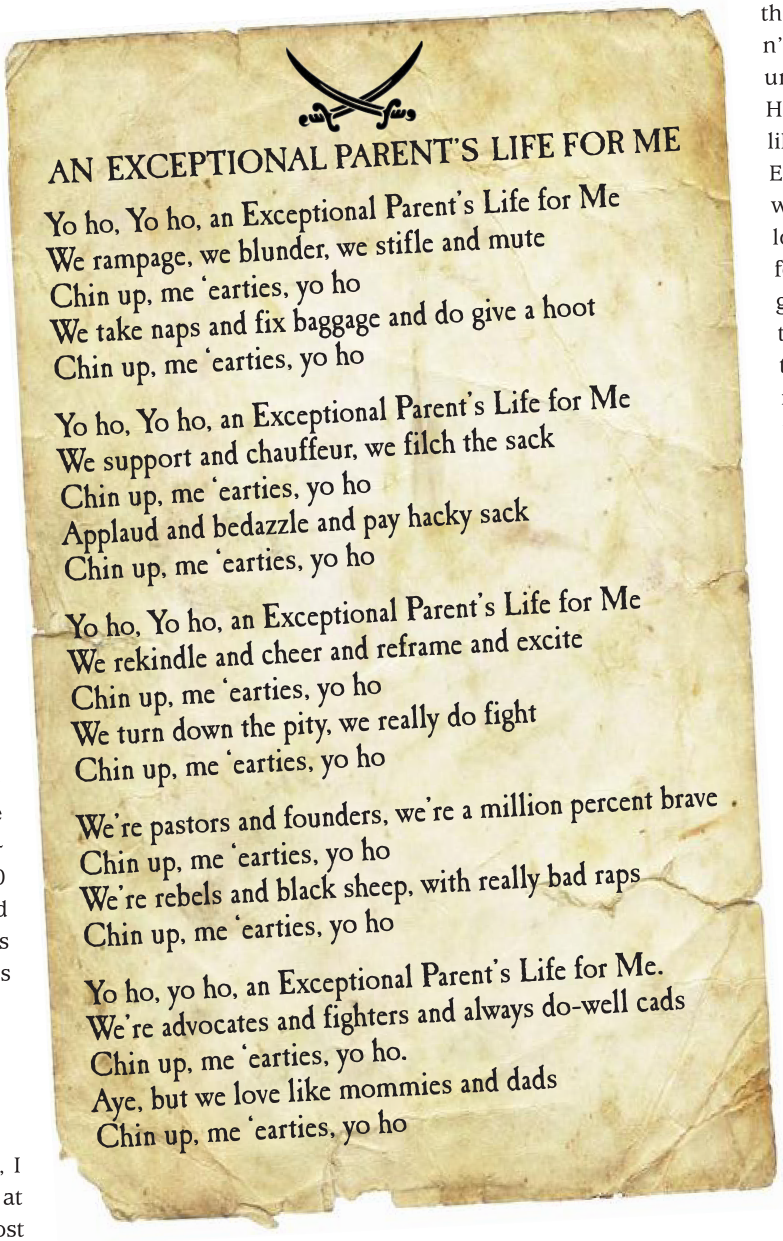
PHOTO PROVIDED BY JACKIE SCHWABE

You see, all the noise and standing in line would have been torture to Zoe. We would have had to split up, me with the other kids one time, my husband the other time, because there is no way she would have been able to handle that long of a wait in line and all the people and noise. Luckily, we didn't have to wait too many times, so we only had to split ranks a few times. Zoe got to go on It's a Small World and a few other rides that she would never have had the patience to wait in line to enjoy.

PHOTOGRAPHERS: WORTH EVERY PENNY

While we were at the resort, we wanted to make it magical, of course. So, we purchased the ability to get pictures taken with the various characters. I gushed about this online after our vacation and I will gush about it again here. The photographers – every one of them – were fantastic. They just seemed to know that our daughter needed a little extra consideration. I mean, we didn't have a sticker saying, look at her, she needs more help. Nope, they just knew.

One of the photographers told her that the stickers in his pocket were magic and that if she had it on, then no one in the park could see her. From that point forward, we got to see our daughter's face in the photos. They say a picture is worth at least 1,000 words. In our case, I would say the photographer was worth $1,000 and the pictures were priceless.



AN EXCEPTIONAL PARENT'S LIFE FOR ME

Yo ho, Yo ho, an Exceptional Parent's Life for Me
We rampage, we blunder, we stifle and mute
Chin up, me ‘earties, yo ho
We take naps and fix baggage and do give a hoot
Chin up, me ‘earties, yo ho

Yo ho, Yo ho, an Exceptional Parent's Life for Me
We support and chauffeur, we filch the sack
Chin up, me ‘earties, yo ho
Applaud and bedazzle and pay hacky sack
Chin up, me ‘earties, yo ho

Yo ho, Yo ho, an Exceptional Parent's Life for Me
We rekindle and cheer and reframe and excite
Chin up, me ‘earties, yo ho
We turn down the pity, we really do fight
Chin up, me ‘earties, yo ho

We're pastors and founders, we're a million percent brave
Chin up, me ‘earties, yo ho
We're rebels and black sheep, with really bad raps
Chin up, me ‘earties, yo ho

Yo ho, yo ho, an Exceptional Parent's Life for Me.
We're advocates and fighters and always do-well cads
Chin up, me ‘earties, yo ho.
Aye, but we love like mommies and dads
Chin up, me ‘earties, yo ho

YOU DON'T KNOW UNTIL YOU TRY

When we left for vacation, I was scared to death. Granted, at one point, we did think we lost our daughter on the bus. Turns out she liked to sit in the same spot on the bus and didn't like that we sat in the front – yes, I did have a heart attack – so she went to the back without us. So, not the entire vacation was perfect, but it was very, very close.

Our daughter seemed to "wake-up" after our vacation. She saw more of the world. Stopped running toward tractors and running face-first into trees. Maybe the sensory overload fixed a short circuit. Maybe she was just ready to evolve to another level. Maybe she needed to be in a new surrounding or needed a break too. I don't know. But I do know that you don't know until you try.

You know what else I know? I know that you deserve to get away. Your child and the rest of your family deserve to enjoy some time away from the everyday stuff. I also know that the agencies didn't set up services for them not to be used. The travel agent, the airlines, the doctor, and resorts create these services to allow you to take time away.

I also know that these are not the only services out there. I didn't really know there were any until we planned this trip. However, there are organizations like the Autism Society of South Eastern Wisconsin (ASSEW) that work in collaboration with the local airports and create a way for your children to experience getting on and off a plane before they have to do it. Essentially, they make social story into a real experience, so you and your child can plan ahead.

There is no shame in using the provided services. In fact, if you don't use them, they will go away. Those groups set up the services so we can enjoy our families. So please, toss the guilt, take the vacation, and travel like the exceptional parent you are!

MAGIC KINGDOM'S PIRATES OF THE CARIBBEAN

I was scared to death. Yet the true magic of the Magic Kingdom and the generosity and care of so many people allowed our vacation to be pretty darn great. While we were there, I heard the "Yo Ho Yo Ho A Private's Life for Me" song and it made me think about how exceptional we all really are. We do go through a lot. We all deserve a little fun. Our kiddos and our families all deserve a little fun.

Again, travel is not easy for us. However, it is not impossible either. I know you can do it! Chin up, me ‘earties! •

ABOUT THE AUTHOR:

Jackie Schwabe is CEO of MindLight, LLC, based in the Greater Milwaukee Area.

BOOK REVIEW

It’s More Than ‘Just Being In’

Creating Authentic Inclusion For Students With Complex Support Needs”

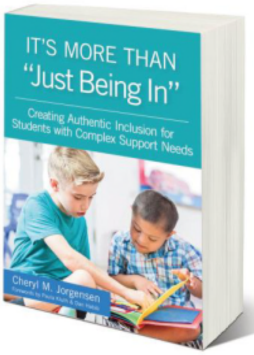
BY LAUREN AGORATUS, M.A.

EdWeb recently held a webinar, “Inclusion Is More Than ‘Just Being In’” presented by Cheryl M. Jorgensen, Ph.D., who just wrote a book on this topic.

LET’S START AT THE BEGINNING…

Chapter 1 begins with the basic tenets of inclusion. Marsha Forest coined the term “inclusion” at a 1987 parent conference. The definition of inclusion means that all students “are presumed competent, are welcomed as valued members of all general education classes and extra-curricular activities in their local schools, fully participate and learn alongside their same age peers in general education instruction based on the general education curriculum, and experience reciprocal social relations.[1]” And they are truly welcomed, not just “tolerated.”

When the Individuals with Disabilities Education Act (IDEA) was reauthorized, Congress indicated its support of the principle of inclusion, stating, “Disability is a natural part of the human experience and in no way diminishes the right of individuals to participate in, or contribute to society. Improving educational results for children with disabilities is an essential element of our national policy of ensuring equality of opportunity, full participation, independent living, and economic self-sufficiency for individuals with disabilities.[2]” IDEA promoted the concept of Least Restrictive Environment (LRE), and the IDEA regulations read, “To the maximum extent appropriate, children with disabilities, including children in public or private institutions or other care facilities, are educated with children who are nondisabled; and [2] Special classes, separate schooling, or other removal of children with disabilities from the regular educational environment occurs only if the nature or severity of the disability is such that education in regular classes with the use of supplementary aids and services cannot be achieved satisfactorily [§300.114(a].”[3] This can be summed up as indicating that inclusion is more than just physical presence – it’s about participation. The chapter concludes with research indicating the benefits of inclusion for students both with and without disabilities.



Title: **It’s More than “Just Being In:” Creating Authentic Inclusion for Students with Complex Support Needs**

Author: **Cheryl M. Jorgensen, Ph.D**

Paperback: **256 pages**
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CHAPTER 2

Chapter 2 expands on the notion of presence vs. participation. There is a range from being present/having presence, to participating, to connecting/contributing. There is a discus-

sion of person-centered planning using processes such as MAPs (Making Action Plans). This involves a strengths-based approach for students. The chapter includes examples of vision statements. There should be a vision statement on the IEP which can be updated as the student progresses each year. One of the most important considerations using MAPs is, "What does the student need in this school year to put him or her on the path to achieving the dream?" Another good statement of needs using the MAPs process is giving the student more control over their environment. The plan can include student strengths, what is important to the student (not to the adults), and how the student can best be supported.

CHAPTER 3

In Chapter 3, there is an explanation that the "least dangerous assumption" is to presume competence. High expectations lead to a less harmful outcome. Presuming *in*competence is the most harmful approach. Research shows that when teachers had groups of children with the same IQ, when one group was told one group of students' IQs were higher and the other group's were lower, the outcomes met the teachers' expectations.[4] Indeed, traditional assessments are "flawed" as they too often measure what students can't do rather than what they might be able to do with supports.

When students have means of communication, it shows previous assessment of cognitive disability was incorrect. Constructing competence can include speaking to students in an age appropriate manner and, if needed, providing them with a way to communicate. One study showed that of students who needed AAC (augmentative and alternative communication), less than half had access.[5] Peers will also model how teachers and other adults speak to children with disabilities. One thing adults can do if they notice that children are speaking to the other student as if they were younger, is to remind them that they are all the same age. "Not being able to speak is not the same as not having anything to say" (quote by Rosemary Crossley.) A literature review is presented which indicates that 96% reported positive changes for students with significant cognitive disabilities. It is noted that "lack of communication competence is highly predictive of poor post-school outcomes." It is further noted that "without use of AAC, students with significant disabilities cannot indicate their true abilities." Reading materials and other classroom content must also be age appropriate. This includes sex education because "not educating [Selena] about sexuality would deprive her of the very knowledge and skills she would need to prevent abuse. Furthermore, her parents fully anticipated that Selena would someday date and then get married, and they wanted her to enjoy sex as a natural part of life." Students must also be included in social relationships and "age-appropriate and inclusive work and career learning experiences alongside their classmates." This chapter ends using an excellent checklist to presume competence, assist with communication, and enhance inclusion through age-appropriate activities.

MEMBER BENEFITS: "Membership is more than simply tolerance; it comprises all the symbols and signs of belonging that are afforded to typical students in a classroom and within the larger school environment. Membership means arriving at and leaving school and the classroom at the same time as other students; having a desk situated alongside others, rather than in the back of the room, being called on in class; having a classroom job; and having a locker alphabetically arranged like everyone else rather than in the special education wing of the school."

CHAPTER 4

Chapter 4 covers inclusive IEPs. How to write a standards-based, inclusive IEP is explained. There are checklists, and examples of standards-based (for accountability) versus traditional IEPs are presented. One of the key features is that that the IEP is written using a strengths-based approach, particularly as this is the first information the new teacher will learn about this student. A strengths-based strategy will use person-centered planning and involve the family and student, and a positive student profile. As with traditional IEPs, the most recent assessments and Present Levels of Performance in Academic and Functional Areas are used. There are annual goals, short term objectives, and benchmarks using the SMART goals approach. This means that goals are specific, measurable, attainable, relevant, and time-bound. Sample goals include the condition, performance measure, demonstrated skill, level of mastery, and time frame. Other key considerations are supplementary aids/services to reach goals, progress monitoring, assistive technology, percentage of time in general education, participation in state assessments, transition, challenging behaviors, extended school year, and language access if needed. The only caveat is that the related services checklist had duration/frequency but not whether it would be provided on an individual or group basis.

CHAPTER 5

Supplementary Aids/Services is covered in detail in Chapter 5. This can include physical/ environmental, emotional/behavioral, sensory/vision/hearing, accessible materials, communication, executive function, personalized instruction, and technology. Distinction is made between accommodations which change the format of how material is presented but don't affect the content versus modifications which change the level of difficulty, but allow students to access the general curriculum. Each of these supports is detailed. If needed, the use of Functional Behavioral Assessments (FBAs) and Positive Behavioral Supports and Interventions (PBIS) are noted in this section. Sensory support is noted to help students avoid being overwhelmed and avoid meltdowns. The different types of sensory issues, such as low registration, sensory seeking, sensitivity, and avoiding, are presented. There are also tools described, such as therapy balls, fidget

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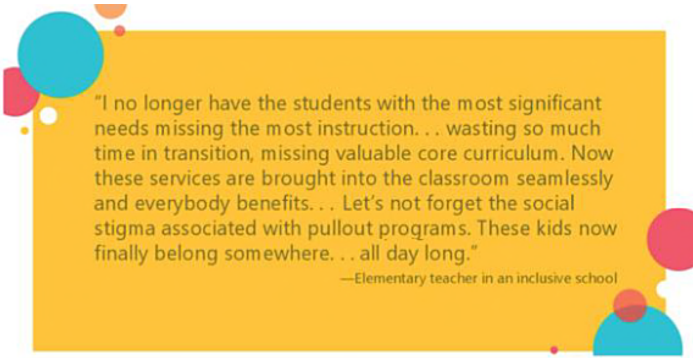
tools, and activities for proprioception, movement, tactile, etc. Lastly, there must be support for child study team such as planning time, professional development, use of consultants, and tools like a home-school communication notebook.

CHAPTER 6

Chapter 6 describes the shifts in team member roles and new roles for staff. General education teachers need to see themselves as teachers for all students. It's no longer "my kids, and your kids" (general vs. special education) but it's *all our* kids. Self-contained teachers can become inclusion facilitators. The knowledge, skills, and responsibilities of inclusion facilitators are described in this section. Related services providers can move to support group activities. Samples of inclusive IEP goals written by related services professionals as presented in an integrated manner to the "authentic learning activities in the general educational classroom" are shared. For example, a physical therapist can work with a student who has mobility issues on getting in/out of seating in the class. Students best learn skills where they need to use them rather than having to transfer skills from an artificial environment to the classroom. This is also less disruptive to instructional time and social relationships. Paraprofessionals can shift from one-to-one support to whole class support.

CHAPTER 7

This chapter covers "establishing valued membership in general education." There are several indicators of "membership." The child goes to the school they would have attended if he/she didn't have a disability. There is a natural proportion of students with and without special needs. Membership includes participation so that all students are included on class job lists, etc., and the students are called on by the teacher equally. There are also suggestions on transitioning into general education classes from segregated ones.



"I no longer have the students with the most significant needs missing the most instruction. . . wasting so much time in transition, missing valuable core curriculum. Now these services are brought into the classroom seamlessly and everybody benefits. . . Let's not forget the social stigma associated with pullout programs. These kids now finally belong somewhere. . . all day long."

—Elementary teacher in an inclusive school

CHAPTER 8

Social relationship mapping is covered in Chapter 8 which is similar to Circles of Support. The inner portion features the immediate family. Then the next layer has friends. Further out in the circle or chart are paid providers. Representation in all areas is equal for typical students. For students with complex needs, the chart could appear lopsided with supports mainly from family and paid providers, but no friends. The intent is to fill in the gap areas so they are more even. There is information on addressing barriers to reciprocal relationships. There is also information presented on strategies to intentionally facilitate these relationships if needed. These include presuming competence, providing a means of communication, age appropriate materials and clothing, extracurricular activities, etc.

CHAPTER 9

Chapter 9 covers developing a learning and participation plan which is a blueprint for students with special needs. It is important to have fidelity of implementation which means supports are provided accurately and consistently. The learning plan includes consideration of short-term goals, communication needs, accessible materials etc. There is a learning/participation plan template which includes:

what all students are learning
what we want this student to learn
how other students show they're engaged
what supports does this student need to fully participate
who writes the plan/when, and reporting

There is a table of indicators of full participation, including note-taking, going to the board, answering questions etc. which applies to all students. The appendix contains case studies and sample learning and participation plans.

CHAPTER 10

The last topic covered in Chapter 10 is transition to inclusive life after high school. One strategy used is the personal future planning process utilizing the MAPs process explained in Chapter 2. Community-based instruction is seen as an essential component to transition. One of the goals is to have the student run their own IEP meeting. Post-secondary education must be a goal for all students. Self-determination is a key ingredient to future independence with community living as the goal.

CHAPTER 11

The last section in Chapter 11 is a Q&A on challenges to implementation of inclusive education. It includes information on preventing and addressing challenging behavior. In addition, there is information on inclusion as mutually beneficial to both students with and without disabilities.

SUMMARY

It is noted that "inclusion is an easy thing to do poorly" (quote by Joe Petner). This book shows "how to do inclusion well." There is all the latest research, information on current laws and, most important, tools and templates for implementation.•

EdWeb Webinar:
https://home.edweb.net/webinar/inclusiveeducation20180418/

References

1. http://tash.org/advocacy-issues/inclusive-education/
2. https://sites.ed.gov/idea/about-idea/
3. https://sites.ed.gov/idea/regs/b/b/300.114
4. https://onlinelibrary.wiley.com/doi/pdf/10.1348/000709909X466334
5. https://eric.ed.gov/?id=EJ920309

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A Family Journey to Gold

BY STEPHANIE CORKETT

In the hot month of July 1994, Mallory and Kasey Morris unknowingly made history with their sisters and brother. Mallory and Kasey were part of the first set of quintuplets born in Kansas. Mallory, Jordan, Evan, Kasey, and Holly each weighed only a pound and a few ounces apiece and had to fight for survival.

It was an uphill battle for them as they encountered surgeries, struggles, and setbacks. Sadly, Evan passed away a few weeks after birth. "The sisters persevered and slowly made progress over the following months. They were all cleared and sent home just in time for Thanksgiving; and our family had so much to be thankful for that year," explained Shawn Morris, father to the quintuplets.

All four sisters grew up side by side and very close with one another. Mallory and Kasey were raised no different than Holly and Jordan. Any differences were never obvious to them. "We shared friends, teachers, classrooms, and experiences," said Kasey. Holly and Jordan were always very protective of each other and ensured no one was left behind. If you were friends with one sister, you were friends with them all. Mallory and Kasey never experienced any negativity, and in large part this was due to the supportive and watchful eye of Jordan and Holly.

It was not until middle school and high school that Jordan and Holly started to become active in clubs and activities like dance team and yearbook committee that were difficult for Mallory and Kasey to fully participate in. When they walked in to meet their new math teacher on freshman orientation night, their lives changed forever. She just happened to be the president of the local Special Olympics team and the rest was history! They immediately found their own special place to belong and excelled in the sports. "They became more social, grew leaps and bounds in confidence levels, and gained so many skills and experiences we never would have thought possible without this amazing organization," said Stefanie Morris.

As the years passed, Mallory and Kasey attended a training to become Special Olympics Global Messengers where they were taught how to speak in public and promote Special Olympics Kansas. With these skills they have given many informative, as well as inspirational speeches around the state of Kansas. "We've delivered speeches to end the use of the R-word, educated differ-

ALL FOUR ONE: *(Above)* The Morris sisters *(left to right)* Mallory, Jordan, Kasey and Holly.

PHOTOS PROVIDED BY STEPHANIE CORKETT/SPECIAL OLYMPICS

GOLDEN MOMENTS: *(Clockwise)* Holly, Jordan, Mallory, and Kasey *(left to right)*; Mallory and Kasey blinging with medals after swimming and track at 2018 Kansas Special Olympics Summer Games; Mallory and Kasey speaking to hundreds of people at a Kansas State University pep rally as Global Messengers; Manhattan, KS Special Olympics Family of the Year 2013 attending the annual Special Olympics Polar Plunge.

ent groups on the impact of Special Olympics and shared our story and journey. We've even thanked and accepted thousands of dollars on behalf of Kansas Special Olympics from awesome and dedicated donors," explained Mallory.

In January 2018, Kasey and Mallory were invited to a Special Olympics training in Indianapolis, IN. They joined athletes from all over the country who were to compete in Special Olympics USA Games in July to become Athlete Health Messengers. These athletes were trained on the importance of living a healthy life and how to take steps to motivate themselves and others to live as healthily as possible. They are members of a prestigious group who can speak about health disparities for people with intellectual disabilities. A nationwide fitness challenge was issued to all athletes to each walk one million steps between February and the Games in July. Kasey and Mallory, along with all the competing athletes in USA Games, received Movbands, which are wearable activity trackers designed specifically for people with ID to monitor steps. Since January, Mallory and Kasey have been competing with each other on how many steps they can each get per day. They take this challenge seriously and have been completely focused on achieving the challenge for the last three months. "Kasey reached her one millionth step first but I was only a few days behind her!" explained Mallory. They made sure their basketball teammates got their Movbands and got them setup so they could participate too.

On a hot summer day in July 2018, Kasey and Mallory represented Team Kansas at the Special Olympics USA Games in Seattle where they were part of a 10-person, all-female basketball team. They trained hard and stayed fit on their own time, and had team practices each week. They were honored and excited to represent Kansas in one of their favorite sports.•

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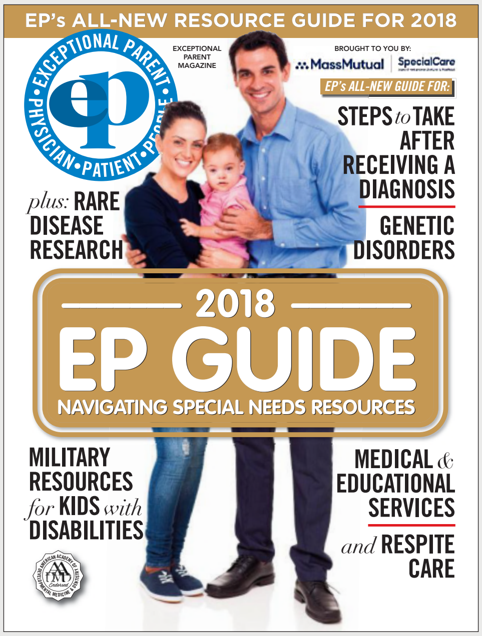

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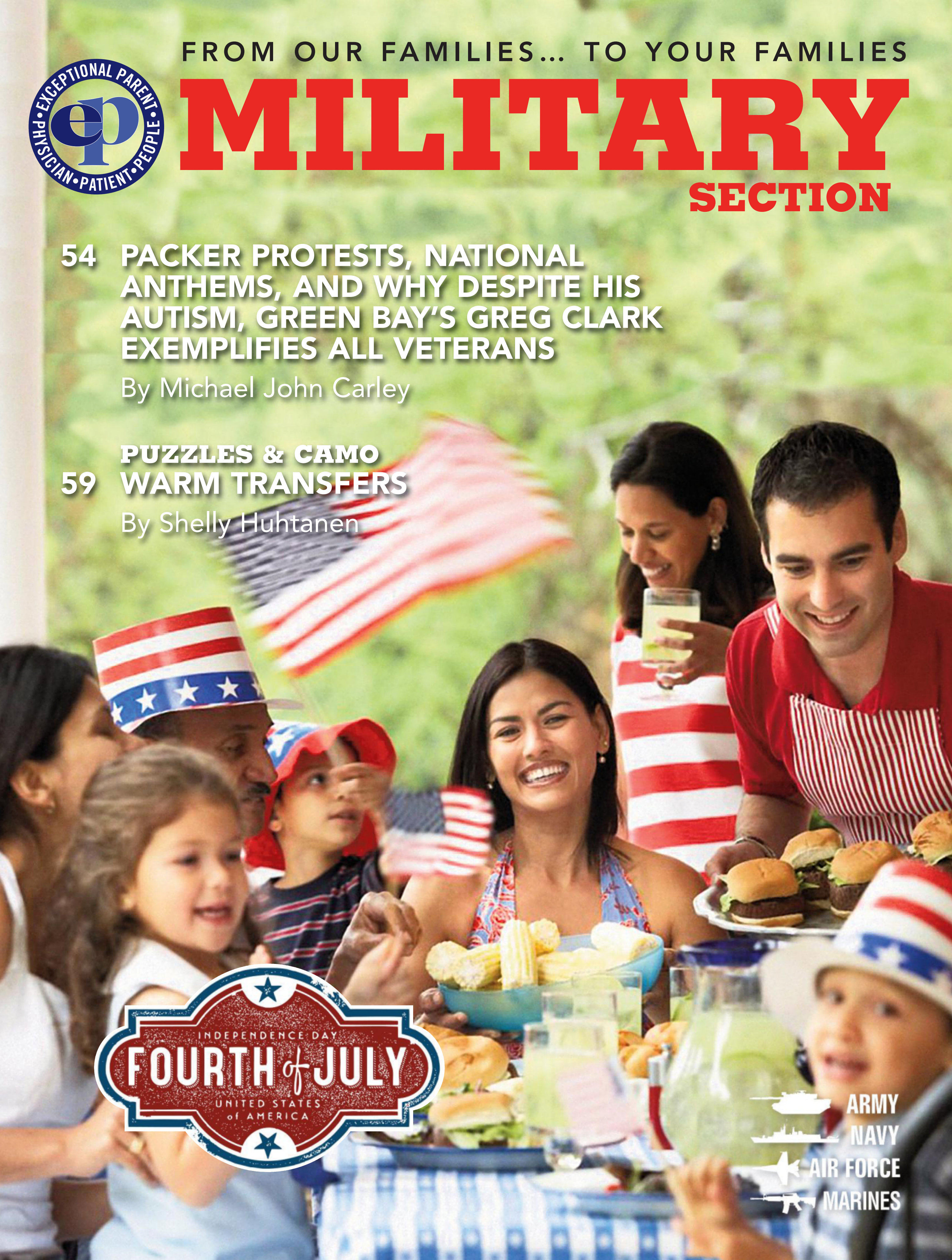

PACKER PROTESTS, NATIONAL ANTHEMS, AND WHY DESPITE HIS AUTISM, GREEN BAY'S GREG CLARK EXEMPLIFIES ALL VETERANS

BY MICHAEL JOHN CARLEY

Though it has not completely healed, the city of Green Bay recently survived an almost unheard-of trauma: Its football team and the town actually experienced a disagreement – a strong one actually, and one that played out on national television.

[This article is a reprint[1] from Michael John Carley's column with the Huffington Post that was published in January, 2018.]

In response to the nation-wide tumult surrounding the Star Spangled Banner, the Green Bay Packers and star quarterback Aaron Rodgers had asked the town to lock arms with them[2] as a show of unity during their September 28, 2017 game against the rival Chicago Bears. But instead of Green Bay's usual "ask, and ye shall receive" relationship with the team, the Lambeau field crowd booed the interlocking players during the song.[3] A clear majority of fans rejected the team's wishes and instead placed their hands over their hearts in the traditional manner. Respect for veterans, and veterans' concerns were cited as the fans' primary reasons for dismissing the players' request, and one wonders if the whole team – front office, concessions, sales, etc. – was at all in favor of the request. Coach Mike McCarthy, just for starters, has very strong and well-publicized feelings[4] about the national anthem.

GREG CLARK, 2004: His drill sergeant at boot camp first alerted him to the possibility of a spectrum diagnosis.

Whether we like it or not, we've been inundated – for almost a year – with media stories about football players not standing during the national anthem. It started in 2016, when Wisconsin-born, San Francisco 49ers quarterback Colin Kaepernick, refused to stand for the anthem[5] as a means to protest of the killing of unarmed African-American civilians by law enforcement. But the actual focus of the story, over time, became suspiciously blurred. As Kaepernick's methods underwent more scrutiny than his topic, the topic then changed to Kaepernick himself, and then changed again to being about respect for the flag, and about veterans. Whether this was an organic segue of issue-hopping or a successful diversion* remains to be seen. But Donald Trump certainly enjoyed chiming in,[6] media outlets had their content needs met for quite some time, the NFL was scrambling for a (non-existent) response that would please everyone, and one could even argue that a small, opportunistic, economic market[7] had even been created.

**Patriotism has often been used as a political strategy to deflect attention away from other flaws. Hence, the phrase, "Down in the polls? Start a war!"*

PHOTOS COURTESY MICHAEL JOHN CARLEY

Though the true subject of the protests (Racism? Patriotism?) has yet to be identified, the fact remains that while Rohingya people were butchered, while mass shootings in the US continued, and while Bitcoin's rise threatened to cause market upheaval over the long run, our news outlets instead smothered us with non-stop coverage of what, when you boil it down, amounts to a labor dispute; i.e. what you can and cannot do at work. *Can you* order an employee to stand for the anthem? Yet isn't *playing the anthem at work* a clear violation of civil rights? The story is not at all without its unprecedented angles.[8] For starters…

Wait a minute… Now it's happening to *me! See?* I too, just got *my* attention diverted – I'm 400 words into this article, and I haven't even mentioned who this story is about!

Green Bay resident, Greg Clark, served in the United States Army where he developed Post-Traumatic Stress Disorder (PTSD). Yes, Greg Clark also has autism. Oddly enough, it was his drill sergeant at boot camp who first alerted Clark to the possibility of a spectrum diagnosis. Clark was struggling one day, and the drill instructor said, *"You're autistic, aren't you?"* Clark replied:

"What's 'autism'?"

The two then sat down for an hour to discuss it.

Fast forward over a dozen years to a cold, fall night as Greg and I sat at the Blackstone, a well-known local diner west of the Fox River on Walnut Street. I asked Clark – a short, stocky, wintry, 32-year-old "sconnie" – what he'd thought of the whole arms-locking ordeal at Lambeau.

To Clark's credit, he didn't have a knee-jerk reaction to it, and even struggled to find an answer. Like many, he eventually felt that while he didn't like Kaepernick's stance, he believed that Kaepernick had the right to take it.

Further discussions with Clark revealed him to be a young man with the potential to have a family of his own some day, but also one who does not want the pressure to adhere to that life any time soon. The necessary higher income, and the ability to juggle more complex relationships are simply not attractive enough goals right now.

His PTSD is controlled. And like all others who have it stabilized (the vast majority, by the way), he doesn't come across as threatening whatsoever. Clark is extremely gregarious in our meeting, perhaps a little nervous, but whatever his challenges are, he retains the ever-important ability to trust.

Now, the idea of a spectrum individual serving in the armed forces should not come as a surprise. I've been writing about it[9] and speaking about it[10] for over a decade – and I'm not alone. Yes, the pressures and the physical demands of boot camp and combat, if not the ability to immediately process instruction, will cause most spectrumites to run for the hills. But some of us will paradoxically find the military to be a paradise. How? Well, in the military, we won't have to interpret *a thing*. In most jobs you need to do a lot of "reading between the lines," which we can suck at; but in the military, they are going to tell you how to behave from the moment you wake up until the moment they turn the lights out at night. They will teach you exactly how to address this person, and that person. They are *clear*. They may not provide context all the time, but they are communicators – there are no Midwestern dirty looks and cold shoulders when you err in the military: they will *tell you* what you did wrong – and that life is *heaven* for some people on the autism spectrum.

BIG BOOTS TO FILL: Greg had a father who had served in the military, and for whom the military seemed to have done well by. So he followed in his dad's footsteps.

As a result? I'd wager that our armed forces are stock full of undiagnosed or undisclosed spectrumfolk, and that this is not only a good thing, but also that the ones who stay are actually *very good* soldiers.

Clark is unique, though. He acquired his PTSD through two long-term exposures (as opposed to short-term incidents) while serving. But neither of the two experiences included Iraq, Afghanistan, or even combat.

Academically and socially, Clark struggled as he grew up in the Green Bay area, arriving at East De Pere high school around the turn of the millennium. There, he was picked on by the jocks and misunderstood by the administration. But thanks to "band geeks" he wasn't without friends. He did not have grand plans for college, but he did have a father who had served in the military, and for whom the military seemed to have done well by. So Clark followed in dad's footsteps; and in 2004, he enlisted right out of school into the National Guard.

He struggled in basic training at Fort Benning, even to the point where he had to do the first half over again. And because he couldn't latch on to instructions or concepts as fast as others, he was picked on. His fellow recruits even duck-taped him to his bed one night; mouth, head – everything, and hit him with padlocks wrapped in bath towels (similar to the harrowing scene in the movie *Full Metal Jacket*, though in the film they used lighter soap bars inside the towels). A second drill instructor walked by but said nothing, and Clark to this day, cannot remember how he got out of all the tape.

SERENITY, COURAGE, WISDOM: Greg now senses what he can and what he cannot change. He has accepted the dysfunction that surrounds him.

He and a friend, one Michael Forbes, were referred to as "Dumbass 1" and "Dumbass 2." And a few days before graduation, by Clark's account, Clark stumbled upon Forbes' body, slumped alongside a wall, an empty pill bottle next to him. Clark was whisked away. The army never confirmed for him that Forbes had indeed died, nor did they provide him with any contact information for Forbes' family. What Clark was offered was the excuse to not attend graduation. He turned it down.

"I'd worked too hard."

That first drill sergeant who knew about autism, Clyde Harris, was the person Clark cites for having gotten him through boot camp. But needless to say, his boot camp experience contributed mightily to his PTSD.

The other contributing exposure came from his deployment to Camp Shelby in Hattiesburg, Mississippi in 2005. While most of his unit left from there to go to Iraq, Hurricane Katrina changed Clark's plans. He was ordered to stay behind and help, and as a result, never went to Iraq. But while spared combat, no one could imagine how infamously careless, and inefficient – if not also cruel – those so-called relief efforts would show themselves to be. Exposed daily to families that had lost their homes, Clark felt culpable for the government's failure, and took the overall inadequacy personally.

Today, Clark is okay. I wouldn't say "great," but okay. After an endless stream of jobs that didn't work out, he now feels – like previous "Autism Without Fear" subject, Scott Hacker [11] – as though he finally works for people that get him (at the St. Vincent De Paul Thrift Store). That has meant a lot to him.

It should be noted that PTSD requires a treatment regimen[12] that combines both medications and therapy. Greg Clark is satisfied with the medications he receives, but he only sees a social worker (no therapist) irregularly. And when I press him on those missing benefits, he is reluctant to wonder what is available to him, or what he is entitled to. I wonder if by making peace with (what only I am calling) his inadequate treatment, he is succumbing to feelings of second-class citizenship. But that can't be right. Emotionally, he's doing too well. Some closure from the army about his friend might have been nice (to put it mildly), but he has come to terms with his situation in ways that I might not be able to measure up to… were I in his shoes. And it's his choice.

He also really comes across as a great guy.

So what makes Greg Clark embody all veterans if he's so unique? No big surprise, but it's because of the very fact that he's unique.

We tend to lump all veterans as though they're one, unified group that all thinks alike. They're not, and it's both intellectually and morally inexplicable to think of them that way. My father's Marine Corps helicopter squadron[13] fought in Vietnam and pretty much votes to the right. And my old colleagues at Veterans for Peace[14] (where I worked for ten years[15]) pretty much vote to the left. But even "pretty much" is an unfair pigeon-holing of both of them. Newer veterans organizations – composed of just Afghanistan and Iraq veterans[16] – seem to have even more complex opinions; ones that admirably defy categorization.

All veterans have opinions and feelings that are just as disparate as those that you and I feel. Yes, we need to listen to veterans. And the majority of them might have supported the fans at Lambeau, but it is by no means an overwhelming majority. There are many other veterans [17] (particularly those of color[18]) who strongly support Colin Kaepernick.[19] There are those who support the wars they fought in, and there are those who denounce the wars they fought in; those who still believe in "my country: right or wrong" and those with strong feelings about democracy; and all these vets have the audacity to confuse things further by not conveniently fitting into the camps of right and left.

If we were to ideologically go further, did a child who lost her father in Iraq not sacrifice[20] times more for this country than a two year, rear-echelon Navy officer? Is the female corporal less of a veteran because she "ratted out" the army colleague who sexually assaulted her? Do all vets enlist straight out of high school? Do all vets have Ivy League Master's degrees? Don't veterans, just like us, succumb to varying abilities to both think critically, and yet need simplicity? Should the right-leaning veterans organizations carry more clout because they have larger memberships, or should the left-leaning veterans organizations carry more clout because they have higher percentages of combat veterans amongst their memberships? Is Greg Clark less of a veteran because his PTSD wasn't the result of a Taliban assault?

One thing that vets *do* have in common is that the vast majority of *non-veterans* – us – always want to use them.[20] We cherry pick them for our stories, or our campaigns, and we appropriate their suffering for our politics until our need has passed. Furthermore, we ask them to separate from their families, to experience trauma, to die – fine. They agreed to do it, and often wanted to with the full support of the families they were separating from (whether due to economic necessity or patriotism).

But to deny them medical and therapeutic assistance when they come home... I feel (though this may be *my* baggage) is to throw them in the garbage.

If we got emotional – in either direction – about those NFL protests, then let's ask ourselves this: When we're exposed to harrowing stories of gross inadequacy[21] in our treatment of combat vets back home, do we care as much? When we see the destruction of military marriages as a result of ill care[22] back home, do we care as much? When we see the disproportionate amount of homeless[23] who are veterans, do we care as much?

Football?

Do we need veterans who have sacrificed so much for this country to want salutes, parades, and a "thank you for your service" more so than proper medical and psychological care? And if so, is that need based in guilt, or economics?

You could argue that herein I've actually short-changed how awful Greg Clark's experiences have been, maybe even the influence of his autism. But although he wants his story told, he now senses what he can, and what he cannot change. Remarkably, he resists my prods to be angry at his lack of access to proper therapy, perhaps even my as-yet veiled offers of advocacy. He has accepted the dysfunction that has, and continues to surround him. It may be autism-related, Stockholm Syndrome-like discouragement; it may be autism-related, Mr. Spock-like pragmatism. And it may also not be related to his autism. But Greg Clark will not let others, like me (even if he likes me), use him.

Green Bay has not completely healed from that night, no, but 90% of said healing was accomplished within 3 hours. I wouldn't want to anthropologically analyze why – the results would be too scary – but nothing unites this town like a (35-14) beatdown of the hated Chicago Bears. Those boos became loud cheers quicker than human behavior would argue possible. I'm not sure that's a compliment to us, but it sure is Green Bay.

Still...

My buddy Stephen Shore invented a great phrase about the autism spectrum: *"If you've met one person with autism, you've met one person with autism."* Vets could really use something similar.

Oh, and by the way, I emailed the local VA office in Green Bay for an interview, and my appeal went unreturned. And what I'd hoped was a good call with the National Guard (trying to get the process rolling to get Greg access to his friend's family)?... Became dead air immediately after.

Military service has costs – both necessary and unnecessary – that Greg Clark (dare I say it, Greg?) seems to have made his courageous peace with. Clearly, the rest of us aren't there yet.•

References

1. https://www.huffingtonpost.com/entry/autism-without-feargreen-bay-edition-packer-protests_us_5a5b6c30e4b01ccdd48b5d5a
2. http://www.packers.com/news-and-events/article-press-release/article-1/Statement-from-the-Green-Bay-Packers-players/d745d3ad-bfa7-4e74-9130-b3180b0171be#ixzz4u47adqjg
3. http://thefederalist.com/2017/09/29/green-bay-packers-asked-fans-link-arms-thursday-game-refuse/
4. https://www.packersnews.com/story/sports/nfl/packers/2017/08/17/packers-stress-national-anthems-importance-amid-nfl-protests/577917001/
5. http://www.nfl.com/news/story/0ap3000000691077/article/colin-kaepernick-explains-why-he-sat-during-national-anthem
6. https://www.washingtonpost.com/news/early-lead/wp/2017/09/22/donald-trump-profanely-implores-nfl-owners-to-fire-players-protesting-national-anthem/?utm_term = .10a692857474
7. http://www.sportingnews.com/nfl/news/neal-mccoy-song-national-anthem-protests-nfl-colin-kaepernick-donald-trump/1cpwpiljrul5t11andnzvx7f6q
8. https://www.thenation.com/article/understanding-the-split-in-the-nfl-players-movement/
9. https://www.amazon.com/Aspergers-Inside-Out-Supportive-Practical/dp/0399533974/ref = sr_1_1?ie = UTF8&qid = 1515518221&sr = 8-1&keywords = aspergers + from + the + inside + out
10. https://www.youtube.com/watch?v = 4OsPVH5AhsA
11. https://www.huffingtonpost.com/entry/59c86121e4b08d66155043dc
12. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5047000/
13. www.hmm-362.us/
14. https://www.veteransforpeace.org/
15. https://www.huffingtonpost.com/michael-john-carley/autism-without-fear-advice-for-young-autistic-authors_b_9672754.html
16. https://iava.org/
17. http://www.cnn.com/2016/08/31/us/veterans-for-kaepernick-trnd/index.html
18. https://theundefeated.com/features/an-open-letter-from-american-military-veterans-in-support-of-colin-kaepernick/
19. http://www.businessinsider.com/veterans-colin-kaepernick-2016-9
20. https://twitter.com/i/web/status/949111561787977728
21. https://www.washingtonpost.com/opinions/the-va-is-failing-veterans/2013/04/10/0fd9e264-a1f9-11e2-82bc-511538ae90a4_story.html?utm_term = .b05ee4ba8153
22. https://www.npr.org/sections/health-shots/2017/01/01/507749611/for-veterans-trauma-of-war-can-persist-in-struggles-with-sexual-intimacy
23. http://woundedwarriorhomes.org/homeless?gclid = EAIaIQobChMI3rHxoqvL2AIVXbbACh220wQIEAAYASAAEgLYg_D_BwE

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Michael John Carley is the Founder of GRASP, a School Consultant, and the author of *Asperger's From the Inside-Out* (Penguin/Perigee 2008), *Unemployed on the Autism Spectrum,* (Jessica Kingsley Publishers 2016), the upcoming *Book of Happy, Positive, and Confident Sex for Adults on the Autism Spectrum...and Beyond!,* and the column, "Autism Without Fear," which for four years ran with the Huffington Post and will soon be transferred to Sinkhole at https://sinkholemag.com For more information on Michael John, or to subscribe to his updates, you can go to www.michaeljohncarley.com

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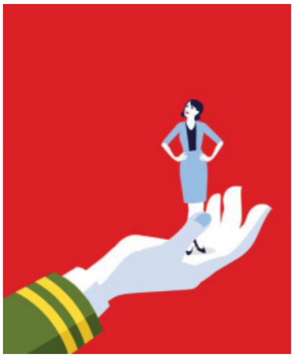
Warm Transfers

My advice to families is to not stop trying. After my frustrating interaction with the EFMP located at our future home, I received another phone call. It was from the School Liaison Office from that same installation.

At Martin Army Hospital, we have started to meet twice a month to discuss ways our EFMP (Exceptional Family Member Program) can support families. The Army has two EFMP's, one office under ACS (Army Community Service) and one office located at the hospital. Each EFMP has a different focus, but they have one thing in common. They exist in order to support Army families who have family members with special needs. Twice a month, we have come together to create relationships and find ways to work together and to be more efficient. As the Army spouse at the table with a special needs child, I work to remind the team of whom we serve. We serve families who have also chosen to serve.

In the last meeting, one of the members of our group asked, "What are your experiences PCS-ing from one installation to another with a special needs child?" I leaned back into the chair contemplating on how to answer his question. I needed my husband's help to answer. Every family is different, but my husband decided that it was in our family's best interest for me to keep a certain level of sanity so he works the EFMP side of the house concerning transition. I focus on researching ABA services and school options. After I left the meeting, I thought I would try to have more of an active role in our next transition. Granted, it's a year out, but I wanted to see what services were available in the area and start to build a relationship with people at the installation where we are moving to next. In our EFMP meeting at the hospital, they call this a "warm transfer." In the end, what families strive for in a PCS move is a warm transfer. I visualize a warm transfer as an invisible hand that guides the family into the installation to let them know that support is waiting for them on the other side.

I was saddened when I attempted to reach out to where we thought we were headed next year. I was told that my family would not be allowed to PCS to their installation. I called someone else because surely the Army would not send us to place where there were no services for our son. She continued to question if the correct channels had been followed concerning our move. She wanted dates of letters validating the EFMP "nominative process" to prove we were allowed to move there. Being a spouse, I did not have that information. I began to realize that I would not be able to assist my husband in this process due to the responses I was given, so I handed the torch back over to him. From that point, I admitted to my husband that I was incapable of taking part in the transition at that level. I'm not sure how other families do it, but hats off to them.



REACHING OUT: "I could hear him take a deep breath. He said, 'Ma'am, we are going to learn how to figure this out together.'"

In May, the GAO (Government Accounting Office) published a report entitled, "DOD Should Improve Its Oversight of the Exceptional Family Member Program." In a nutshell, EFMP has a lot of work to do. According to the report, the OSN (Office of Special Needs) that was created due to legislation in the NDAA (National Defense Authorization Act) in 2010 has to first establish "common performance measures and assess monitoring activities" for DOD to "fully determine the effects of its efforts to better support families with special needs and the adequacy" of its services. In common layman's terms, we still haven't even figured out a standard of measurement to hold our branches of service accountable. Again, we have a lot of work to do. Until then, families who are enrolled in EFMP will struggle with transitions and may even fight to stay out of the program because they do not see its benefits.

My advice to families is to not stop trying. After my frustrating interaction with the EFMP located at our future home, I received another phone call. It was from the SLO (School Liaison Office) from that same installation. He introduced himself as Gary and seemed very eager to help. After giving him our son's background and why I was calling a year out to start planning for his transition, I could hear him take a deep breath. He asked for my email so we could keep in contact over the year and said, "Ma'am, I've been working in this job for only three months so we are going to learn how to figure this out together." I appreciated his honesty and his willingness to want to help. I could tell from his voice he was sincere and was creating an invisible hand towards me. You could say he was creating a "warm transfer." •

PUZZLES & CAMO

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

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