PLUS: UNITED STATES MILITARY SECTION

EXCEPTIONAL PARENT

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EXCEPTIONAL PARENT
MAGAZINE
OCTOBER 2020
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IN THIS ISSUE:

HELPING PEOPLE with DISABILITIES to CHOOSE WORK

AND:

THE ROADBLOCK to INCLUSIVE EMPLOYMENT

AN EP EXCLUSIVE:

THE TOUGHEST BOSS I'LL EVER HAVE

PLUS • AADMD:

A WORLD WITHOUT DISABILITIES?

EMPLOYMENT & TRANSITION

ALSO:

THE AMERICAN CHURCH and the ADA

AMERICAN ACADEMY OF DEVELOPMENTAL MEDICINE & DENTISTRY
AADMD
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ON OUR COVER

Employment is a fundamental value and ambition in American culture, and people with disabilities want to be a part of their communities just as everyone does. EP's Annual Employment and Transition Issue explores the transition into the employment or postsecondary education stage for people with special needs, and its challenges during the pandemic. In addition, EP continues to cover the back-to-school season with a variety of practical tips and expert advice.
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Information and Support for the Special Needs Community

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

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

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

WE HAD IT ALL: *To Have and Have Not* paired 20-year-old Lauren Bacall in her debut with the aging Humphrey Bogart. Their connection was immediate, their chemistry electric. They were happily married until Bogart's death in 1957.

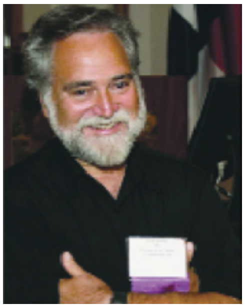
Whistle Blower

Exceptional parents will never acknowledge or accept the idea that their team will call it quits. To them there is no final whistle; even when time runs out.

Being an "insider" as a result of the pandemic I have enjoyed the guiltless allowance of watching old movies.

I recently saw a favorite of mine, *To Have and Have Not* (1944) starring Lauren Bacall and Humphrey Bogart. This was Bacall's debut and it paired her as a 20-year-old with the aging Bogart. Their connection was immediate, their chemistry electric. The most memorable scene is when Bogart flirts with Bacall. At the height of their cat-and-mouse exchange about getting together, Bacall delivers her most famous line, "You don't have to say anything and you don't have to do anything. Not a thing. Oh, maybe just whistle."

She pauses and then delivers, "You know how to whistle, don't you Steve? Just put your lips together, and blow."



While I'm sure Bogart knew how to whistle, it probably wasn't too loud. The average sound of the human whistle has a range of about 20 feet. Certainly not enough for competitive athletic events. Before the advent of whistles, umpires used handkerchiefs to signal to the players.

Ancient Egyptians first carved whistles out of gourds, while ancient Greeks used whistles to keep the stroke of galley slaves, and the English employed whistles to signal orders to archers during battle.

Joseph Hudson invented the first brass whistle in 1870 and it became the official referee's whistle used in British football (soccer) matches in the late 1800's. By 1883, he designed a whistle that could produce an intense sound that could be heard over a mile away. This invention followed the formula of many innovations; it was derived from a well observed accident. Hudson accidently dropped his violin and watched it shatter on the floor. He was astonished by

IMAGE COURTESY COMMONS.WIKIMEDIA.ORG

the "trill effect," the sound made by the discordance of the breaking strings. This led to his putting a pea in the whistle. His whistle was quickly adopted by the British police and the public quickly associated the sound of the whistle with that of responding constables.

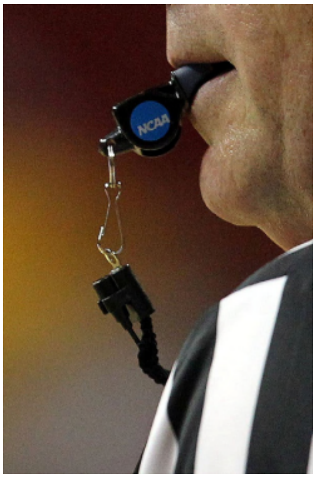
Over the years, the whistle became the most recognizable sound in sports. Chantel Jennings sums it up, "It often marks the beginning and the end of an event, signals pauses and restarts in tense moments, and acts as an exclamation point after a big play. In the symphony of sport, the whistle is the soprano, crisp, distinct and capable of leaving one's ears ringing."

And while the potential for hearing damage due to repeated exposure to loud whistle blowing has caused sports medicine specialists to rethink the use of whistles, it appears as if COVID-19 will result in the whistles being relegated to the top shelf of the ref's lockers.

The mechanics of whistle blowing requires a deep breath and then a forced burst of droplet-filled air. Research has demonstrated that the potential for viral spread is directly related to the speed, intensity, and volume of the propelled droplets. The whistle has been named as a potential instigator of viral spread.

Enter the electronic whistle. It is operated with the push of a button and it features variable tones that can be selected and adjusted. The whistle is being tested by every major sports organizations (National Football League, National Basketball League, NCAA etc.) and has even gotten the attention of the White House. We might soon see the President of the United States using an electronic whistle to start the annual Easter Egg Roll on the White House lawn. When you factor in the need for umpires to wear face masks, the use of a hand-held electronic whistle appears to be the choice for the future.

WHILE YOU WORK: By the 1880s, British police had adopted Hudson's new whistle, which could be heard over a mile away; In the world of sports, whistles have been named as a potential instigator of viral spread.



And while whistles announce the beginning and end of a competitive event, it is one sound that has never been respected by parents of children with special needs. For one thing the beginning of play is never at a specific point in time. The announcement that you are to begin being an exceptional parent comes at different times to different parents. Some begin when they hear the diagnosis from their pediatrician, or from teachers, or from watching their children at a play date, or thinking that this one is different from their first child. There isn't a two-minute whistle warning to announce the end of the game is approaching. There are few, if any pauses in the action for our parents. Exceptional parents will never acknowledge or accept the idea that their team will call it quits. To them there is no final whistle; even when time runs out.

In real life, Bogart and Bacall got together and were happily married until Bogart's death in 1957. It was obvious that both of them knew how to whistle and worked at perfecting it. The notion "to have," and "have not" appears to be the running theme in the lives of exceptional parents. •

ANCORA IMPARO

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

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

CONNECT AND DISCOVER

Join EP's Facebook Community

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

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

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

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

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

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

WHAT'S HAPPENING

AUTISM HOUSING NETWORK ADVOCATES FOR THE RIGHT TO HOUSING ON A GLOBAL SCALE

UN-HABITAT invited the Autism Housing Network (AHN) Director, Desiree Kameka Galloway, to virtually attend and speak at the World Human Rights Cities Forum (WHRCF).

LOCAL AND GLOBAL: Sessions at the WHRCF are conducted in person and online internationally, like this one in October 2019. The forum brings together international governments and organizations for advocacy and discussion to advance human rights to housing across the globe.

Kameka Galloway will discuss how COVID-19 has impacted housing options and highlights the urgency to prioritize housing solutions for individuals with intellectual/developmental disabilities (I/DD) on a global scale.

Kameka Galloway stated, "For people with disabilities to be included in society and find accessible homes, physical, environmental, technical and social barriers must be identified and dismantled. COVID-19 has widened the gaps of those often left behind, shedding light on those whom systemic injustices have hidden and kept quiet in its shadows."

The theme of WHRCF's 10th anniversary event is "The Future of Human Rights Cities: Local Memories and Global Sharing." This forum brings together international governments and organizations for advocacy and discussion to advance human rights to housing across the globe. This particular event will host speakers to discuss various global issues related to residential needs in the COVID era.

"The right to housing is a freestanding right, but public awareness of this basic right remains low. The youth, the hope for the future, should be entitled to a safe and secure home. The effects of the ongoing COVID-19 pandemic are disproportionate and the youth are vulnerable to poor housing conditions." according to the WHRCF. The WHRCF is dedicated to policy and social change to assure that everyone has a peaceful place to live, while amplifying the voices of excluded and marginalized communities.

UN-HABITAT partners with government agencies, organizations, foundations, etc. to address challenges of urbanization. UN-HABITAT is currently involved with 100 countries to help protect people against COVID-19 and the effects of the pandemic particularly in poor and densely populated areas. The collaborative effort will help nations work towards inclusive, safe residential environments in a neurodiverse world. The event takes place at the Kim Daejung Convention Center October 7-9, 2020. Registration is closed, but interested parties can access the live video stream through this link. Desiree Kameka Galloway will be presenting on October 8th between 12:30-3:30pm KST (UTC +9).

The AHN, a project of Madison House Autism Foundation, compiled and maintains one of the largest databases of user-generated resources and residential opportunities while fostering a supportive and encouraging online community. Kameka Galloway is nationally recognized for her expertise in neuro-inclusive housing, empowering local leaders to create inclusive communities, and leading advocacy and action alongside adults with autism and other neurodiversities.

If you want more information, please contact Christina Wandry: **cwandry@madisonhouseautism.org asha.org/public**

A NOTE FROM DIFFERENT BRAINS FOUNDER, HACKIE REITMAN, M.D.

I want to highlight an upcoming free virtual event hosted by and featuring some very dedicated advocates for neurodiversity!

From Saturday, October 17th through Wednesday, October 21st, Stanford University will be hosting their Stanford Neurodiversity Summit. Dr. Lawrence Fung will be leading this free virtual event dedicated to looking at neurodiverse employment and careers. I will be presenting along with an impressive list of world neurodiversity leaders, including Judy Singer and previous Exploring Different Brains guest Dr. Nancy Doyle! Click here for more information!

So please take advantage of this important free event, and thank you to Brooke Schnittman, Dr. Lawrence Fung, and everyone at Stanford University for all they are doing for those of us with different brains!

– Hackie Reitman, M.D.
President and Founder, Different Brains Inc.

PHOTO COURTESY RIGHT2CITY.ORG

XRHEALTH ANNOUNCES VR THERAPY APPLICATION TO TREAT ADHD

XRHealth, a leader in extended reality and therapeutic applications, announces a new VR therapy application for ADHD.

The application is aimed to improve well known ADHD cognitive functioning such as attention, impulsivity and higher, more complex thinking functions such as: initiating, organizing, planning and fully executing daily tasks. The VR solution closely monitors user progress based on sustained focus while distractions are present.

A new FDA policy enables clinicians to prescribe VR therapy for patients with ADHD during the public health emergency of COVID-19 as an adjunct to clinician-supervised outpatient treatment. The VR training solution is based on the brain plasticity principle, which is the brain's ability to restructure itself in attempt to overcome existing challenges. The application uses well based cognitive principles shown in the research field that are effective in facilitating this process. To further enhance its effectiveness, the application allows the clinician to create, monitor, and adjust the training process at every step.

In every training session a user-adaptive mechanism, backed by eye-tracking technology, is available to allow the clinician to adjust the task difficulty level in accordance with the patient's ability. This mechanism is meant to challenge patients and constantly motivate them to enhance their performance.

"Our training method is able to help a child or adult brain better cope with ADHD," said Eran Orr, CEO of XRHealth. "The interactive nature of the therapy is able to give clinicians critical measurements of improved concentration and attention span as well as reduced impulsivity."

Clinicians using the XRHealth VR training method will prescribe the number and length of VR therapy sessions for each individual ADHD patient. Some of the application's core advantages, include:

- ***Motor activation:*** *Patients with ADHD commonly experience issues with both cognitive and motor abilities. The XRHealth application is one of the few digital cognitive training applications that intertwine motor and cognitive activity into an integrated digital, clinically monitored training program.*
- ***The visual and auditory experience mimics real life activity to improve motor movement.***
- ***Better clinical monitoring:*** *The application gives the clinician comprehensive, detailed and precise information about patient performance and improvement during every session.*
- ***Integrated eye tracking technology:*** *The eye tracking technology provides unbiased, objective, and quantifiable data that can be used for better patient assessment, training, and monitoring.*

The therapeutic platform will be available to consumers later this year on the XRHealth web site. The XRHealth platform is not intended to represent a substitution for a patient's medication, and any recommendations provided by the application are supportive in nature and should not be solely or primarily relied upon to treat ADHD.

XRHealth, is a leader in extended reality therapeutic applications providing both VR and AR solutions for the medical industry. XRHealth is the first certified Extended Reality medical company in the world; their Medical Applications are FDA & CE Registered. They provide first-of-its-kind healthcare technology that helps clinicians better manage their patients' care via specialized extended reality technology solutions and data analysis. XRHealth created the first virtual reality telehealth clinic in the world that utilizes the VRHealth Platform, which collects and examines user data through artificial intelligence (AI) and cloud-computing algorithms to deliver advanced data analytics in real-time, consistently enabling healthcare providers to enhance their users' and payers' healthcare experiences. The company offers a variety of patent-pending solutions from rehabilitation services to cognitive assessment and training, to pain management. XRHealth works with several world-renowned U.S. healthcare providers, hospitals and rehabilitation centers.

Founded in 2016, XRHealth is headquartered in Boston, Massachusetts. For more information, visit **www.xr.health**.

VIRTUALLY REAL: XRHealth's VR training solution for ADHD will help develop focus and concentration in the presence of distractions. VR has been gaining steam as a treatment for various medical challenges, ranging from mid-procedure surgical pain to social anxiety, loneliness and isolation.

IMAGE COURTESY XRHEALTH

WHAT'S HAPPENING

OCTOBER IS NATIONAL DISABILITY EMPLOYMENT AWARENESS MONTH

HAPPY ANNIVERSARIES: This year marks not only the 75th observance of NDEAM, but also the 30th anniversary of the ADA. Both milestones are being commemorated with a range of events and activities centered on the theme "Increasing Access and Opportunity."

The American Bar Association joins the country this October in observing National Disability Employment Awareness Month (NDEAM). This year marks the nation's 75th observance of NDEAM and the 30th anniversary of the Americans with Disabilities Act (ADA). This month provides us with an opportunity to recognize and celebrate the contributions of workers with disabilities and to educate others about the value of a diverse workforce.

This year's theme, "Increasing Access and Opportunity," emphasizes the importance of expanding the role that people with disabilities play in America's economic success and ensuring that workplaces continue to include and accommodate their needs through technology, best practices and awareness.

One of the ABA's core goals is to eliminate bias and enhance diversity. The legal profession benefits from the skills, talents and perspectives of persons with a wide range of abilities, yet lawyers with disabilities are often overlooked when bias, diversity and inclusion are discussed. The profession must reflect the clients we serve and that includes persons with disabilities. All lawyers, law schools, judiciaries and legal employers must do everything possible to make the profession accessible, inclusive and welcoming and to make disability diversity and inclusion a priority.

The ABA is a voluntary association of lawyers in the world. As the national voice of the legal profession, the ABA works to improve the administration of justice, promotes programs that assist lawyers and judges in their work, accredits law schools, provides continuing legal education, and works to build public understanding around the world of the importance of the rule of law. View our privacy statement online. Follow the latest ABA news at **www.americanbar.org/news** and on Twitter @ABANews •

AMERICAN ACADEMY OF DEVELOPMENTAL MEDICINE & DENTISTRY

A World Without Disabilities?

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

“Some genomic researchers believe that within the next few years science will have advanced to the point in which many of the world’s *congenital disorders* can be **eliminated** (sic) and many other diseases can be treated at the cellular level. These advancements mean that we may one day arrive at the point in which congenital disorders become a thing of the past. As a society, should we seek a world without disability? Genome research means that parents may ultimately choose traits in their children in the future.” [1]

THE SETTING

- Not all disabilities are congenital. Disability encompasses a wide range of conditions, inherited or ‘acquired’ during a lifetime and some are far worse than others.
- A cochlear implant is a surgically implanted neuroprosthetic device to provide a person with moderate to profound sensorineural hearing loss (i.e. when sensory cells and/or nerves are damaged) resulting in a modified sense of sound. For some in the deaf community, cochlear implants are an affront to their culture, which as some view it, is a minority threatened by the hearing majority.[2] In the deaf community, the art of communicating through sign language is part of their culture; however, if gene editing lowers the rate of people that are deaf, how will this culture manage to sustain itself in the future?
- With the emergence of new biotechnology such as the CRISPR Cas 9, the possibility of preventing and curing some disabilities is now on the horizon. CRISPR Cas 9 is a genome editing tool that will be able to correct mutations that often lead to cystic fibrosis and sickle cell anemia. The biotechnology will also be able to edit HIV out of a person’s genome or lower the risk of cancer and heart disease that are more prevalent today.[3]

CONCERNS

There is the potential of a “cure” vs “prevention” possibilities for individuals with disabilities in discussing the manipulation of human genes for future generations of any type of disabilities. However, while research efforts strive to “cure disability”, there is continued indifference to the social and cultural factors that make not walking, hearing, seeing, etc. a problem. Advocates for the “curing” ideal will argue that we cannot assume that society is obliged to undertake changing the world for people with disabilities so as to render them “not disabled” in all cases. Thus, impairments can be avoided and eliminated through abortion, sterilization, and infanticide, or cured through general body and gene line therapy. This view underestimates the prevalence of disablement, which is increasing, especially in wealthier, developed societies due to a combination of an aging population and medical interventions which prolong life. [4]

- Discussions surrounding genome research ethics has the potential for the creation of “designer babies”. We may arrive at the point in which parents are choosing certain traits that they want in a child, such as blonde hair, dark eyes, to be tall etc. One potential problem around picking and choosing dif-

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.

ferent traits for your child is that it could lead to a further class divide. Children from wealthy families that already have better educational opportunities and access to health services, could be given a genetic advantage above their peers. "Those that cannot afford further genetic enhancement become a disabled class; a class of lower intelligence, physically weaker, less desirable through any number of naturally occurring genetic traits."[1]

- *An example of the consequences of extremes in family planning:* China's population started outpacing available resources long before the introduction of the one-child policy. Following the establishment of the People's Republic of China in 1949, the Chinese government began preaching the importance of family planning and encouraging the use of birth control as a means of managing the population. The one-child policy was implemented nationwide in 1980 in order to limit most families to one child each. The "importance" of a male child for economic and cultural factors produced on over-balance of the male population with significance consequences as the youngsters reached ages for marriage and their family planning. [5]

> "Throughout history, people with disabilities have unfortunately been treated as objects of misfortune, pity and a burden to society, to the point where society automatically associates disability with tragedy."

- In addition, there are the questions related to **eugenics**; *the set of beliefs and practices that aim to improve the genetic quality of a human population, historically by excluding people and groups judged to be inferior and promoting those judged to be superior.* (Developed largely by Francis Galton as a method of improving the human race; it fell into disfavor only after the perversion of its doctrines by the Nazis.) [6]
- With the advances in new technology, there have been limited discussions that include the voices of people with disabilities. The issue is not with the technology, but rather the "curing" concept that ignores the key group of people who will be affected and how they are being presented as less than normal. People with disabilities have constantly been excluded from the rest of society, and with the new emergence of gene editing, it will further push them into exclusion.[7]

Throughout history, people with disabilities have unfortunately been treated as objects of misfortune, pity and a burden to society. The misconception has permeated the minds of society to the point where they automatically associate disability with tragedy. *This ultimately leads to society's mission in trying to find a "cure," hence the development of gene editing, rather than accepting individuals with disabilities.*

COMMUNICATION BREAKDOWN: With the advances in biotechnology such as the CRISPR Cas 9, there have been limited discussions that include the voices of people with disabilities.

ONE PERSON’S PERSPECTIVE

“I have achondroplasia, the most common form of dwarfism, which has affected my family for three generations. I’m also a woman and a mother – the people most likely to be affected by human genetic editing. I remember clearly when John Wasmuth discovered fibroblast growth factor receptor 3 in 1994. He was searching for the Down syndrome gene and found us. I remember my mother’s horrified reaction when she heard the news. And I remember watching other adult little people react in fear while average-height parents cheered it as “progress”… It remains critical that we drive decisions about the future of disabled people and our health care. Many of us see our disabilities as a rich and diverse culture, many of us want to pass that culture down to our children through our genes, and many of us see no reason not to. **We should have that right.”** *(emphasis added)* [8]

THE AUTHORS’ PERSPECTIVE

We have written hundreds of articles regarding the issues faced by individuals with disabilities. We have delivered untold number of lectures to students, presentations to politicians, examined and advised Special Olympic athletes, provided oral health care to children with disabilities and brought our efforts to reach populations throughout the world. It was only when we began reviewing the literature for this presentation that we recognized the intensity of the different views regarding the efforts to consider “A world without disabilities.” *And what are your views?* •

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AADMD

The Roadblock to Inclusive Employment

let's re-educate society that people with special needs is a natural part of human diversity. Re-education is a slow and extensive process, but our approach is as long-term as our vision.

The pandemic is clearly driving a shift in the employment landscape. The special needs community needs to get up to speed with the mainstream workforce. But before we can take the first steps, there are intrinsic issues adversely affecting the state of employment of people with disabilities that need to be addressed. To uncover the likes of these problems, let's take a tour of the different areas where some community members are deemed productive. The following are real-life situations, but the names are fictitious.

DOUBLE STANDARDS

Rick is an IT expert in an organization that employs people who are blind and visually impaired. He can fix anything that runs on 1's and 0's. You'd wonder if he was born a tech-nerd. But Rick's sighted peers are paid more for the same work.

In his seven years with the organization, Rick has proven his impeccable skills in computer-related jobs. Still, his obvious disability detracts from the value of his work. Perhaps the organization's leaders have a myopic view of what a totally blind tech can do. This institution does not value the production of workers with special needs as much as those without visible disabilities. Like other establishments, this particular organization has double standards.

WORK ACCOMMODATIONS

Annie has a hearing impairment and works in a hospital kitchen. Sometimes she needs to consult managers about job-related issues. However, no one is trained in American Sign Language. Everyone is too busy to converse through mobile devices or uses pen and paper. So Annie has to do without consultation that other workers have access to. Afraid to lose her job, Annie refuses to discuss communication accommodations with leadership.

Accommodations in the workplace means any adjustment necessary to help an employee with disability work or keep a job. It could mean modifying the work environment, adaptive equipment, assistive technology, peer support, breaks, leaves, or whatever is needed for optimum productivity. Often, accommodations don't cost much, and businesses can take advantage of tax credits and other benefits for employing people with disabilities. Unfortunately, several corporations aren't aware of what they're missing. Meantime, most workers with disabilities in mainstream businesses would rather suffer the stress of getting work done while barely passing performance goals.

PITY HANDICRAFT SHOP

Imagine that you're searching for a unique gift for a special someone at a souvenir store. You browse through the handmade art pieces that look beautiful, but don't see one stunning enough for a purchase. You determine to hop to the next shop. But wait, on a row of the handiwork was a label that says, "Made by the special needs community."

Most of us have experienced buying a product made by a person with special needs. It has often been not because it is beautiful or functional, but because we feel the need to help. Apparently, buying a product is considered a noble act, not a dole-out. As a society that encourages such transactions, we're condoning selling disability when craftsmanship should be the selling point. The marketing strategy, in this case, is to appeal to pity. Income will be generated for sure, but would it be sustainable? After all, mainstream business does not operate on charity.

SHELTERED WORKSHOPS

Sally is paid less than half of the state minimum wage to remove labels on bottles before they're recycled. She's been living and working in the center for almost ten years. Occasionally, family members visit and bring her goodies, but her peers in her work circle have become her family.

Sally feels grateful for her job because she believes no one else would employ her. Traditionally, a sheltered workshop is a work setting exclusively for people with disabilities who are paid subminimum wages. The workers are segregated from the mainstream. Are these work centers empowering, or are they a disservice?

These work scenarios have evolved from long-standing worldviews of disability and of minority groups.

WORLDVIEWS

For the longest time, society has adopted the medical model, which sees disability as something wrong with a person's body or mind. Fixing the problem prescribes treatments or cures through therapy, surgery, drugs, or other methods. It may include preventing transmission of the disability to future generations. Impairment is the defining aspect of a person who is merely a ward under professionals. A person with impairment can never be equal to society unless the medical problems are treated. Considering that the standard for wellness is those without visible disabilities, people with impairments are regarded as second-class citizens.

As a reaction to the medical model, people with disabilities developed the social model in the 1970s. It was endorsed by the World Health Organization (WHO) in 2001. This framework posits that physical, sensory, intellectual, and psychological impairments don't necessarily lead to disability. But if a

BREAKING BARRIERS: Social models developed in the 1970s and endorsed by the World Health Orgaziation posit that physical, sensory, intellectual, and psychological impairments don't necessarily lead to disability. But if a society fails to address systemic barriers to inclusion, people become disabled.

society fails to address systemic barriers to inclusion, people become disabled. Therefore, impairments are differentiated from disabilities. According to the social model, some strategies that address disabilities consist of creating access through accommodations, universal design, and inclusive learning environments. The bottom line is that society, not the individual, is tasked with including all minority and marginalized groups into mainstream life in its entirety. www.artbeyondsight.org/dic/definition-of-disability-paradigm-change-and-ongoing-conversation

Today, despite its deficiency, the social model is an ideal starting point towards an inclusive economy and employment, but people with special needs need to be more accountable and proactive in self-advocacy. As a former social activist, I have sounded like a clanging cymbal confronting public and private institutions about their failure to eliminate barriers that disable the special needs community. Being aggressive and belligerent, I've turned potential partners into enemies. Young and relatively inexperienced, I expected a paradigm shift from a medical to the social model overnight. But five decades later, societies are mostly respecting our rights more than our value, as evidenced in policies and programs based on tokenism. Although no one would admit it, I suspect that some people are still fixed on the old model. Failure as an advocate led me to change my perspective. Addressing symptoms, not the root causes, and finding piecemeal solutions can't sustain equal opportunity. I realized that the sector's deep problems must be addressed and solved through an honest and holistic approach, not merely pointing a blaming finger at society or at people with special needs.

RE-EDUCATING SOCIETY

Society isn't unwilling to change; it just doesn't know any better because of the orientation that's been so long engrained. This is a call to re-educate society **to unlearn the previous framework and adapt the truth.** I'm not talking about merely creating awareness or raising consciousness. People have known our existence since the dark ages and have rejected us. But society doesn't know our colorful personalities, resourcefulness, originality, and courageous heart, characteristics born from our challenge-ridden lives. We need to promote not just tolerance but appreciation for our talents and abilities. They may be different, but they're integral to economic growth.

THE GOVERNMENT SECTOR

Re-educating the government sector is a systemic move. The government can make and implement laws and could be model organizations for equal opportunity. Several policies for people with disabilities, including our so-called benefits, are oriented towards welfare. An example is supplemental income, which could be a bane or a boon. It's a boon for those who can't work, or don't get hired, but how many employable people with special needs choose to receive supplemental income over working? I don't blame them. It makes sense to receive money without grinding, especially if the potential earnings from employment are less than the benefits. However, in some cases, individuals are complacent with receiving their services without improving their status in life. So they opt to not seek employment nor be productive. On the other hand, I admire peers who choose to receive benefits so they can pursue their passion.

Some volunteer their services to different communities, develop their talents, and a few brilliant people source more income from fulfilling undertakings.

Usually lumped with the supplemental income is Medicare. Consider this "damned if you do, damned if you don't" situation. If you are part of the manual labor sector, you tend to weigh your opportunities in light of your welfare dependence. When given a chance to work more hours, do overtime, or even get a promotion, you may not readily jump for better options. You are not only in danger of losing all of your monthly government-issued income benefits but your medical insurance. You may be placed in a position where you can afford to go without the government check, but not afford your own medical insurance even through your employer. So, if you don't have the chance to be promoted or seek a better position elsewhere, the small increases in wages won't be worth it.

PRIVATE BUSINESSES

Profit-oriented establishments often assume that employing people with disabilities would be a financial burden because of the cost of accommodations. This can't be farther from the truth. Businesses will be hiring more people with special needs if they understand that they'll gain a competitive advantage by increasing workplace diversity. As a result, productivity will rise, and so will the bottom line. They will also have higher retention rates and an expanded market. www.forschungsnetzwerk.at/downloadpub/7-benefits-of-hiring-a-person-with-a-disability.pdf

ORGANIZATIONS PROVIDING TRAINING

Employment-related training for people with special needs often does not match the opportunities available in the job market. Currently, the potential of people with special needs are not aptly developed and maximized. A crucial initiative towards economic inclusion is to identify the career paths aligned with those of the workplaces. It is a good idea to partner with potential employers of trainees. Training modules would be designed to develop competencies needed to perform work activities within the required benchmarks in a particular career path. Trainees who fail to meet the competency level requirement for a certain path would undergo career guidance counseling to explore other options. It is logical to employ graduates as trainers if they have the heart to serve their community. This is empowerment at its peak, and the graduate becomes a role model. I would also recommend high-performing trainees to provide peer counseling and receive some form of benefits. Success stories should be published and popularized to keep our community members motivated.

> "People with disabilities have a better chance of jobs and promotions with remote employment."

Service institutions could also consider the strengthening and empowering of organizations of people with special needs who will potentially manage and implement training. I believe the community of special needs should be stakeholders of their own sector and not remain mere beneficiaries.

OUR COMMUNITY

Families need to be re-educated as well. Parents, please don't overprotect your children. Remember, we are raising kids that would overcome obstacles that look impossible to the majority. Individuals with disabilities contend with difficult issues before entering the workforce, and even more tumultuous challenges as they pursue employment, develop a career, or become entrepreneurs. First and foremost, they must learn how to go beyond coping with their limitations. This requires accepting one's disability, acquiring life skills to sustain independence, maintaining confidence, and motivation to succeed. A good education partnered with a clear direction towards attainable employment would prepare children to look to economic inclusion versus benefits and supplemental income.

MY PERSONAL THOUGHTS

Looking for a job is daunting. You may be qualified and hard-working. But if you don't have enough confidence or social skills, you may not overcome pre-existing biases that your employer might have. On the other hand, a person without a visible disability needs only to prove he's qualified for the job. As a person with special needs, you must exceed what a regular applicant could offer. Also, the opportunity to work yourself up the proverbial ladder is slim and becomes slimmer the further up you go. You have to prove that you have something more to give despite your physical limitation than someone who may be less capable but doesn't require additional accommodations.

The good news is, I believe that people with disabilities would have a better chance of landing jobs and getting promoted with remote employment. Video interviews somehow cut out much of the fear factor. Also, when in our homes, we could be in our element to perform our best. So let's brush up on our technical skills. After all, today, almost all jobs require some knowledge of technology. In the meantime, let's re-educate society that people with special needs is a natural part of human diversity. Re-education is a slow and extensive process, but our approach is as long-term as our vision. Our narrative needs to change if our community were to be a part of a competitive global economy. Let's transform our employment landscape by re-educating society one person at a time.•

HEARTSIGHT

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

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WORK INCENTIVES HELP PEOPLE WITH DISABILITIES TO CHOOSE WORK

BY ALEXANDRA BAIG, MBA, CFP®

In addition to their well known ssa.gov website where a person can go to get information and sign up for benefits, the Social Security Administration also maintains this site: choosework.ssa.gov. The site's subtitle is: Access to Employment Support Services for Social Security Disability Beneficiaries Who Want to Work.

If you are a person with a disability, Social Security wants you to work. However, they also know that you may, honestly, not know whether, or to what extent you can be successful at work until you try; that it requires time and unusual expenditures for you to go to work, that you cannot afford to lose your safety net if your work cannot take you to the point of self-sufficiency and that, even if your work does enable you to get by without your Social Security cash benefits, you may need to keep Medicare and Medicaid to maintain your health, and the support services needed for both work and for daily life.

First, we will briefly recap the financial eligibility criteria. In order to meet the Social Security definition of "having a disability," the SSA must agree that you are incapable at the time of application of performing Substantial Gainful Activity. For 2020, this means that you cannot earn more than $1,260/month. In addition, SSI recipients must not have more than $2,000 of assets held directly in their own names.

To make beginning or returning to work an attractive, rather than a frightening possibility, Social Security has created a host of what they call Work Incentives. The work incentives enhance the benefit recipient's financial eligibility. Some of them pertain to Supplemental Security Income, the means-tested disability benefit available to people without much of a work history. Some pertain to Social Security Disability Insurance, SSDI, the disability benefit available to people with sufficient work credits. Some pertain to both. This article will take you through how these incentives can support your start or return to work.

SSI WORK INCENTIVES

Since SSI is a means-tested benefit, it is reduced for income you receive from other sources. While unearned income reduces SSI dollar for dollar, earned income receives preferential treatment.

The Earned Income Exclusion. The first $65/month of unearned income is excluded from any reduction calculation. If you have no unearned income, then the first $85/month is excluded. Then, the earned income that remains only reduces SSI by fifty cents on the dollar.

The Student Earned Income Exclusion. If you are a student worker under the age of 22, the earned income exclusion is even more generous. For 2020, a student worker can earn $1,900/month up to $7,670 in the calendar year before the student's SSI benefit will be reduced.

Section 1619a. If you do the math using the (non-student) earned income exclusion and the subsequent 50 cents on the dollar reduction, you will see that a worker could reach the Substantial Gainful Activity threshold of $1,260/month without having the SSI benefit reduced to zero. Generally, income over SGA would result in SSI ineligibility, but a worker is allowed to receive an ongoing residual benefit under this section of the Social Security regulations.

SSDI WORK INCENTIVES

SSDI is an all or nothing benefit. As long as your work keeps you below the SGA threshold, you continue to receive your entire benefit. However, you do not lose your benefit the first month that your income exceeds SGA. There are several steps.

Trial Work Period. As the first step, Social Security counts how often you reach a lower threshold, called the Trial Work level. For 2020, this figure is $910/month. Once you have accumulated nine Trial Work Months in which you have earnings above $910/month, in a rolling 60-month period you have completed Phase I. During that period, you continue to receive your entire SSDI benefit.

Extended Period of Eligibility. Subsequently, you enter a 36-month period in which you do receive your SSDI for any month where your earnings are less than $1,260 and DO NOT receive your SSDI for any month when your earnings exceed that SGA threshold.

SSI AND SSDI WORK INCENTIVES

Impairment Related Work Expenses (IRWE). As a person with a disability, you may have additional expenses. Any good or service, including doctors' or therapists' visits, medication, assistive technology, service animals, special transportation or clothing or similar, may be considered an IRWE if: 1) it is necessary because of your disability, 2) it is necessary for you to work and 3) no insurance or other third party pays for it. Once your IRWE have been approved by Social Security, the Administration will deduct them before counting your earned income.

Employer Subsidy. If your employer makes accommodations for you and can quantify them, their value may be excluded from your countable monthly earnings. If you require more breaks than co-workers without disabilities, or if you are expected to complete a lower volume of work, or are able to opt out of certain tasks generally expected of your role, you can petition the SSA to consider these employer subsidies.

Unsuccessful Work Attempt. If you are able to work at a level where you lose either your SSI or SSDI but then find yourself unable to sustain that level of work for more than six months, your work will not count when Social Security continues your ongoing disability eligibility.

Expedited Reinstatement. If you are successful in going off your SSI or SSDI benefits, but within the subsequent five-year period, are again unable to work above the SGA threshold because your disability has worsened or special accommodations have been removed, your benefits can be reinstated without a new application.

The Ticket to Work. The Ticket to Work is a suite of services available to anyone who receives SSI due to disability or SSDI. Services include vocational counseling, resume and interview preparation assistance, help locating and applying for jobs, and help understanding and managing the impact of work on cash and medical benefits and services and supports.

Plan to Achieve Self Support (PASS). A person who has a work-related goal may create a plan to realize the goal and accumulate funds in excess of the typical SSI/Medicaid threshold of $2,000. The plan must have specific steps and a timeline, and must be approved by the SSA. Income allocated to a PASS is not counted for SSI calculation purposes.

Medicaid Continuation. People with disabilities whose Medicaid eligibility is linked to their SSI recipient status, who then lose SSI due to work earnings, remain eligible for Medicaid under section 1619(b) of the Social Security Regulations. People who never receive SSI who lose their Medicaid due to work earnings may buy in to Medicaid for a modest premium under the eligibility category of Workers with Disabilities.

Medicare Continuation. People who work enough that they lose their SSDI may still retain their Medicare Part A without additional charge for 93 months. Subsequently, they may buy in to Medicare for a modest premium.

Social Security knows that many people with disabilities have a strong motivation to work, but also face addition hurdles to obtain and maintain employment. Work Incentives help you to maintain critical safety nets while exploring and developing your capacity to work.•

ABOUT THE AUTHOR:

Alexandra Baig, MBA, CFP® is a fee-only financial planner and an employment network service provider who helps people with disabilities make the most of government benefits and personal resources to support their work and life goals. Alexandra has previous experience running L'Arche Chicago, an innovative residential community for people with and without disabilities.

The Toughest Boss I'll Ever Have

BY MICHAEL JOHN CARLEY

SISSY GOODWIN, 1946-2020: To the end, Sissy was a force for compassion, for benevolence, for warmth, for respect, for affection, and for love (in its highest)

PHOTOS PROVIDED BY MICHAEL JOHN CARLEY

During my years with Veterans for Peace Inc. (VFP, 1991-2001), I reported to a noteworthy Board of Directors of former service men and women. I've written about them before on several occasions.[1] I'll probably never stop. But out of all the toughfolk they were and are, one stood out as the toughest – a rodeo cowboy, bull rider and Vietnam-era veteran from the conservative state of Wyoming named Sissy Goodwin. Sissy wore women's clothing.

Sissy had been raised by a horror-movie mother and stepfather, the latter of whom went from oil rig job to oil rig job and town to town, often being fired for beating up his ever-changing bosses. One year, Sissy went to eight different schools. At home, he was physically abused, and constantly called a "dumbshit" despite his having later recorded a 145 on an IQ test. Having succumbed to their assessment as a means to get by, Sissy chose the Air Force because he didn't deem himself smart enough for college. Secretly wearing women's clothing was the only thing that made him feel good inside.

But then he met his future wife, Vickie. To her, he was simply the embodiment of the kind of guy who, while tough, really just wanted to pull over to help someone whose car had broken down.

Shortly after their engagement, he shared his truth—that even when performing in rodeos, he was wearing women's panties underneath. In a 2015 NPR StoryCorp episode[2], she recalled herself thinking, "'Well, that's not a big deal.' But one of the hardest things was that people made fun of this person that I loved."

Probably strengthened by that love, he stopped hiding, and the "better or worse" aspect of their lives really kicked into high gear. In "A Boy Named 'Sue'"–fashion, he changed his name to "Sissy," figuring that if he was going to be called that name constantly, that he might as well own it. Vickie often made him stand in front of a mirror and say, "I am a good person."

Due to his intelligence, the dress-wearing employee offset how uncomfortable he made his colleagues, and rose through the ranks at the power plant where he worked. He eventually went to college for math and science. They had two children, and, at the end of his career, he taught power plant technology at Caspar (WY) College, and on the side served for ten years on the board of the ACLU's state chapter.

But he was stopped frequently by police, who separated and quizzed his family as to whether he abused them. He was arrested a few times – "public indecency" or whatever, though charges never resulted. At a work trip to Utah, he was asked to leave a store by a hotel manager, and when Sissy refused, the hotel manager ordered his security forces to throw Sissy to the ground, cuff him, arrest him, and bring him to jail. Another time his ear was split open from an assault in the Kansas City airport. And once, in front of his family on his own front lawn, a stranger beat him up so badly that his teeth were pushed in. He was assaulted frequently but rarely called the police. In a state like Wyoming, the chances were simply better that he, and not the assailant, would be the one arrested.

His children went through periods of vocal and painful resentment. He and Vickie had rough patches—she constantly feared for him, and for their children. "I questioned my belief systems. He questioned my belief systems," she later wrote. The comments from strangers seemed daily. Sissy struggled with intense depression from the guilt he felt for what his family was going through.

"P. S. I am tired, you know how strenuous tipping cows can be?"

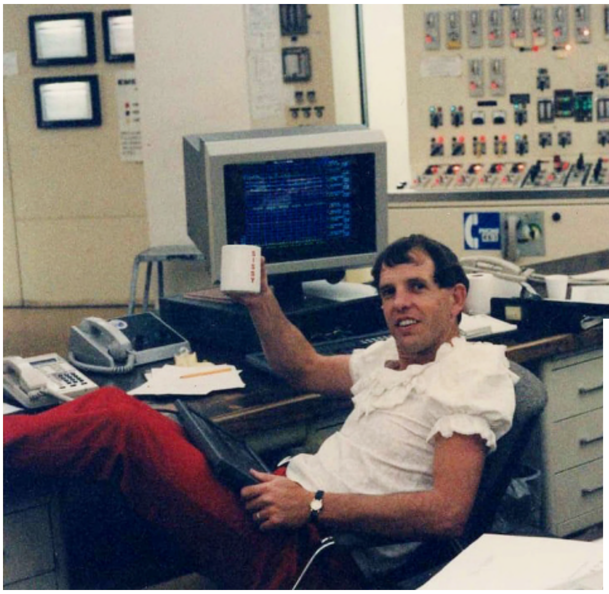
"P.S. Lay off the corn liquor and eat a crepe for God's sake."

"Crepe? What in the hell is a crepe? Never drank one of them things!"

"Nicely done at the meeting today, hickster."

"It's easy being your friend. Just do not tell anyone. I have a reputation to protect. Love ya, Sissy."

As my Iraq Water Project (IWP), was threatened by Board members who felt they weren't getting enough credit, Sissy kept them at bay for me. And I only somewhat was able to return the favor. For even in a progressive organization like VFP, Sissy's cross-dressing often ran afoul. I got into more than one argument with Board members who complained that Sissy's attire was "misrepresenting" the organization, or "confusing our message." To my, but not Sissy's astonishment, even a gay veterans organization didn't want his involvement.



POWER MOVES: *(Above)* Sissy rose through the ranks at the power plant where he worked, went to college for math and science, and eventually taught power plant technology at Caspar College; *(Right)* Vickie Goodwin with Iraqi teachers in the Basra area in March 2001. Seeing her handle the drama of that trip, much of Sissy's strength was explained – for how could lesser partners stick with someone who elicited in their surroundings so much fear, unless that partner was of at least equal strength?

He was voted to the Board of VFP by membership in the late-1990s. This came after starting the state's only VFP chapter in his hometown of Douglas, and after having appeared as a VFP representative on "Pastors for Peace" delegations to Nicaragua, Chiapas Mexico, and El Salvador, where he served as an election monitor.

I worked for VFP from 1991-2001. My post as UN Representative with VFP starting in 1997 was my (cooler than usual) "stupid day job" that supported a NYC playwriting career. And being the brash young man that I was, one surrounded by far healthier LGBTQ culture than anything Sissy had seen, I immediately felt a dual promise to myself to both protect him, and change his wardrobe (to infinitely more stylish women's clothing). I did not succeed in the latter.

But our commitment to one another was instantly solidified. Three years away from my spectrum diagnosis, my superiors always credited me with brains and guts, but they also had to add disclaimers about how weird I could be. Sissy never made me feel weird.

In our email conversations, before getting to the raison d'etre of the communication we small talk-jabbed at one another based on big city vs. country boy iconography, rather than any discrepancy of orientation. I was "Slick" to his "Hickster."

And when he and I were being serious, I begged him to leave Wyoming. I asked him to choose life instead of death. I promised him that he couldn't even conceive of what true self-love, or true community could feel like. I wanted him and his family to feel welcomed. But Sissy, being older and wiser, knew that his life couldn't be addressed on my terms.

Lucky enough to have someone like Sissy in my life, I was one of the few who also got to know Vickie. A very active participant in Wyoming's democratic party, she'd been sharing her grant writing skills for VFP when she asked to take part in a 2001 delegation I was bringing to Iraq as part of the IWP. And seeing her handle the unexpected drama of that trip, much of Sissy's strength was explained – for how could lesser partners stick with someone who elicited in their surroundings so much fear, or so many insecure external questions about pride, community, bedroom activity… unless that partner was of at least equal strength?

She once wrote of how she long ago stopped lamenting, and instead was so glad that she had not married the man she had originally wanted to marry.

After Sissy and I both left VFP, the world woke up, took notice, and Sissy was suddenly a media darling. In addition to the aforementioned StoryCorp episode (bring Kleenex), there was a 2004 Dateline NBC story on him (which I couldn't find on the internet), and a lovely video made by the *LA Times* in 2015.[3]

Even Wyoming was starting to change. In 2017, a Wyoming Republican senator named Mike Enzi, in speaking to high-school students, referred to Sissy by saying "I know a guy that wears a tutu and goes to the bars on Friday night and is always surprised that he gets in fights. Well, he kind of asks for it a little bit."[4] Well, Enzi's remarks sparked the hashtag #liveandlettutu. All throughout the state, residents posed in tutus on twitter to show their support for Sissy. Even Sissy's entire class of students at Casper College showed up one day wearing tutus, and pink hair ribbons similar to the ones Sissy loved to wear.

TUTU FOR THE SHOW: *(Left)* After Senator Mike Enzi's remarks sparked the hashtag #liveandlettutu, residents gathered for special events and posed in tutus on twitter to show their support for Sissy. Even Sissy's entire class of students at Casper College showed up one day wearing tutus, and pink hair ribbons similar to the ones Sissy loved to wear; *(Above)* A University of Wyoming student poses in front of the university building that bears Sen. Mike Enzi's name.

Try to remember, as you read all this, that Wyoming is the state where in 1998, college student Mathew Shepard was tortured and killed for simply being an out gay man,[5] an event that occurred during Sissy's and my period of working together. Herein especially, I pushed Sissy to get out of Wyoming. But despite his agony over the event and all that it illuminated, Sissy wouldn't leave. Maybe he saw what others couldn't – that he would eventually change people in his state, and that the beatings and dehumanizing would somehow have meant something.

What I have to reluctantly admit is this: that Wyoming is also one of the most beautiful states in this country. It really is an honor to look at, even if it renders the actions of its bigoted inhabitants even more inexplicable. I've had four speeding tickets in my life; and despite a speed limit of 80 or 85 on those empty highways, two of them were in Wyoming. I simply couldn't take my eyes off the scenery. Maybe that was part of it too (I know it was for Vickie).

A final factor to consider was that Sissy's formative years occurred without a true trans community. He felt he was going it alone, and maybe was. Many readers may have wondered why I used masculine pronouns in this writing, and didn't refer to him as "trans," "drag queen," or even a "cross-dresser." I used the terms that Sissy chose, as do we all when referring respectfully to anyone. Maybe in another era Sissy would have joined the parade. But where he was at, he wanted to be known as "a guy who liked to wear women's clothes."

Recently though, he gave in a little to the young people, and started referring to himself as a "gender-enhanced man."

"Slick," he wrote me after I resigned from VFP, "here is wishing you that the muggers treat you well and the drive by shooters have bad aim. Be at peace and know you are loved."

His toughness got him in the end. By the time he either felt, or admitted to the fact that there was something wrong, it was too late. The brain cancer had advanced too far. He had five, well-spent weeks before he passed.

By that time, he had two children that were proud of him. He had grand, and even great grandchildren. One of his children even changed her pronouns. Vickie, a writer herself, once clarified in an article;

“To be clear – (Sissy) doesn’t wear women’s clothing – everything he puts on belongs to him.”

And his beloved state? His body was interred with military honors at Wyoming’s Oregon Trail State Veterans Cemetery. And the Wyoming Legislature recognized Sissy with a bipartisan resolution that listed his service during Vietnam, plus his experience as a rodeo cowboy, and bareback bull rider. Enzi apologized to him away from the cameras, and Sissy reported that the apology was sincere.

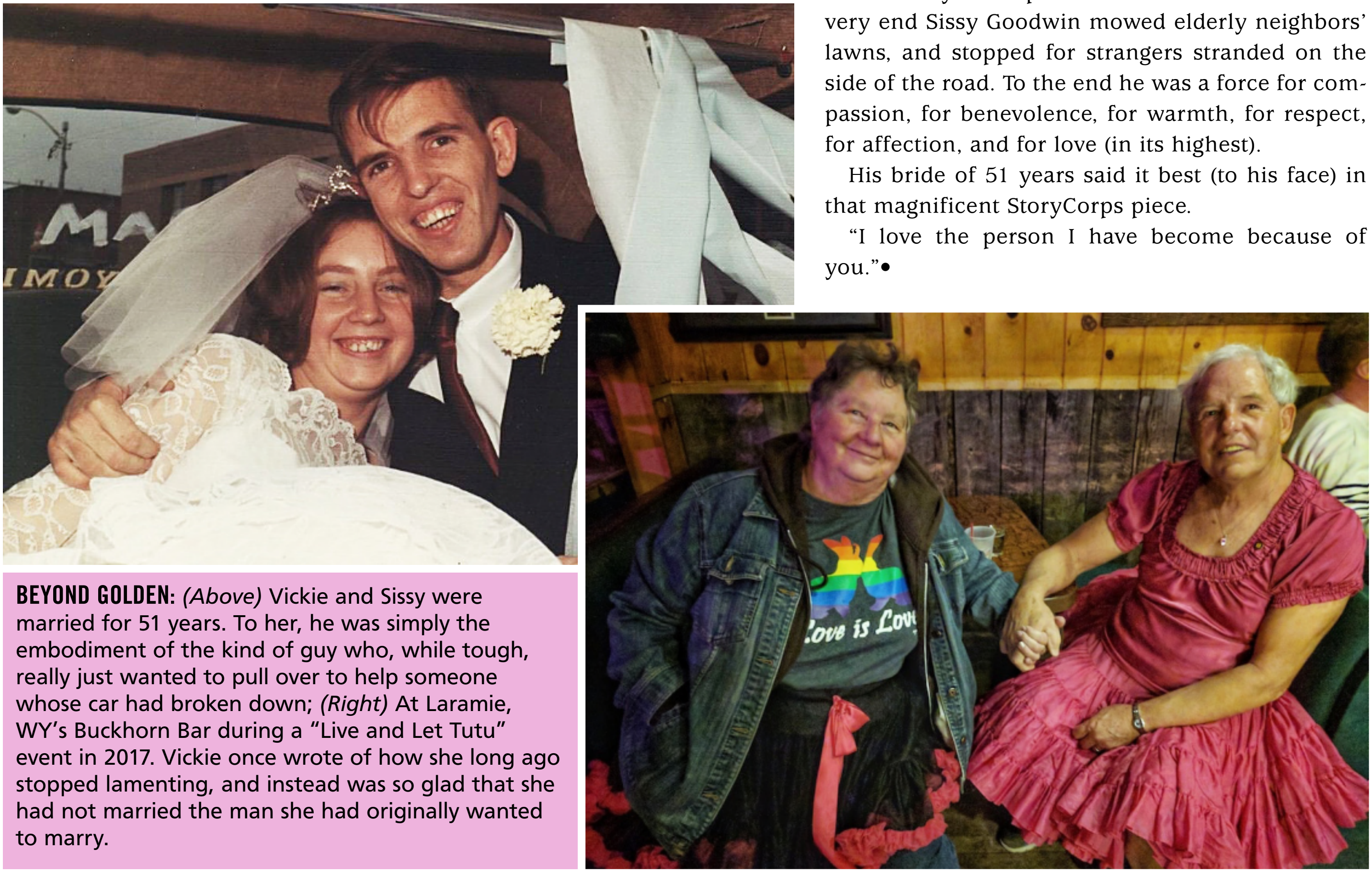
Sissy always protested, and he always flew the flag from his house. Of his military time he once said: “I served to protect your right to say, or dress, or look, or act or have the religion you want to.”

His first name was a doozy. But his family name had value too.

Sissy was the stubbornest cowboy, and the toughest boss I ever had not because of his ability to replicate the staples of macho iconography. Any moron can do that so long as they’re confident and willing. Sissy was the toughest because amidst all the cowardice around him—that was so determined to punish the very concept of the unknown—that to the very end Sissy Goodwin mowed elderly neighbors’ lawns, and stopped for strangers stranded on the side of the road. To the end he was a force for compassion, for benevolence, for warmth, for respect, for affection, and for love (in its highest).

His bride of 51 years said it best (to his face) in that magnificent StoryCorps piece.

“I love the person I have become because of you.”•



BEYOND GOLDEN: *(Above)* Vickie and Sissy were married for 51 years. To her, he was simply the embodiment of the kind of guy who, while tough, really just wanted to pull over to help someone whose car had broken down; *(Right)* At Laramie, WY’s Buckhorn Bar during a “Live and Let Tutu” event in 2017. Vickie once wrote of how she long ago stopped lamenting, and instead was so glad that she had not married the man she had originally wanted to marry.

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. Currently he is the Consultant for Disability Inclusive Culture at New York University, a writer for many, and on Mondays he sees individual clients. For more information on Michael John, or to subscribe to his free newsletter, visit www.michaeljohncarley.com

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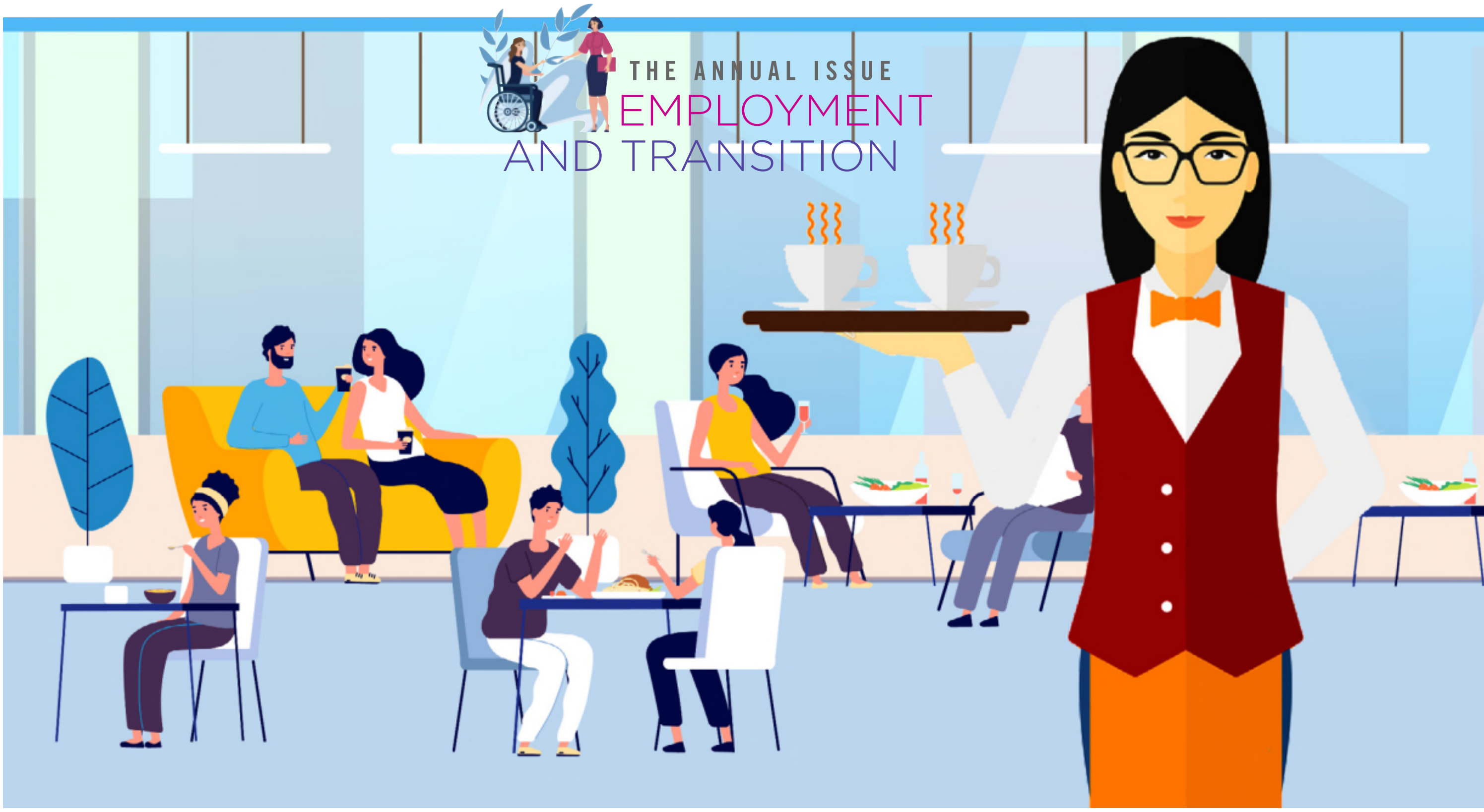

DANGER SPOTS TO REMEMBER WHEN YOUR SON OR DAUGHTER STARTS WORKING

BY ROB WRUBEL, CFP®

My daughter with Down syndrome has her career pretty well mapped out. She gets asked, a lot, about what she wants to do – it's a regular theme for anyone in their senior year in high school. "What will you do next?" She answers that she is considering school or maybe working. Like any senior, she has a quick, pat answer ready to go for that question as it comes up all the time. And the eye roll that goes with it.

My three children and I have plenty of conversations around the dinner table. Sometimes, they are doing things beyond my abilities to help. My son, long ago, stopped asking for help in his math and science courses – he is well past what I remember or ever learned and his homework just baffles me. Engineers need to learn very different approaches to thinking than financial folks.

My daughter Sarah will answer that she wants to be a cosmetologist. Now, I am a single Dad and I'd love to help my children reach their goals in life. My talent in make-up is about as good as my engineering skills - pretty much nothing. I am okay about asking for more information, and so I've asked her what she really wants out of her career.

Her answer is consistent and highly entertaining. Ideally, she will work in Hollywood on a TV show and have an apartment (not a house) there, and another in New York. Good on her. I'm not sure she really gets the distance between the two cities though I do think she expects to have a private plane to take her back and forth. These are career dreams I do understand.

Work will be an important part of her life no matter what she does. Sarah loves the social environment of school and I cannot imagine her sitting home during the day without people, pay, and purpose.

Part of special needs planning means preparing for and receiving funds and supports from benefit programs. These programs don't pay enough to live a high quality of life and can be seen to keep people in poverty. SSI recipients cannot have more than $2,000 in countable resources and most benefits are tied to maintaining income far below Federal poverty levels.

Still, the value of benefits is so big that it cannot be replaced by working. Health insurance from Medicaid, supported living, community access and Supplemental Security Income (SSI) can be worth tens to hundreds of thousands of dollars per year.

There are a few danger spots to remember when your son or daughter starts working.

1. Income. *Unfortunately, benefit program rules mean we have to watch the income our family members earn. SSI and Medicaid can be lost if your family member earns too much money. It's an unusual problem to have – we want people to work but if they work too much, their health insurance and community supports disappear. Check with your state rules to find out the income ceiling and watch that closely. Work with employers to create a schedule that fits for them and for your family member.*

2. Retirement plans. *Some companies and nonprofits deposit funds into retirement accounts, whether or not the employee contributes. Almost all the time (I've seen one case different), these funds are considered the employee's upon receipt or after a certain amount of time worked. Consult with your family member's employer to redirect those funds to income, or to develop a strategy to remove funds from the plan periodically and either spend them or fund an ABLE account.*

3. Payroll deposit accounts. *Today, most wages are deposited electronically to a checking account. You will want to monitor these accounts for your family member. I have met with families where funds pile up – children get SSI and employment income and it's easy for a bank account to accumulate more than $2,000. Have a system in place to automatically transfer funds to pay for rent, food, personal expenses and other regular, trackable expenses that support your family member. You can also send these funds to an ABLE, but remember there is a limit each year to how much can be put into an ABLE.*

Recently, I consulted with a family with an adult son with autism who has held a job his entire adult life. His employers have loved him – he shows up on time, doesn't spend too much time on office gossip and everyone can feel the value he brings and gets from his career. It's the ideal.

For many of us, it's unlikely our family members will have this same experience – transportation, training and abilities are hurdles that cannot always be overcome. I expect my other children to go to school, start careers and launch. Employment will be great for my daughter, and, like you I know that it is another area for me to engage and learn about how to do it best. I want her to make lots of money, fly across the country and, somehow, keep those benefits she needs to live a healthy, productive and entertaining life. •

ABOUT THE AUTHOR:

Rob Wrubel is a CFP who has a daughter with Down syndrome. He is recognized as a leading expert on financial planning for families with special needs members. Wrubel has written two books about financial planning and special needs families – *Financial Freedom for Special Needs Families: 9 Building Blocks to Reduce Stress, Preserve Benefits, Create a Fulfilling Future* and *Protect Your Family: Life Insurance Basics For Special Needs Planning* – and he has been published recently by Law360.com and The Good Men Project. Wrubel holds the Certified Financial Planning (CFP®) designation, the Accredited Investment Fiduciary® (AIF®) designation from Fi360, and the Accredited Estate Planner (AEP®) designation from the National Estate Planning Council.

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[1] *Based on a 08/25/20 search of officially registered human clinical trials of known broccoli product competitors found on ClinicalTrials.gov.*

ADVERTORIAL

Supporting Your Immune System and Natural Detoxification with Sulforaphane

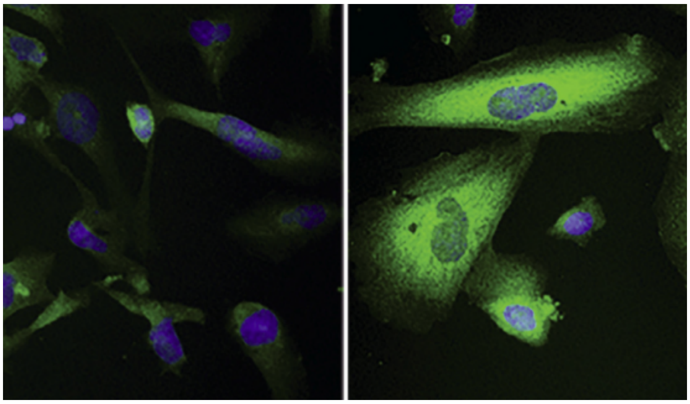
By Brian Cornblatt, Ph.D., Medical Director of Avmacol and Nutramax Laboratories

Individuals today are faced with an array of threats in the air we breathe, the food we eat, and the water we drink. Often unknowingly, we are ingesting and breathing in a variety of potentially harmful microbes and environmental toxins that can have both immediate and lasting negative impacts on our health. Luckily, our bodies are equipped with natural defense mechanisms to combat these threats. The immune and natural detoxification systems work together to help fight off harmful effects, but there are many actions we can take to ensure these systems are working at full capacity.

Diet and exercise are two such actions in the promotion of general health and well-being most people are familiar with and should not be underestimated. There are extensive recommendations, however, which make it difficult for individuals to determine where they can truly make a difference in supporting their immune and natural detoxification systems. Additionally, repetitive moderate to extreme exercise, often suggested as beneficial for health and wellness, can negatively impact our immune system and drive chronic inflammation if not done correctly. Here, moderation is essential with a mix of high intensity followed by low intensity workouts. One safe way to help support both our immune and natural detoxification systems is through the phytochemical sulforaphane.

Why Sulforaphane?

Sulforaphane is produced through the conversion of glucoraphanin (sulforaphane glucosinolate), which is facilitated by the active myrosinase enzyme. The essential ingredients needed to promote sulforaphane production (glucoraphanin and myrosinase enzyme) are found in cruciferous vegetables such as broccoli, Brussel sprouts, and cauliflower. Sulforaphane helps increase the production of critical Phase 2 detoxifying enzymes, promoting your body's natural detoxification process, supporting the elimination of potentially harmful environmental toxicants.



In control cells (left panel), NQO1 protein expression is indicated by the green straining. When cells are exposed to sulforaphane and Maitake (right panel), the level of NQO1 staining, representing the amount of protein, is increased.

Why Avmacol® Extra Strength?

Unfortunately, it is difficult to get meaningful amounts of glucoraphanin and myrosinase from eating vegetables alone due to widely varying cultivation and fertilizing techniques. The cooking process can destroy the myrosinase enzyme, further diminishing the possibility of any meaningful conversion of glucoraphanin to sulforaphane.

For these reasons, supplementation is an ideal way to support sulforaphane production in the body. Avmacol® Extra Strength provides consistent amounts of glucoraphanin (sulforaphane glucosinolate) and active myrosinase enzyme to help promote sulforaphane production. The addition of maitake mushroom extract (Grifola frondosa) provides beta-glucans which work in combination with sulforaphane to support your body's natural detoxification process better than sulforaphane alone. In a laboratory study, the treatment of RAW 264.7 cells with the combination of maitake mushroom extract and sulforaphane resulted in higher induction of the expression of the Phase 2 detoxification enzyme quinone oxidoreductase than either individual component alone. The maitake mushroom extract found in Avmacol® Extra Strength also provides the bonus of immune support by promoting neutrophil function and natural killer cell activity.

The Avmacol® brand has been selected for use in more sulforaphane human clinical trials than any other supplement*. When faced with today's environmental threats, in particular, a supplement backed by clinical research that promotes sulforaphane production is one essential way individuals can help boost immune function and promote the body's natural detoxification system in support of overall health.

**Based on a 08/25/20 search of officially registered human clinical trials of known broccoli product competitors found on ClinicalTrials.gov.*

SHOULD DISABILITY BE DISCLOSED TO A POTENTIAL EMPLOYER?

BY LAUREN AGORATUS, M.A.

Most individuals with disabilities want to work. However, only 33.6% were employed in 2019, vs. 77.3% of nondisabled peers.[1] *Students with disabilities may be unaware of their rights upon entering the workforce. Protections and rights in a school climate no longer apply. However, there are employment laws in place for individuals with disabilities.*

PROTECTIONS UNDER ADA AND THE REHAB ACT

The ADA (Americans with Disabilities Act) and the Rehabilitation Act cover workplace protections. There are also protections in post-secondary education. The definition of disability under the ADA includes physical/mental impairment that "substantially limits" one or more major life activities; record of impairment; and perception by others as having an impairment.

EMPLOYEES DON'T HAVE TO DISCLOSE

It is important for students to know that they do not have to disclose their disability. According to the 411 Workbook on Disability Disclosure, "When you disclose, you are intentionally releasing personal information about yourself for a specific purpose." The individual's disability is "only important if it affects… your ability to perform the essential functions of a job."

BUT, EMPLOYERS DON'T HAVE TO PROVIDE ACCOMMODATIONS UNLESS THE DISABILITY IS DISCLOSED

Employers cannot provide reasonable accommodations if they aren't informed about the employee's disability. "In general, an accommodation is any change in the work environment or in the way things are customarily done that enables an individual with a disability to enjoy equal employment opportunities."[2] The 411 workbook suggests discussing "the environment, supports, and services you'll need in order to access, participate in, and excel in your job, studies, and community." Employers cannot ask if an individual has a disability, or use tests, unless measuring job skills, to

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[1] https://www.dol.gov/agencies/odep/publications/statistics

[2] 3. 29 C.F.R. pt. 1630 app. § 1630.2(o) (1997).

IMPORTANT CHOICES: According to the 411 Workbook on Disability Disclosure, it's important to remember that accommodations in the workplace are only provided when a worker discloses his or her disability and requests job accommodations.

screen out people with disabilities, but can ask about an individual's ability to perform a job. Some examples of workplace accommodations are using computer software, changing a workstation to be accessible, or providing readers/interpreters.

MAKING THE DECISION WHETHER TO DISCLOSE

The Job Accommodation Network has some useful tips to help make the decision on whether or not to disclose a disability.

- ➢ *Do disclose if accommodations are needed. Again, an employer cannot accommodate an individual if s/he is unaware of the disability.*
- ➢ *Know Who to Disclose to. Find out who is responsible for accommodations.*
- ➢ *Know How to Disclose. "You only have to let your employer know that you need an adjustment or change at work for a reason related to a medical condition."*
- ➢ *Don't disclose too early. Wait until after the initial interview but…*
- ➢ *Don't disclose too late. Don't wait until there are problems with job performance.*
- ➢ *Not everyone needs to know. Only supervisors need to be aware of the disability; coworkers do not need to know why and employers must keep the information confidential.*

Advantages of disclosure in the 411 workbook include allowing reasonable accommodations as discussed above, and legal protection against disability discrimination. Some disadvantages of disclosure could be misperception of inability to perform job duties so being treated differently.

TIMELINES FOR DISCLOSURE

According to the U.S. Department of Labor, there are many steps throughout the employment process during which to decide to disclose. These include:

- *In a letter of application or cover letter;*
- *Before an interview (only if accommodations are needed for the interview);*
- *At the interview;*
- *In a third-party phone call or reference (e.g. One Stop Career Centers);*
- *Before any drug testing for illegal drugs;*
- *After you have a job offer;*
- *During your course of employment; or (it is the responsibility of the individual)*
- *Never (if the individual can perform the job without accommodations).*

Again, if accommodations are necessary, it is important not to disclose too soon before a hiring decision is made. However, it is equally important not to wait until the disability adversely affects performance of the job duties. The most important thing to remember is individuals with disabilities want to be chosen for a job because of their capacities, not their incapacities.

In disclosing a disability, the following would be most helpful to an employer:

- ✓ *How the disability affects the ability to perform job tasks;*
- ✓ *Types of accommodations that have worked in the past;*
- ✓ *Types of accommodations that are anticipated to be needed in this workplace.*

Students with disabilities entering the workplace must remember that it is their responsibility to disclose their disability and request accommodations if they are needed. Employers cannot meet the needs of employees with disabilities if the employer is unaware of those needs. In this way, more students with disabilities can successfully participate in the workplace, increasing their independence.•

ABOUT THE AUTHOR:

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

WE CAN WORK IT OUT : DISABILITY DISCLOSURE RESOURCES

CENTER FOR PARENT INFORMATION AND RESOURCES
Disability Disclosure Video
www.parentcenterhub.org/disability-disclosure-video

RAISE TRANSITION TA CENTER WEBINAR
Disability Disclosure Decisions
www.raisecenter.org/webinar-disability-disclosure-decisions

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Talking about Disability Disclosure
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STUDENT TRANSITION TENNESSEE
Student Learning Module on Disability Disclosure
https://transitiontn.org/student/work/needs-and-rights/disability-disclosure

Anyone, visually impaired or not, will take time to learn the ropes of an online platform, the content they're working with, and communicate with support staff. People with visual limitations would just have to work smart to function efficiently.

Work Smart

BY JEM MABALOT

"Nice forehead," my brother sarcastically remarked. "Might as well draw lips on it. The kids would love a talking forehead."

I asked my brother to Skype me to check how everything looked through my new HD webcam for my new online ESL (English as a Second Language) teaching job. Unfortunately, my forehead covered the camera. Dad and I arduously set up my work station. Still, the camera, a most essential equipment, was giving us trouble.

People advised, "Put the camera up at a slightly higher angle. You'll look more flattering that way."

So we put the webcam on top of a 25-inch monitor. Nobody said that this tip doesn't work for visually-impaired people who need to look closely at the screen. My students would either get a front-row seat to my fivehead pores with my faint Harry Potter-like scar at the center, or my restless left eye, all in HD. My dad is a miracle worker with logistics. But, after that Skype call with my brother, I wondered if even he could set the camera to show my face as I work. We put the webcam in various unimaginable angles, but Harry Potter (my scar) always took the spotlight. Luckily, as a last resort, my dad and I experimented with putting my webcam, mounted on a desk tripod, between my two monitors. Sighted individuals use dual monitors to increase efficiency in their workflow by using the screen real estate to get a good layout of what they're working on. This decreases the hassle of flipping through multiple tabs. But because I use a zooming application for the computer, I can't have this layout. Instead, I

use my monitors like binoculars and direct the mouse to focus on my target. This gives me the ability to look at things from afar and have my face and upper body centered on the camera, with a flattering angle of course, and my backdrop would fill the rest of the view. We finally found a way to fix my biggest logistical issue through trial and error, and I began my online ESL job.

Once I started teaching online, there were still things I had to be mindful of. A sighted teacher has the advantage of having the full view of their student, the PowerPoint slides, the chatbox, virtual classroom controls, timer, and their teaching schedule, among other things. I, on the other hand, am only able to focus on one thing at a time. I needed a work-around to teach, monitor the students and the time, access the classroom controls and keep an eye on the chatbox if the students or IT people need to relay something via text. Fortunately, the company I work with provides the curriculum and PowerPoint slides. I take about 10 to 15 minutes looking through each lesson until I master it. This way, my eyes don't need to be glued to the slides so I can watch my student, and occasionally glance at the chatbox. Like how we use landmarks, I orient myself with each color, shape, and placement of the control icons in the classroom and make a mind map of their position. This way, I know which control to click without reading the label.

My phone and iPad play a large role in my teaching. Instead of looking at the timer on the screen, I have my phone timer set to the class time to keep track of my pacing. Parents usually don't have a problem with me looking at my phone because most of my reward systems are on my devices. I keep an album on both these devices for pictures I show students throughout the lessons. When my small whiteboards are full of notes, I use my iPad as a virtual whiteboard. I still use physical props, so I arrange them in the order of most frequently used; this way, I can quickly feel through and grab the one I need. I always keep this part of my office organized to prevent catching the wrong thing and wasting time.

TAKING CONTROL : THE BENEFITS OF ONLINE WORK

Adjusting to a new work setting will always be challenging. But an online environment, though it may seem daunting at first, is better than you might think. Here are some benefits to working online.

No More Transportation Hassle

What I hate most when going anywhere is that I always need someone to take me to my destination. Uber and Lyft put a dent in my budget. Public transport puts me at risk of being late for work or my appointment. And, let's face it, asking someone to take us places is not easy. Personally, I would bite the bullet and take an Uber rather than feel embarrassed for bothering someone for a ride. Now, with an online job, I don't have to deal with the stress of arranging a ride for work and back home. It saves me embarrassment, transportation costs, and gives me more time to get some well-deserved sleep or me-time.

A Flexible Schedule

This has to be my favorite part of working online. Your time is yours, and you set the schedule for when you work and how long you do, for as long as you are consistent with your plan. The company I am contracted with uses a booking system. I open my schedule when I want to work and block out times I need for myself and days I want to take off. My work day is from the wee hours until 9:00 AM, Saturdays through Wednesdays. The rest of the day is devoted to my personal projects, language learning, or working out. Evenings are for my family. Thursday and Friday are my more intense gym days and chill days. When I was prepping for the Japanese Language Proficiency Test (JLPT), I needed to study when I was mentally alert. So my schedule was all over the place, but I maintained a minimum number of work hours. I doubled my shift to save up more money for presents and shopping for the holidays at the end of the year. I also make sure that I keep my regular students booked to make sure I don't lose them.

When I took the CELTA (Certificate in Teaching English to Speakers of Other Languages) course, my class hours were from nine in the morning to about five in the afternoon. It is a very intense program, so I barely had time to sleep because of all the homework and lesson planning. My sighted colleagues complained about the workload, but assignments and lesson planning take me longer to finish. Still, to keep my regulars and favorites, I sacrificed the little sleep time I could have had to teach my dear students. I felt like I was going to die. Still, I was happy I had the privilege of keeping my job and taking on the most accredited ESL certification program. Consistency is the key to keeping your clients, but your time is in your hands.

Professionalism with the Dress Code

The 80s had the "business in the front, party in the back" mullet, but 2020 takes it to a whole new level: Business at the top, chillin' at the bottom. Nothing beats a morning at work with my Pikachu plush socks, flip-flops, and my joggers. As a fashion artist, my sister-in-law always gives me the look of disgust whenever she sees my work get-up, calling it a fashion crisis. But my students and their parents won't notice because all they see is my professional-looking top half. My sister-in-law will just have to deal with it.

Assessments

Checking students' work is easier for me with an online class than in a physical classroom. When I was a teaching intern in Japan, the teachers would always tell me to walk around the classroom to check on the students' progress while doing their exercises. This was difficult and frustrating because I needed to bring my face close to their work to check for errors. It was so awkward asking them if I could see their work, and I didn't want to break their concentration. To make it worse, I found some of their handwriting too small for me to read. On the other hand, during my teaching practice in CELTA, it's much easier for me to make corrections because I can see their work on the screen. No more awkward interactions and no more straining to read paper materials.

I've chosen to teach students in the pre-intermediate to advanced levels because they're usually older, and teaching them requires less animated body movements and actions. But I would sometimes find little Einsteins or naughty kids march into my classroom. They need more body movement, quicker mouse clicks, and focused attention. I sometimes catch the little rascals looking away from their camera or notice lights shining on their faces change colors as they click on a different tab. But I can't see all the sneaky tricks with their nimble fingers. This is where my ears come in handy. I listen for the unnecessary mouse or keyboard clicking and screen tapping from somewhere that's not in the virtual classroom. I've learned to be sensitive to them to manage my classroom better.

I once had a nine-year-old, let's call him Jackie. He was a playful little whiz. Jackie's reading and grammar skills are above standard compared to his older peers. He was fully aware of this. He switched tabs every chance he could and scribbled all over the interactive slides until he was called out. Furthermore, Jackie stalled for time so that he wouldn't be asked to do much. The only way to keep his undivided attention was to give him a chance to show off his superstar reading and his past participle prowess or give him rewards.

Applying all of the things I learned from the platform, I strategized to keep Jackie's eyes on either me or the material. I turned the volume on my headphones up to hear any unnecessary clicks. During instruction, I made sure I controlled any interactive function from the students' side to keep him from scribbling obnoxiously on the slides. Jackie loves bright lights and popping colors, so I always used my iPad to explain things or do exercises with him. In fear of missing reward time, Jackie's eyes were fixed on the iPad. My mouse always underlined any mispronounced or unknown words for us to go over immediately after he finished a slide. Then, I quickly clicked the next button to make sure I didn't lose Jackie's attention. I had alarms set every five minutes on vibrate to keep track of pacing. Whew! Sounds stressful, right? Luckily, most students aren't like Jackie, but I'm ready for them, in case they come.

It sounds overwhelming, and it was at first, but now I've learned and adapted to my work environment. Anyone, visually impaired or not, will take time to learn the ropes of an online platform, the content they're working with, and communicate with support staff. People with visual limitations would just have to work smart to function efficiently.

MY CAREER PATH

It's hard to believe that in the age of technology, there are still some haters who don't consider jobs like online ESL as "real work experience." Work is work, and putting it online doesn't make it less legitimate. In fact, it can get intense. It takes discipline to make your online job successful. Millennials like myself prefer to work in their comfort place and have control over their schedule. This is the reason why more businesses are taking on online ventures.

As a fresh graduate, I decided to take on this online teaching because it helps build my teaching experience. A lover of other cultures, I get first-hand experience of what my Chinese students go through daily. My adult students also give me insights into their culture, which I consider valuable for extending my worldview. Though I still have much to learn, I have improved my discipline and time management, things that the professional world values. In the future, I aim to have my own business, influence younger generations with my voice and my pen, and bring different cultures together through my work. This online teaching may not be my end goal, but it is a stepping stone for my future with lots of benefits. For the visually impaired interested in switching to online businesses or education, take the plunge! You will be surprised by how much you get enriched from your experience.•

ABOUT THE AUTHOR:

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

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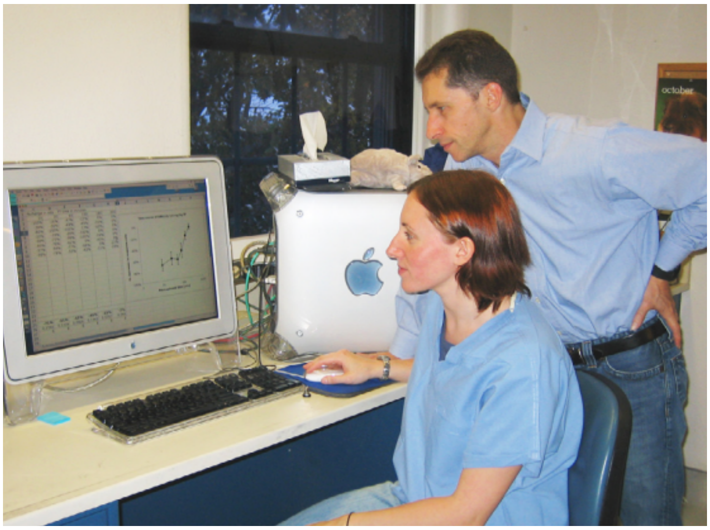

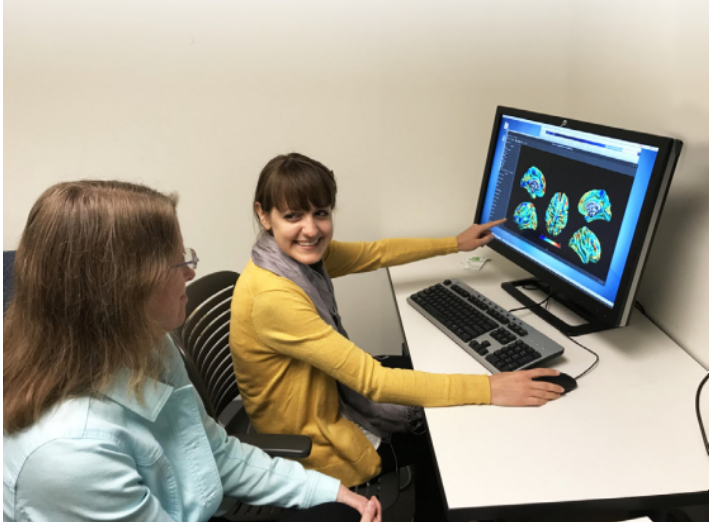

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IES Brain Research Foundation thanks everyone who has participated & donated and wishes everyone a safe 2020.

ALL DOES NOT MEAN ALL

BY ERIN CROYLE

All does not mean all. Anyone with a disability knows that. This pandemic is magnifying the problem tenfold.

The Centers for Disease Control hosted a live Question and Answer session this summer about factors affecting reopening schools. One person asked, "How can we keep children with disabilities safe as they return to school?"

John T. Brooks, MD, who serves as a medical epidemiologist for the CDC, said students with underlying risks have choices. One: keep them engaged, but safe. Educate them remotely from home. But he acknowledged that not everyone has the privilege of access. Two: If a child really needs to be in a structured setting, it should be set up so it limits their chances of being exposed; maintain higher disinfection levels and screen for symptoms before entering. Those working with these students must maintain a high level of sanitation and handwashing. Caregivers at school should limit their contact as much as possible, he concluded.

Erin Sauber-Schatz, PhD, MPH leads the CDC's Division of Injury Prevention. When Dr. Brooks turned it to her she added, "That is actually more information than we have on our website."

Let that sink in.

That basic advice, which any parent of a child with a disability could tell you, was not only all that the CDC had to offer, but it wasn't even provided in their official guidelines.

People with disabilities, left behind yet again.

Two of my colleagues who advocate for individuals with disabilities and their families were also participating, looking for guidance on decision-making for themselves and others. They found the CDC offered "absolutely nothing" to help them.

Disability rights advocate Kymberly Deloatche, who has a teenager with complex medical needs, said, "It's almost like our kids don't exist in their deliberations."

The American Academy of Pediatrics (AAP) released reopening recommendations with a bit more attention to students with IEPs (Individualized Education Program). They recognize how detrimental the loss of instructional time and related services can be for students with disabilities. The AAP stated:

"Students receiving special education services may be more negatively affected by distance-learning and may be disproportionately impacted by interruptions in regular education. It may not be feasible, depending on the needs of the individual child and adolescent, to adhere both to distancing guidelines and the criteria outlined in a specific IEP. Attempts to meet physical distancing guidelines should meet the needs of the individual child and may require creative solutions, often on a case-by-case basis."

While the AAP did better than the CDC, it simplified what families and schools are facing when keeping children with disabilities both healthy and educated.

There are so many more questions we face:

- *How do we support high risk students learning?*
- *How do we engage students with disabilities in distance learning?*
- *How do we make sure materials are modified?*
- *How do we support caregivers who are now serving as teaching assistants?*
- *Do we keep the siblings of high-risk children at home?*
- *Where is the emotional support for families in long-term isolation?*
- *How do we support friendships and engagement for students with disabilities?*
- *How do we educate school nurses about the unique risks students with disabilities face?*
- *How do we manage the inequities of long-term isolation because our families must be at a higher level of quarantine?*
- *How do we explain to our children why their friends and peers can go to the pool/playground/park and we cannot?*
- *How do we convince others to do their part in containing COVID-19 so we can ALL reenter society?*

WHAT DO WE DO?

We are going to do what we always do. We will unite as a community. We will lean on and collaborate with disability groups such as our local Family-to-Family organizations, The Arc, Family Voices, and others, to decide what is best for individuals with disabilities. We will contact our children's specialists and talk to them about the safest options for our families. We will work with our schools and communities and WE WILL EDUCATE THEM about what our children need to learn to be safe. Some ideas for the fall:

- **We are already masters at adaptation and modification – utilize those skills.** We need to apply these skills to the pandemic, and think outside the box.
- **Advocate for what is best for our families.** Reach out to others at your school or in your school district in similar situations. Provide an outline of your needs. Offer suggestions. This can be through phone calls or email; contacting the special education department, principal, or superintendent. Consider a virtual presentation at a school board meeting, partnering with a local special education, or disability organization.
- **Collaborate with your school.** Education as we've known it for decades will not exist this fall, whether it's distance learning or in-person. We need to work together to help students with IEPs learn. Can teaching assistants provide support to students in their home? Can aids help teachers facilitate adapted lessons virtually? How can students participate in virtual classrooms in a meaningful, inclusive way? This will look different for every class, and we will need to put effort into doing it well.
- **Technology is our friend.** Utilize it. Reach out to your school to see how they can help.
- **Insist on appropriate services.** The Individuals with Disabilities Education Act (IDEA) still applies. All students are entitled to a Free and Appropriate Public Education (FAPE). Schools are required to provide them.
- **Be flexible.** At the same time, we insist on services, we must also be understanding of what teachers and therapists are up against. They are juggling work and family just as we are. They are scared and nervous about COVID-19 too. They are reimagining their job on the fly, teaching in a new way with very little training or planning time. Summer break is just that, a break. Even for those who are doing professional development, we're looking at just a couple of months to revamp how we've done things for YEARS. Parents and teachers will need to be patient with each other, and the children.
- **Consider a cohort.** We've probably all heard of podding by now. Finding a family or two who is at the same level of lockdown as you are and latching on to them. This could be especially helpful in the fall. Families could rotate teaching duties and exchange respite care. For it to work, everyone involved must be completely honest and transparent about their whereabouts.
- **Identify and potentially share a respite provider.** It might be possible to find someone who would be willing to work for you, and only you. This would be an employee who you know and trust who is also practicing the same level of quarantine that you are. Bonus if you can work out a way to share that provider with another family.
- **Use what we're learning now to innovate for the future.** Much of the innovation we're seeing right now are things that individuals with disabilities and their families have been requesting for decades. We can use distance learning to teach students on extended medical leave. We can turn to virtual IEP meetings so parents do not have to take a day off work to attend. We can encourage mask-wearing during the flu season so medically fragile children are protected. We can remind IEP teams that changing the way we have always done things is absolutely possible, and then some.
- **Accept this is hard, but not compared to the alternative.** See https://centerforfamilyinvolvementblog.org. •

GUARANTEED ACCESS: The Individuals with Disabilities Education Act (IDEA) still applies. All students are entitled to a Free and Appropriate Public Education (FAPE). Schools are required to provide them.

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LEARNING LESSONS: While many details about COVID-19 are still unknown, we as a society can educate ourselves and make well thought out decisions for children, our families and ourselves in keeping us healthy and safe

COVID-19 NOTES
FOR SCHOOL YEAR 2020

BY LAURA GEORGE, EMDL

Gym shoes. Lunch bags. Folders. Doctor appointments. Meet the teachers. All phrases related to the fall season. It's that time of year again when parents find themselves moving very quickly to get their children ready for school. Except this year it is different. This year has us adding new terms, new conditions, new supplies, and new emotions. For parents of children who will be or are attending school this fall of 2020, we are learning new terms such as COVID-19, masks, sanitizer, social distancing, and addressing new questions for school. So let class begin!

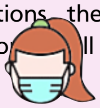
If you are a person with a disability, Social Security wants you to work. However, they also know that you may, honestly, not know whether, or to what extent you can be successful at work until you try; that it requires time and unusual expenditures for you to go to work, that you cannot afford to lose your safety net if your work cannot take you to the point of self-sufficiency and that, even if your work does enable you to get by without your Social Security cash benefits, you may need to keep Medicare and Medicaid to maintain your health, and the support services needed for both work and for daily life.

First, we will briefly recap the financial eligibility criteria. In order to meet the Social Security definition of "having a disability," the SSA must agree that you are incapable at the time of application of performing Substantial Gainful Activity. For 2020, this means that you cannot earn more than $1,260/month. In addition, SSI recipients mus t have more than $2,000 of assets held directly in their ow ames.

COVID-19

According to the Centers for Disease Control and Prevention (CDC), the term COVID-19 is actually known also as the Novel

Coronavirus Disease 2019 and also as Corona Virus Disease 2019. The CDC further states that, "Corona means crown and is used to describe the shape of the virus itself."[1] Coronaviruses are not new and commonly occur in people and animals. But this version is brand new and according to the CDC, "The exact source of the virus is unknown." Through various messages and simple searches on the Internet, several medically based entities have discussed how the virus can affect us by being shared from one person to another via water droplets expelled and entering another person's nose, eye or mouth. It will act like a cold, except that it has an ability to inflame the lungs making it extremely difficult to breath. As further noted by the CDC the more compromised or weakened your health is by one or more conditions, the more concern should be had fo[illegible]ll health and safety".[2]



MASKS

According to the article, "Masks Save Lives," by Dr. Francis Collins, Director of the National Institute of Health, it states that even a "crude cloth covering" could significantly reduce the spread of the virus and reduce the deaths that come from it." The article further states that even if the mask was less than perfect, it could reduce the amount of infection or symptoms that a person might contract even if affected by COVID-19.[3] Dr. Lisa Maragakis of Johns Hopkins University writes in her article that the mask, "Should cover your face from the bridge of your nose to under chin; be loose yet secure enough to stay in place and non-irritating so that you don't limit its effectiveness."[4] These should be worn anytime you are out in public, in gatherings of ten or more or especially around children or the elderly who have serious medical concerns. The pre-made masks can be purchased at just about any store in a variety of styles, fabrics and purposes. Some are merely rectangular in shape, have a piece of bendable wire positioned at the nose to help the mask stay on the face, or have been created to look like fun animal noses with ears at the sides. Then there are bandanas, neck gaiters (a circular piece of fabric sitting around the neck that is pulled up over the nose), KN95 for filtering out fumes, and transparent masks revealing the mouth and a variety of unique masks designed to fit a variety of specific needs. Safe' N'Clear (https://safenclear.com) is an FDA fog resistant clear window mask that is being sold to the medical community to help aid in the communication to Deaf/Hard of Hearing community. For those who want to wear a mask while eating, in Israel, a remote control mask has been designed to accommodate those who want to eat out.[5]

The CDC understands that there some instances in which a mask cannot be worn. According to their website, "Children younger than 2, those who have trouble breathing and those who are unconscious, incapacitated or otherwise unable to remove the mask themselves, should not be wearing a mask." This may be also be difficult for those with developmental disabilities or those with sensory issues.[6] However, Harvard Health Publishing of Harvard Medical School has a great article by Dr. Thom and Ms. Turner on, "Helping People with Autism Spectrum Manage Masks and COVID-19", that should prove to be very helpful to anyone looking for more information on that topic.[7]

SANITIZER

Hand sanitizer is sometimes used in place of washing hands. However, during this time of COVID-19 it is recommended especially when one is outside of the home as an extra layer of protection to help keep the germs away. In the home washing hands is important but sanitizer is helpful. Outside the home it is easier to have access to sanitizer but washing hands beforehand is supportive. Sanitizer helps to keep the germs away and comes in a variety of liquids forms. Many stores will limit the amount that can be bought, so it may take several trips to get what your child needs for school. If they can use the school's version, then it will not be important to purchase a lot of sanitizer. However, if your child has sensory issues, then it will be important to find out what they like to gain their participation in using the sanitizer. If the child has allergies, then it will be very important to read the label to ensure its safety. If you need more detailed information about the ingredients in hand sanitizer or which ones are not safe, the US Food and Drug Administration has two items, "Q&A for Consumers: Hand Sanitizers and COVID-19," and another, "FDA Updates on Hand Sanitizers Consumers Should Not Use," that very detailed and helpful.[8, 9]

SOCIAL DISTANCING

Repeatedly throughout the day, televisions, radios and other forms of communication will remind us of the six-foot distancing rule and depending on which community you live in the allowable number of people to be gathered in a group at one time. What has not been discussed is how caregivers, children who are deaf/hard of hearing, children who are deaf and blind, or those with developmental delays can still have their communication and emotional

TOUCH OF CLASS : RESOURCES FOR COVID-19 THIS SCHOOLYEAR

CDC: HOW TO MAKE YOUR OWN MASKS
www.cdc.gov/coronavirus/2019-ncov/prevent-getting-sick/how-to-make-cloth-face-covering.htm

NATIONAL ASSOCIATION OF THE DEAF
www.nad.org/covid19-communication-medical-access-for-deaf-hard-of-hearing

NATIONAL COUNCIL ON INDEPENDENT LIVING
https://ncil.org/covid-19

PARTNERSHIP FOR INCLUSIVE DISASTER STRATEGIES
https://disasterstrategies.org

NEW QUESTIONS FOR SCHOOLS

Beyond learning the terms, there are basic questions that you as a parent need to get answers to, address, and make your personal best decision for your child and your family. Here are some of the questions I had to address with my own child:

- Will school be open for face-to-face teaching or online only?
- If it is online, will the school provide computers if needed?
- If it is open for face-to-face teaching, will it be Monday through Friday, alternate dates or another option?
- What COVID-19 standard procedures are going to be put in place and what additional procedures will be used for your child with disabilities?
- Is wearing a mask mandatory for attending in person?
- Are specific mask types encouraged, allowed or not allowed?
- How will school desks, equipment, supplies and even the lunch line be subject to COVID-19 guidelines?
- When they are at their desk or at lunch, will there be social distancing?
- What procedures does the school have in place to identify children who come down with COVID-19 and keep them separate from those who don't have it?
- If your child is exposed to COVID-19, what are the quarantine procedures and will the school provide supplies when the children are sent home to enable them to keep up with the rest of the class?
- What needs to be added to the child's IEP or 504 in terms of accommodations?
- How will your child attend school? If by bus, what procedures will be established for keeping them safe?
- On the bus will the children be observing "social distancing" and required to wear masks as well as the bus driver?
- What will your child need to return to school after having COVID-19 or being exposed to it?
- If you as their parent are exposed or have COVID-19, what procedures have you set up to keep your child safe or if necessary looked after while addressing the virus?

needs met. For caregivers, it obvious to intensely follow all the above-mentioned protocols, yet also be taking their temperature daily to help protect the person being cared for. For children who are Deaf or Hard of Hearing, wearing a clear face mask and taking advantage of mobile communications (such as video chats, EyeHear, Eye-D, Zoom, What's App, etc.) may be beneficial. The Helen Keller National Center for Deaf-Blind Youths and Adults notes that there are many different types of communication that can be used during COVID-19. Their blog page on "COVID-19 Communication Guidelines," offers many different types of communication methods that can be used, tools for working with service providers and even offers downloadable cards and sheets for addressing COVID-19 symptoms. (They are also available in Spanish.)[10]

RESOURCES cont.

US DEPARTMENT OF HEALTH AND HUMAN SERVICES

www.hhs.gov/coronavirus/index.html

*Don't forget! Your local health department will also be a good resource to go to.

Besides all of those questions, it is also important to plan for unusual medical situations. In my case, my child is attending school in person. Recently she was diagnosed with a rare allergy called Colophony, and she cannot use an EPI-pen for her reactions. Her medication is completely non-standard. Working with her teachers and administrative staff I have emailed sheets explaining her situation, her symptoms, her reactions and the items involved. In turn the school created a protocol plan just for her. I am pleased to say that only a day ago we narrowed her reaction time down to 10 minutes from two hours in a four-week time span of implementing the plan. Do not be afraid to share your concerns. Make all the players involved into a team. Be confident that you the parent are making the most well informed and thoughtful decisions for your child and their wellbeing during this time of COVID-19.

While many details about COVID-19 are still unknown, we as a society can educate ourselves and make well thought out decisions for children, our families and ourselves in keeping us healthy and safe. Yes, this school year is different. But every time our child enters another grade, the school year is different. As parents of exceptional children, we should be happy because we know better than most parents how to advocate in this time that we wish was not different. While this fall season in the year 2020, seems entirely different because of COVID-19, I'd like to leave you with some wisdom given in song by Bobby McFerrin, "In every life we have some trouble; when you worry you make it double. Don't worry; be happy!"[11] •

ABOUT THE AUTHOR:

Laura George, EMDL is author of *Emergency Preparedness Plan: A Workbook for Caregivers, People with Disabilities, the Elderly and Others*. She is an Emergency Management Disability Liaison and sits on the National Center for Independent Living Emergency Preparedness Committee [www.NCIL.org] as well as other national, state, and local committees. She has assisted in a variety of disasters spanning from Colorado to Florida and back. The last 14 years she has devoted her time to the idea that emergency design needs to include everyone. Her spare time, is spent with her daughter (PANS/Colophony) and dog, Turkey.

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NAVIGATING THE “NEW NORMAL” OF SPEECH-LANGUAGE THERAPY

TIPS FOR PARENTS

BY DR. KATHLEEN WHITMIRE

During this unprecedented pandemic, in the vast world of public education, federal and state officials are working diligently to provide guidelines for navigating all students’ academic needs. Since March 2020, district leaders have regularly met to collaborate on the development of appropriate, wide-ranging remote curriculums. Across the country, leaders have approached these challenges in ways that best fit their community needs. Some districts provided synchronous (live) or asynchronous (recorded) online learning, and others relied on mailed packets and periodic phone and email communication to support continuous learning.

All parents of students from preschool to college are adapting to a “new normal.” Families of children with special education and specifically, speech-language needs, are facing specific unique challenges. These students and families face hurdles such as a lack of individualized, in-person therapy, a lack of service continuity

Since early Spring of 2020, our team of SLPs and speech-language leaders at AmplioSpeech have analyzed the performance of speech-language students during the pandemic. We have identified challenges and provided solutions for students, parents, and therapists to positively navigate this experience:

1 As parents, your primary concern is your child’s continued progress. We need to ensure that all home-bound students receive efficacious therapy that meets or exceeds the quality of in-person therapy. You want your child’s therapist to perform at their best. Online services should reduce workload for clinicians, rather than increase workload. Effective online services reduce pressure for students or staff to return to school, when it is not in the best interest of them, their classmates, or their colleagues. The highest standard platforms are, therefore, recommended.

Solution: With AmplioSpeech, students benefit from high-quality, efficacious online therapy. The platform offloads many of the SLPs’ tasks, reducing workload during these stressful times. AmplioSpeech’s easily-accessible technical support as well as clinical support enables smooth therapy. Parents, welcome the help of a sibling or babysitter to help with technology support. Also, utilize your school district’s tech support team or that of the online platform you are using.

2 You may be concerned about the health risks of sending your child to school in the fall. As students and SLPs return to schools, in some way or another, their safety is the first priority. However, speech therapy the way we traditionally deliver it, does not meet COVID-19 safety guidelines. Therapy is typically delivered with a group of students from different classes, face-to-face, in a small room, without masks.

Solution: When schools reopen, we should make sure that students either receive safe individual therapy or stay in their classrooms during online group therapy, delivered remotely from the SLP’s room. Individual and group sessions can also be effectively delivered over the digital platforms, room-to-room.

In some cases, school-based therapy may not be possible. If your child continues receiving speech therapy from home, establish a schedule but allow for flexibility in order to stay mentally and physically healthy. A schedule will provide routine and a sense of normalcy during a very abnormal time. Built-in flexibility such as regular open break times will decrease possible emotional breakdowns due to unexpected changes that will inevitably occur.

Provide your child with movement breaks, incorporated into the daily routine. For example, 30-minutes of online work, followed by 30 minutes of project or playtime.

Don’t forget to take into consideration your own work and family needs when setting up your child’s schedule. If your child needs 1:1 support from you for certain tasks, schedule those at a time that works with your own schedule. Take time for yourself as much as possible to reduce your own stress. If you stay relaxed, positive, and encouraging, your child will too.

3 As many of you have heard from your school districts, very little about the coming school year is certain. The year likely will be characterized by alternating and hybrid educational models. Schools may open and close with COVID waves. Individual students as well as staff will fluctuate between being at school and staying home. Continuous, regular, and consistent therapy will become a safe haven for fragile students while ensuring continued student progress. Such services can only be provided if the entire therapy cycle is managed by a single platform, regardless of setting (online or onsite), including resources, documentation, Medicaid reimbursement, and home practice opportunities.

and access to reliable online service, and overdue or modified IEP and Eligibility meetings. On a broader level, families find themselves in the role of facilitator or paraeducator without proper training and support of a related service provider, all while balancing drastically-altered family and career needs and expectations. In addition, qualified related service providers, such as speech-language therapists, are requiring reliable, dense online video platforms to deliver quality services to students in their homes.

Many of the solutions implemented this past spring were short-term fixes. As we look at the long- term impacts of alternative learning models, equity is a critical consideration and using digital technology for remote learning is proving to be a reliable option. Schools were forced to shift to remote solutions, such as online instruction using general-purpose video platforms (e.g. Zoom), or SLP-specific AI solutions (e.g. AmplioSpeech). The good news is, these tools have ensured accessibility to technology allowing students with disabilities access to high-quality instruction and therapies. Also, students maintained connections academically and emotionally with their teachers and therapists.

As we look forward to the start of the 2020-2021 school year, numerous suggested learning models are being discussed. Ideally, districts have begun to communicate with you regarding your child's IEP service delivery since school closure. Districts are responsible for reviewing received thoughtful and insightful information regarding the impact from the delivery of special education, and other related services, on students. Then, schools, agencies, and districts should share their ideas and experiences with each other and leverage the opportunity for innovative solutions that can significantly benefit students with special needs from the onset rather than as an afterthought.

Good luck, parents! We may not be with you face-to-face, but we'll see you, talk to you, listen and hear you... remotely! •

ABOUT THE AUTHOR:

Dr. Kathleen Whitmire is an ASHA Fellow and K-12 Lead at AmplioSpeech.

Solution: Find a digital platform that can work for all settings, with students both onsite and online. The same resources and materials should be used in any model, with consistent and standardized documentation throughout the year. Most importantly, IEP compliance should be smoothly transitioned between online and onsite.

Parents, make sure you have a system for regular communication with the IEP team. Do whatever is best for you and your team. In some cases, email may work best. In other cases, messaging or chat channels may be available through a district or an online platform. Get creative with how and what you communicate! Send your therapist a video of your child talking attempting a therapy task. He or she would love to see what your child is doing at home. Make sure to send them feedback about what is working or not working for your child so they can modify their approach as needed within the platform.

4 As many of you know, students have missed tens of thousands of evaluations and therapy sessions since COVID-19 disrupted our lives. Your child may be one that is owed an evaluation or additional therapy. Most schools were not able to compensate for these missed evaluations during the summer. Without proper evaluations to determine service eligibility and necessary compensatory services, students will far further behind their peers. Therefore, we anticipate a need to double the number of evaluations and services during the first months of the fall.

Solution: Platforms such as AmplioSpeech offer a safety net for school districts. A highly trained digital evaluation team of licensed online SLPs is offered to schools and additional AmplioSpeech SLPs complement regular services with after school group compensatory services, to bridge the gaps.

5 Many of you know that school teachers and staff have done their best to meet the needs of students during this unprecedented time, but they are struggling along with you. Special Education directors report that many therapists find it difficult to transition from the status quo to a new modality, and in many cases, they too are struggling with the change. The transition not only involves technology, but it also changes therapy processes and logistics, as well as fundamental clinical aspects, such as engaging the student. Good digital platforms have a lot to offer for those who embrace them. They empower clinicians, reduce workload, and enable oversight. You can help spread the word in your district that the right tools are available for this moment to ease the burdens placed on our hardworking teachers and therapists.

Solution: AmplioSpeech offers guidance, training, and support to school administrators and clinicians, accelerating the transition to digital services. AmplioSpeech training includes the use of the AmplioSpeech platform, translating in-person to online therapy, as well as sessions simulation with an SLP playing a student. Mentorship, daily walk-in sessions, Facebook SLPs community, and other methods are offered to ensure the transition is quick, smooth, and fun.

Parents also should connect with their speech-language pathologist or other related service providers for a visual schedule (i.e., handwritten or picture checklists, calendar, post-it notes) to better motivate students. In addition, check out online resources for examples of visual schedules for children with special needs. Then, incorporate them into the child's workspace to let them know what needs to be completed. For your children who struggle with time management, incorporating visual timers can help them know the start and stop times to their activities. Hourglass timers, standard kitchen timers, or digital timers on the child's screen are all great options. Lastly, provide incentives as motivation using a structured reward system for task completion.

FILLING IN THE GAPS

BY SETH KELLER, MD

There is no doubt that people with intellectual and developmental disabilities (IDD) are lacking in the ability to access quality health services. Oral health and behavioral health services must also be included as key healthcare fields which also lag far behind in being able to provide the much-needed services for this vulnerable population.

This is absolutely true in particular for adults with IDD as compared to young children. The lack of adequate healthcare to this all too often devalued and marginalized population is not new, nor has it been debated or discussed and written about over many decades. What was really lacking was the will and the desire to make a difference that would change the status quo. A broader and more collective effort needed to be done.

Finally, in 2001, Surgeon General David Satcher brought a good number of dedicated people together to shine a light on the issues and concerns of health disparities for those with IDD. *Closing the Gap: A National Blueprint to Improve the Health of Persons with Mental Retardation* was published in 2002. No one had any doubt that people with IDD have unique and often complex healthcare needs that were not being addressed and that these issues and challenges greatly impacted one's quality of life, as well as that of families and caregivers supporting them.

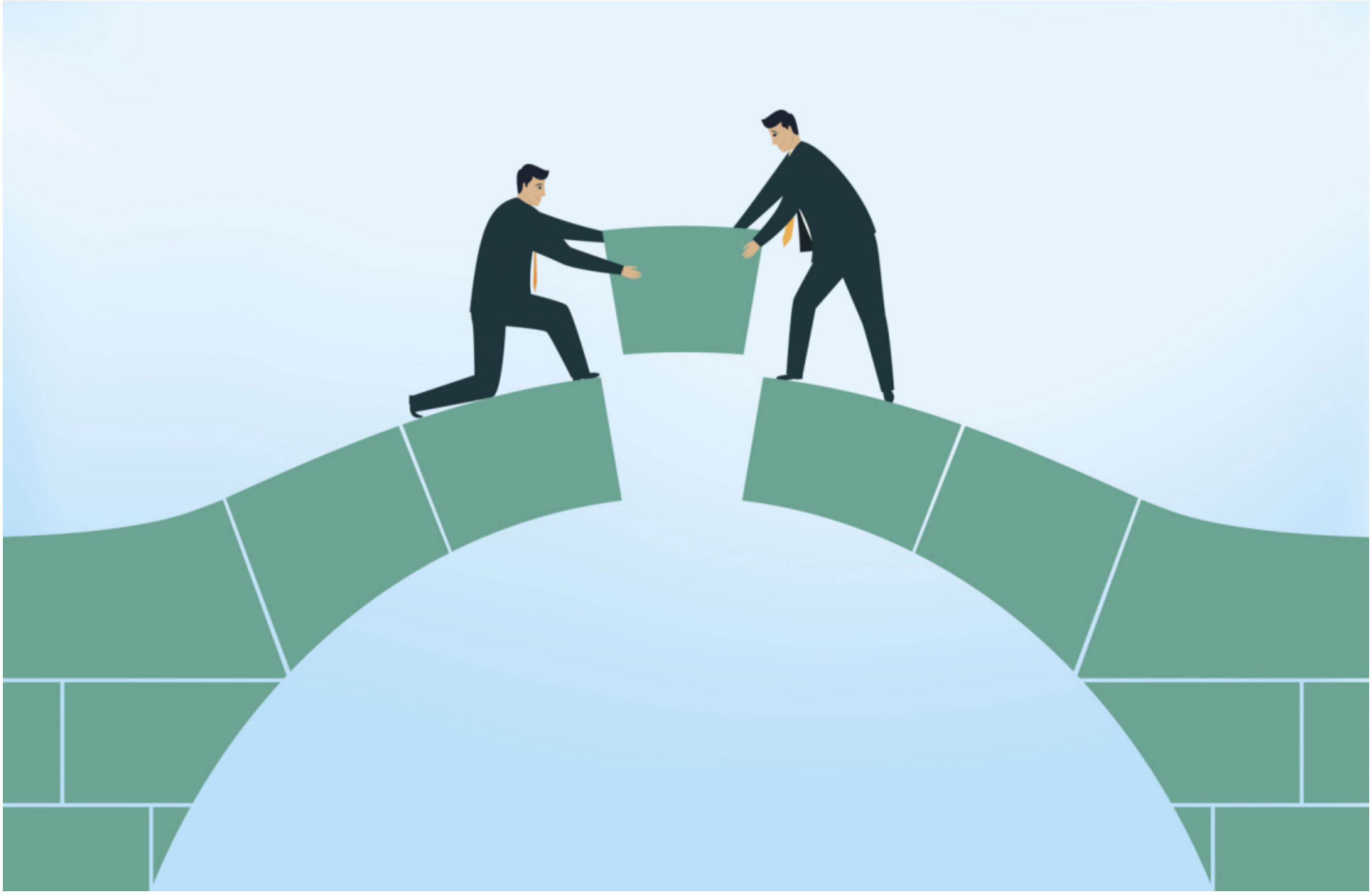
The blueprint was only offered as a guide and it was left to those who were leaders, and dedicated to make a difference to fill in the gaps in helping to provide the much-needed awareness, education, training, and curriculum on IDD health. The turnaround in helping to close the gap began right away during the time of the initial Surgeon General's conference. A number of medical care providers and oral health providers who had a great interest and had experience in IDD health got together and decided to make a difference by deciding that a national IDD healthcare organization needed to be formed in order to provide the structure and guidance to help lead the way in ultimately being able to reduce IDD health disparities. The American Academy of Developmental Medicine and Dentistry (AADMD) was born a year later. Much was needed to be done to reduce the many disparities in IDD health and decisions were made by the AADMD to embark on a number of directions to help offset the inequities of care.

Healthcare providers lacked the training, they lacked the personal experience in understanding the values and issues and concerns of those with IDD and their supports, they lacked a fair and adequate reimbursement for the complex and timely assessments, and care practices that are often needed to provide appropriate care.

As a neurologist practicing in southern New Jersey, I have had an interest in disability health as well as in geriatric care for the general population who had neurologic complications. I learned of the AADMD shortly after it was formed, and I quickly joined to add my voice and energy to the cause.

Our organization recognized that to make a stab at getting healthcare providers to engage and be supported in caring for those with IDD, it needed a national direction. It was known that there was federal mandate for selected populations who were designated as being a "Medically Underserved Population" or MUP. Health Resources and Services Administration (HRSA) is within the US Department of Health and Human Services Administration and they have created the MUP and its specific guidelines. People with IDD have not been designated officially as being MUP despite the data to the contrary. Much effort by the AADMD has gone into pushing for this designation to be applied to those with IDD because it would enable healthcare providers to be provided with loan forgiveness, research into IDD health, and more. Current groups of people that have been designated as being medically underserved include homeless, low-income, Medicaid-eligible, Native American and migrant farmworkers. Currently there is a bill sitting in Congress that may make this action possible.

Additionally, the AADMD has aggressively engaged in IDD healthcare curriculum development thru medical schools, nationally as well as through its various partnerships with a number of IDD advocacy groups in supporting IDD health such as Special



MIND THE GAP: The lack of adequate healthcare to this all too often devalued and marginalized population is not new, nor has it been debated or discussed and written about over many decades. What was really lacking was the will and the desire to make a difference that would change the status quo.

Olympics, National Alliance of Direct Support Professionals (NADSP) , Developmental Disability Nurses Association (DDNA), and many more.

The work in trying to bring IDD health education and knowledge to the great number of US healthcare organizations is daunting. An exception is with US dental care IDD education. The national dental school deans have all agreed about the need to have IDD oral health training and education be a part of all dental students in their training which is a mandate. But this is not true at all for all of the medical primary healthcare and specialty healthcare professional organizations. There is currently no IDD healthcare training on adult oriented issues at all across the country within any university, academic center, or medical school that provides any real depth to it that would make a clear dent in improving care.

As a neurologist, I belong to and work with several neurology focused professional organizations. The largest organization that all neurologists are members of is the American Academy of Neurology (AAN). It was founded in 1948 and has 36,000 members. It has annual meetings, has a strong neurology advocacy voice, it helps to create neurology curriculum, and guidelines of care for all neurologic complications. The AAN is recognized across the world as being the go-to neurology professional organization and has a large number of international members. What it has not had, until recently, is any dedicated focus on the specific neurologic issues and concerns that face those adults with IDD. Epilepsy, movement disorders/spasticity, aging and dementia, as well as behavioral challenges and autism, are all frequent complex health issues frequently encountered by many with IDD.

> “There is currently no IDD healthcare training on adult oriented issues at all across the country within any university, academic center, or medical school that provides any real depth to it that would make a clear dent in improving care.”

The AAN, like many other healthcare organizations, has subsets within it that focus on particular diseases and many practitioners may specializes or have a special interest and knowledge within that area. The AAN has “Sections” which are a group of these specialty areas for which all AAN members can join and learn, network, be a part of advancing education and training relevant to that area of focus as well as to help plan for annual meeting events. The AAN has over 30 Sections that include Child Neurology, Behavioral Neurology, Geriatric Neurology, Genetics, Women's Health, Multiple Sclerosis, Resident/Medical School Education, Ethics, and many others. None of these Sections specifically focuses or discusses adult with IDD issues but some may touch upon it a little but not in depth or with any consistency. Without this focus, the AAN has not had on its plate IDD in general, aside from what might be covered in pediatric neurology for those that have a IDD. The transitioning of care from pediatrics into adult care and focus on older adult neurologic issues has been threadbare in the AAN.

> **"So far, we have neurologists on the leadership team with interests in epilepsy, genetics, behavior, aging/dementia, resident training, as well in cerebral palsy and spasticity. These wonderful colleagues are from across the US and Canada."**

I decided to make a difference by going inside the AAN and creating a formal group that would be able to have a voice and would reflect the specific needs that so far have been absent. In 2014, with the advice and guidance of the AAN administration, I was recommended to apply for a Adult with IDD Special Interest Group (SIG) status. We had to get a petition signed by 50 other neurologists, write up a mission and, once we were able to accomplish that task, it was reviewed and approved a short time later. The SIG then enabled me to hold a specific course on "The Neurologic Complications in Adults with IDD" at the AAN's annual meeting. It went well, but not much else was able to be done with this SIG in hand. I honestly felt frustrated, especially the following year when the AAN denied my request to hold another course on IDD at the annual meeting. I had to go back to the drawing board and come up with Plan "B".

It appeared that one of the main problems was that a SIG held very little power like a Section, so we were recommended to switch our SIG status to become a new Section. This required a number of administrative steps, meetings, and finally a vote by a committee within the AAN to determine whether our Adult with IDD "deserved" to be a new Section. Drum roll please…

Yeah!!! We were accepted, and with this new title we were able to sit on equal terms with all of the other large and well-established and influential Sections.

The acceptance came May 2019 and, as it turned out, other Sections were thrilled we came into existence, especially the Child Neurology Section. The pediatric neurologists have been very frustrated that they could never find a "good" adult neurologist to take good care of their IDD patients. and that our new Section would ultimately help with that. The next step with our Section was what to do with this power and possible influence.

I am the official chair and leader of this group and began to find other like-neurologists who cared about the IDD population, with the realization that we needed a number of people with interests and experience in a number of IDD neurologic subspecialities, such as epilepsy, genetics, aging/dementia, resident training, as well in cerebral palsy and spasticity. These wonderful colleagues are from across the US and Canada. We meet monthly via Zoom calls with a specific agenda of making a change and difference in how Adult IDD neurologic education, training and care will be provided. We have also partnered with the Child Neurology Foundation (CNF) in working on a transitioning plan as well as a number of educational efforts.

We had put into place a terrific program for our 2020 Annual meeting in Toronto. It included a course on Epilepsy, a Section meeting with other colleagues, a Leadership meeting with other Sections, as well as a meeting that we set up separately to work with care providers and physicians in Ontario on a day-long conference to discuss and review the issues relevant to our Section, with participation by a number of my IDD Neurology leaders. We also had set up plans to be active in a AAN Brain Health Fair in Toronto that would also help engage the community. Then COVID-19 hit and it was all cancelled.

We have now regrouped, held a Zoom Section meeting to review our progress to date, with plans for the 2021 meeting in San Francisco. We have created a subgroup of neurologists specializing in IDD epilepsy and have successfully arranged a conference this fall at the American Epilepsy Society (AES) to hold a course on IDD epilepsy, and in addition we have met with leaders in Europe and elsewhere in the US to work on creating guidelines on IDD Epilepsy.

It makes a bigger impact if you have influence within a national specialty healthcare organization that is willing and open to the issues and concerns of those populations that have faced adversity, are vulnerable, and have health disparities. The AAN will be a better organization by looking at themselves in the mirror and want to be better. I am sure other organizations like the AAN would do the same. There just needs to a leader or group of leaders who are persistent with a compelling message and story to tell that includes having advocates alongside of them, telling their real-life stories and challenges that they have faced along the way. We are in a better position now than we were in 2002 when the AADMD was formed, but so much more still needs to be done. •

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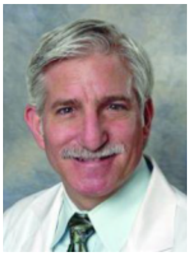

Seth M. Keller, MD is a board-certified neurologist in private practice with Neurology Associates of South Jersey. He specializes in the evaluation and care of adults with Intellectual and Developmental Disabilities (IDD) with neurologic complications. He cares for individuals with IDD both in the community, as well in New Jersey's ICF/DD centers. Dr Keller is on the Executive Board of the Arc of Burlington County as well as on the board for The Arc of New Jersey Mainstreaming Medical Care Board.

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

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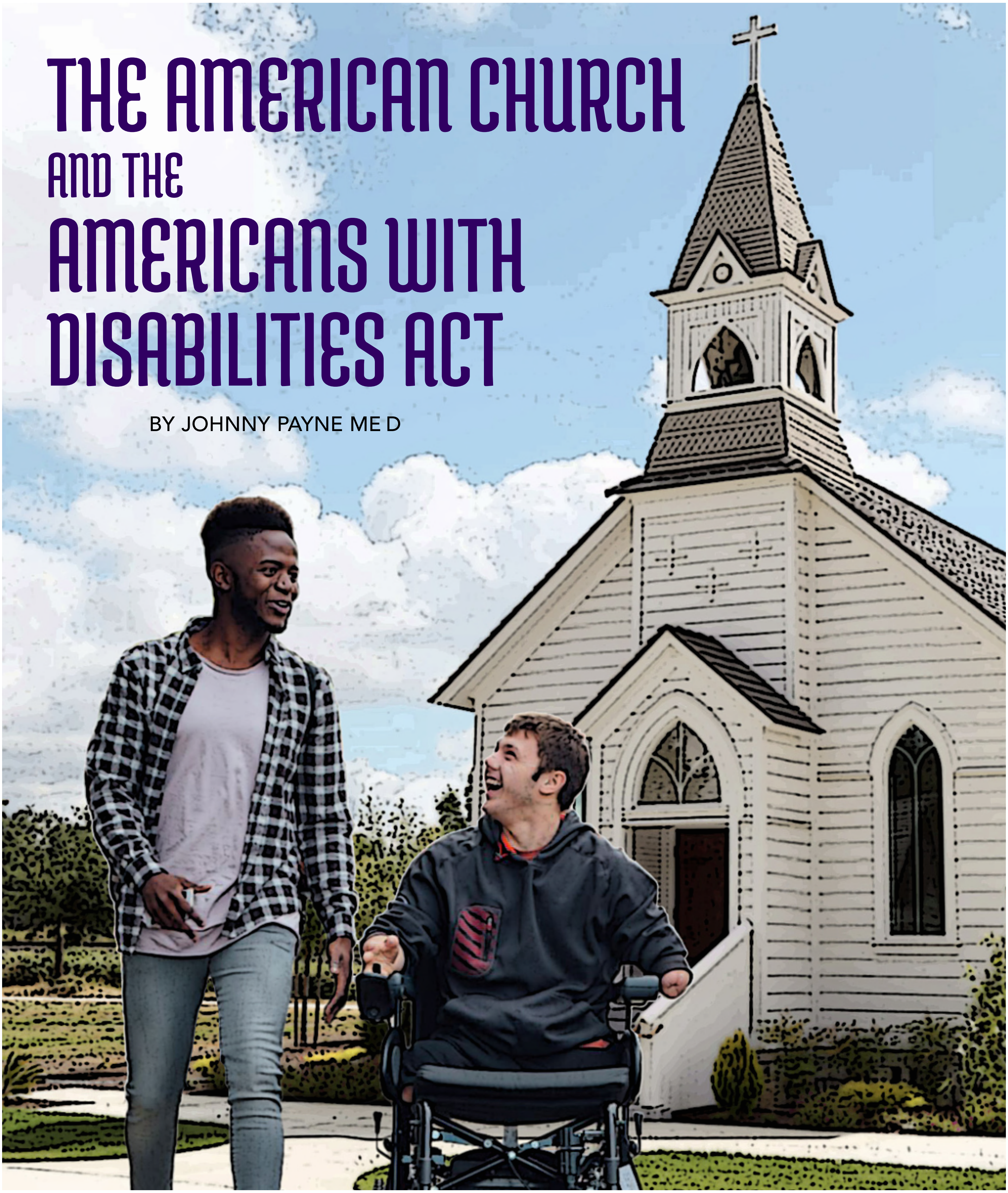
THE AMERICAN CHURCH AND THE AMERICANS WITH DISABILITIES ACT

BY JOHNNY PAYNE ME D



With or without churches' legal obligation to the ADA, there exists a moral responsibility and a set stage to facilitate the fulfillment of its principles.

Rev. Harold Wilke, can be seen in one of the most iconic American photos, alongside President George W Bush and others in 1980, at the signing of the Americans with Disabilities Act (ADA). Wilke was a minister in the United Church of Christ, and many others like him worked tirelessly for greater disability awareness and equality.

At the signing ceremony, Wilke delivered an invocation, an unprecedented event at a bill signing. He spoke of "the breaking of the chains which have held back millions of Americans with disabilities." Here, he did not speak of literal chains of disability, but of the physical and attitudinal barriers of American culture.

Religious groups have unique opportunities to promote inclusion and empowerment for people with disabilities. From jobs, relationships, community connections, these groups provide gateways into community life for their members. Although changing somewhat rapidly, Christian churches continue to represent the greatest majority of religious groups in America (65% in 2019, 75% in 2015, 85% in 1990 per Pew Research Center). The American church holds tremendous tools and opportunities for access to the community for people with disabilities. However, according to the 2019 Census, about 20% (60 million) of Americans have a disability, but disability leaders estimate only about 15% (9 million) of people with disabilities attend any kind of faith tradition.

The ADA is considered by many to be the most groundbreaking piece of American legislation since the Civil Rights Act of the 1960s. Instated as law in 1990, the ADA prohibits discrimination against individuals with disabilities in all areas of public life. This includes jobs, schools, transportation, and all public and private places that may be accessible to the general public. The law, as it was drafted and approved, attempted to ensure people with disabilities have the same rights and opportunities as everyone else. The law provided protection to people with disabilities similar to those provided to individuals on the basis of race, color, sex, national origin, age, and religion. Before the ADA, no buildings were required to have ramps,

SIGN OF THE TIMES: On July 26, 1990, President George Bush signed the Americans with Disabilities Act into law. With him on the South Lawn of the White House are *(left to right, standing)* Rev. Harold Wilke and Swift Parrino, Chairperson, National Council on Disability,*(from left to right, sitting)* Evan Kemp, Chairman of the Equal Employment Opportunity Commission, and Justin Dart, Chairman of the President's Committee on Employment of People with Disabilities.

PHOTO COURTESY NATIONAL ARCHIVES

parking lots did not require "handicapped spots", and public transportation did not have to accommodate people who used wheelchairs. Anyone older than 30 years at the time of this article was born when people with disabilities people lacked the same rights as their fellow Americans.

The ADA is divided into five parts or titles. Under title three, businesses that own, lease, lease to, or operate public accommodations like hotels, restaurants, theaters, shopping centers, banks, museums, zoos, daycare centers, private schools, and health spas must provide 'reasonable accommodation' for people with disabilities to access and participate with their services and spaces. However, all religious groups are completely exempt from this title and from the ADA entirely. All religious groups' facilities, programs, and activities, whether they are religious or secular in nature, are completely exempt. The title 'religious groups' include places of worship, such as mosques, synagogues, and churches. However, the title also encompasses any places or programs controlled by the group including schools, hospitals, daycare centers, adoption agencies, thrift shops, shelters, and food banks.

The American Church's historic relationship with the ADA and government overall is incredibly complicated and multifaceted. From the introduction of the ADA in Congress in 1989, religious groups, particularly the American Church, have aggressively resisted participation. Exemption of these groups has been upheld primarily on the basis that requiring religious entities to comply with the ADA amounts to impermissible government interference with religion.

For example, in 1989 William Bentley Ball, an attorney representing the Association of Christian Schools International and numerous other Christian entities, lobbied against the ADA for two reasons: the cost of making schools accessible and concerns about government intrusion into religious institutions. In July 1989, he wrote to the director of the Office of Policy Development at the White House, "Religious exercise, within the meaning of the First Amendment will be directly involved if churches and religious schools are not expressly exempted from the terms of the ADA." Ball also argued that there was no compelling state interest in religious organizations being accessible noting, "Nothing has been shown to indicate that there is a national necessity to apply the ADA Bill to churches, religious schools, and other ministries."

"Dr. Gaventa notes that if churches should expect residual anger that has been hiding or deeply buried by people with disabilities."

The outcome of exempting Christian churches and schools from the ADA has been significant. Very few other religious groups made similar arguments to Ball on behalf of Christian groups lobbying against being included in the ADA. Christians stood nearly alone against access for disabled people as part of Religious Groups. Many people with disabilities feel this outcome communicated that they did not belong in mainstream U.S. Christianity, as churches either actively opposed the ADA or passively didn't abide by it because they weren't required to do so legally.


BEST FOOT FORWARD: When Harold Wilke accepted a pen from President George H. W. Bush at the signing of the ADA, he grasped it with his toes; he had been born without arms. In 1975 Wilke founded The Healing Community Project to help churches change their attitudes and architecture to welcome persons with disabilities.

Before the ADA, people with disabilities experienced inaccessibility to their communities. After the ADA, many more pathways into community participation were formed for them, but not through the American Church. Leah Smith, Project Coordinator for the Center for Dignity in Healthcare for People with Disabilities notes, "We know this message was received by the disability community when we see that people with disabilities are 40% more likely than those without disabilities to report that they do not attend church. Further, they are 28% more likely to report that church is not important in their lives".

Dr. Erik Carter, Cornelius Vanderbilt Professor of Special Education at Vanderbilt University, has gathered quantitative research on people with intellectual and developmental disabilities in the American Church. He notes that:

- *56% of parents keep their children from participating in church activities because they experience a lack of support for their child.*
- *32% of families changed their place of worship because they or their child was not 'included or welcomed'.*
- *54% of parents say they have never been asked about the best way to include their child in religious activities*

PHOTO COURTESY WKIMEDIA COMMONS

Bill Gaventa, past President of the Americans Association of Intellectual and Developmental Disabilities (AAIDD) notes, "Most advocacy around disability has been in the public policy and human rights arenas. Rights may get you physically into a place that was inaccessible before, but they won't get you relationships. Beyond inclusion is belonging. While people were worried about how a rights-focused ADA would impact church hiring, or forcing them to accept people with HIV or other disabilities, it abdicated the moral call of welcome and the crucial role of religious groups as places of relationship, and abdicated the role of the church, for a long time, in advocacy circles."

Because religious groups are exempt from the ADA as law, religious leaders have to empower their members to uphold ADA practices in terms of morality and decency—and civil rights. As an example, in 1993, the Christian Reformed Church of North America called its members to become ADA compliant to stop what they noted was tantamount to "churches committing disability discrimination even while at the same time they are trying to help people."

There is much that can be done to support people with disabilities within the American Church, and there is much work to do. Dr. Gaventa suggests starting by asking people with disabilities and their families what they feel, to ask them what their experience is or has been with churches. He also notes that if churches do approach being more inclusive towards people with disabilities, they should expect residual anger that has been hiding or deeply buried by people with disabilities. Even so, as churches pursue inclusivity, they should start by having hard conversations to know what people with disabilities experience.

Rev. John Jay Frank, Ph.D., author of several books, including Turning Barriers Into Bridges, provides a theological rationale for the concept of universal design. In designing programs, activities, materials, and spaces, consideration of diverse abilities may be included in the planning process. This concept, called universal design, can be applied in all areas of religious group activity, from leadership and design to membership and participation. He outlines a passage from the Bible, "Do not to dig a hole and leave it unattended, so as to avoid accidental injury or death, and to put up a railing around a porch, so people do not fall off or drop things on those below, and not to put a stone in the road where someone who is blind may trip on it, and not lead someone who is blind astray." (Ex. 21:33-34, Lev. 19:14-15, Deut 22:8, Deut. 27:18). He notes, "Christians should take care not to harm others with what we create and do, regardless of whether or not anyone falls into the holes we dig."

KEEPING THE FAITH : ACCESSIBILITY RESOURCES

For more information on access to religious services as it relates to individuals with disabilities, please visit:

Disability Concerns

DISABILITY CONCERNS

Accessibility Audit tool

https://network.crcna.org/disability-concerns/accessibilty-audit

Church policy on disability template

https://network.crcna.org/church-admin-finance/church-policy-disability

Costs have historically been held as a reason for religious groups to not be held to the ADA. Costs for accommodation can be burdensome, especially when spent sporadically when special needs for accessibility arising. However, if resources are budgeted towards universal design and accessibility during design and planning, costs can be much smaller. As noted previously, about 20% of Americans have a disability. Therefore about 20% for each overall project may be directed towards including those individuals in church participation. For example, a church remodeling may cost $100,000. So about $20,000 could go for accessibility features. $10,000 may be spent on a new sound system so $2,000 might go for an earloop system for hearing impairments. A new instrument might cost a certain amount. So about 20% of that cost might be directed towards the purchase of large-print songbooks or signs.

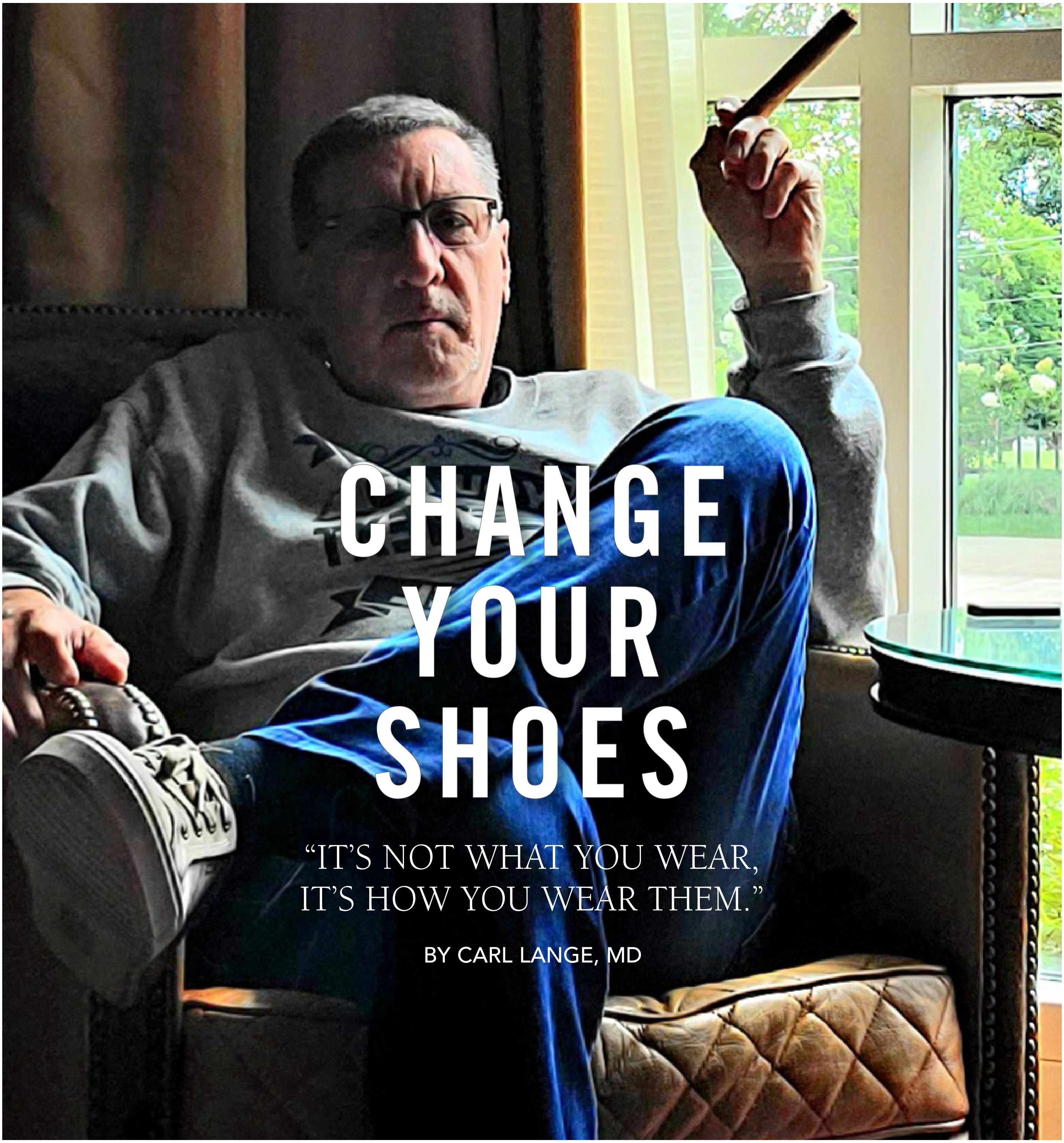
The leadership of a church might adopt (and make known) a Church Disability Policy that includes adhering to the ADA to mitigate discrimination towards and provide a welcome space for people with disabilities. Churches might follow the lead of the Christian Reformed Church of North America as they universally adopted a disability policy for their entire organization. Individual members may also commit to providing an environment of universal design within their own area of responsibilities. A person who makes computer slides for a worship service might take the responsibility of making them accessible with high contrasting colors. A person who produces a church activity, bulletin, or newsletter, might take responsibility for making their material accessible. A religious teacher might provide a sermon outline or study notes for people who experience difficulty managing attention for various reasons. Gluten-free wafers or sugar-free desserts at religious events are simple ways to provide welcome.

"Universal design can be applied in all areas of religious group activity, from leadership and design to membership and participation."

With or without churches' legal obligation to the ADA, there exists a moral responsibility and a set stage to facilitate the fulfillment of its principles. Rev. Herald Wilkes entrusts us with this endeavor as he completes his invocation at the ADA signing. May his words provide a strong charge for American culture now, as they did then: "Today we celebrate the granting… of full citizenship and access to the promised land of work, service, and community.… strengthen our resolve as we take up the task knowing that our work has just begun… Bless the American people and move them to discard those old beliefs and attitudes that limit and diminish those among us with disabilities". •

ABOUT THE AUTHOR:

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



CHANGE YOUR SHOES

"IT'S NOT WHAT YOU WEAR, IT'S HOW YOU WEAR THEM."

BY CARL LANGE, MD

> ***Introduction:*** *Dr. Carl Lange is an emergency medicine physician and emergency department director in Pittsburgh. He acknowledges that, like most physicians, he received no formal training in treating patients with intellectual and developmental disabilities. His teachers have been the patients themselves, their families, and caregivers. He is quick to add that his own diagnosis of multiple sclerosis has greatly contributed to his insights, empathy, understanding and appreciation of how a disability can impact on social roles, outcomes, expectations, perceptions, outlooks and relationships.*
>
> – Rick Rader, MD, Editor-in-Chief, EP Magazine

"You can burn my house, steal my car, drink my liquor from an old fruit jar. Well do anything that you want to do, but uh-uh, honey lay off of my shoes." Shoes are an essential apparatus in our daily lives. At least according to the King, Elvis Presley who was willing to go to great lengths to protect his.

PHOTOS PROVIDED BY: CARL LANG, MD

In 1938, deep within the recesses of an Oregon cave, archeologists discovered a shoe-like object dating back to approximately 3500 BC. The sole was fabricated with bear skin and the sides fortified by deer skin. The device was woven together with bark-string netting which, in essence, served to pull the "foot-bags" together to protect our ancestors' tootsies. Scientists don't know for sure if they had cars, or stored their liquor in old fruit jars, but they did concur with Elvis on the weightiness of footwear. Now, while they in no way resemble Bruno Cucinellis, they served a purpose.

Designed by our predecessors for the purpose of protection from the cold, the adversities of the elements of their time, rocks and debris, shoes were more for function than style. Fast forward to 2020, where some footwear can cost the fashion-conscious buyer upwards of fifty-thousand dollars. All for the purpose of looking good while having the security of knowing that your feet are shielded from the terrors of the outside world.

So, all that being said, why so many brands and styles? The simple answer is that people have many different opinions on exactly what does look good in addition to what is comfortable and practical. Do you mean to tell me that Homo Sapiens are capable of having varied perspectives on the world and the situations that life presents to us? That's right folks. When we look at Mars in the night sky with our naked eye, it looks much different than peering at the Angry Red Planet from the Hubble telescope. Or, how about this? If NASA were to set you down on the surface of the planet, open the door and let you outside, for the fraction of a second that you had left in your life, it would certainly look and feel much different.

It's all a matter of perspective. Albert Einstein was quoted as saying that "When you are courting a nice girl, an hour seems like a second. When you sit on a red-hot cinder a second seems like an hour." So, it seems like your perspective is dictated by your view of the situation. A genius said that, not me.

As an emergency room physician in a busy Pittsburgh hospital, I see thousands of patients a month. The spectrum of acuity ranges from minor coughs and colds to gunshot victims, heart attacks, and strokes. My job gives me the affordance of treating many patients with special needs, or a term I abhor, "disabilities". Because as we know, what one man considers a disability, another would view it as a gift that allows one to accomplish life in a different manner, often creating good along the way. But, since you are reading this, we already agree on this fact.

BODY AND SOLE: On August 26th, 2008, I lost my vision while working in the emergency room. Things sure did "look" different then. The regaining of my sight and rehabilitation took about ten days. The rehabilitation of my soul took much less time.

Twelve years ago, I was diagnosed with multiple sclerosis. This disease is insidious and evil. It attacks your nervous system causing you blindness, muscle spasm, spasticity and pain. I have difficulty walking, among other symptoms. I have gone blind twice, requiring hospitalization. Please understand me. I am in no way singing the blues because I truly consider myself a blessed man. I share this very personal history with you merely to highlight this theory of relativity of which we speak. My job requires me to walk up and down hospital corridors for twelve-plus hours, to "run" to cardiac arrests, and respond in a split second to a gun-shot wound. This brings this whole discussion to the historical timeline outlining PMS verses PMS (pre-multiple sclerosis versus post-multiple sclerosis).

I am ashamed to admit that there was more than one occasion when I saw a patient with multiple sclerosis in my emergency department who I looked upon with a jaundiced eye as a gamer of the system. The thought of this patient trying to scam me out of pain medicine or muscle relaxants was never far from my list of differential diagnoses. Of course, I ran the proper tests and did the proper physical exam, but I always felt bothered by the very fact that this concept even entered my mind. That is, until August 26th, 2008, when I lost my vision while working in the very emergency room of which I speak. Things sure did "look" different then. The regaining of my sight and rehabilitation took about ten days. The rehabilitation of my soul took much less time. Hearing my radiologist colleague and friend tell me "I'm sorry to have to tell you Carl, you have multiple sclerosis" did not heal my vision, but instantaneously healed my outlook, so to speak.

When I eventually attained my ability to see again, I got back to work. Not only was I able to see my patient in front of me, but now I could clearly see the person in front of me.

We've all heard the metaphor "Never criticize a man until you have walked a mile in his shoes." So, never wanting to become too comfortable in my footwear, I'll excuse myself now. I'm going to the mall to buy a new pair of shoes. •

ABOUT THE AUTHOR:

Dr. Carl Lange is an Emergency Medicine physician practicing in Pittsburgh, Pennsylvania. He is Board Certified by the American Board of Surgery and works with University of Pittsburgh Physicians at The University of Pittsburgh Medical Center.

LOOK TO US: The Terrell family; "If you think about it, the rest of the world is now being forced to do what we have been doing every day. They would do well to look to us to learn about patience, and how to depend on themselves rather than on others, and honestly realize every day there are necessary risks to live, and how to avoid the UN-necessary risks."

WHAT IS YOUR PLAN?

BY JULIA TERRELL

I want to tell you a story. Imagine for a moment you just had a new baby and you're told that your new baby has a rare disease called Sturge-Weber syndrome, with which only 1 in 50,000 babies are born. The news is unbearable, and you try to wrap your hands around the diagnosis and what it could mean.

It is overwhelming, and your mind is so stuck on what could go wrong. This little baby has no idea of what is happening, or what will happen but, as a parent, you have so much to think about. You begin to research, you begin to hire the right people, and without you knowing it a plan is born.

Fast forward to today. How many times in recent days, have you read or heard the words "In these unprecedented times…"? No one could have predicted this would happen. But here we are, living through a worldwide pandemic and all of the challenges it presents for everyone. The social distancing is starting to feel like social isolation, and everyone is wishing they could go back to life as usual. No group of people feels that more poignantly than those of us who live with or care for someone with special needs, or are already medically fragile. This five-month long interruption (with no crystal-clear end in sight at the moment) is taking its toll and affecting the health and well-being of an estimated 15% of the population. And when you add in the people who care for them, that adds up to a lot of people feeling the stress of a quarantine and an anything-but-routine schedule.

In addition to dealing with the interruption in services that we've all experienced over the last five months, a lot of us are now finding ourselves in the position of having to create back-to-school plans. Or one could even say back-to-life plans. Special Needs communities, whether a rare disease like the Sturge-Weber, or a more well-known communities like autism and MS, you know that there are so many moving parts. From the day our children and adults with special needs were diagnosed, we knew our lives would be different, and we learned quickly that we have to do more than other parents and caretakers. We have to plan, educate ourselves, and as I often say, "become a specialist or advocate" for our family member. What does that look like? It can look very different in each of our worlds, but here is what we have in common: we are all resourceful. We look outside the box, and when one door closes, we often ask "if we can't do that, what can we do instead?"

PHOTO PROVIDED BY JULIA TERRELL

Funny enough, if you think about it, the rest of the world is now being forced to do what we have been doing every day. They would do well to look to us to learn about patience, and how to depend on themselves rather than on others, and honestly realize every day there are necessary risks to live, and how to avoid the UN-necessary risks. That is where this article began, because this climate is what we are good at doing what needs to be done, and we should all be proud to say we can do this. Now our environment is changing. Sure, it will be quite different from previous years, due to masks, social distancing, class size, lack of in-person services, and many other factors that we may not even be aware of yet. Now is the time that we continue to plan and evolve as the climate changes.

This plan can be used for any situation you will encounter. One more part of the plan that we haven't talked about is YOU! Remember that no matter what happens, it is ok to be overwhelmed, scared, mad, and upset. Just remember the three-day rule: first day to wallow and have a pity-party if need be; the second day, to reach out for support, resources, and to get a plan or update your plan; and the last day, to implement the comprehensive plan to once again right your world and the loved ones you uplift! Take time to enjoy your family and yourself and take care of yourself too.

We will all get through this pandemic, we have to. That reminds me, when I am talking to a new family, I always say, "Congratulations on that new bundle of joy! I need you to take a deep breath and know it will be ok. Now let's get you a plan in place so you can feel better!"

So remember, when you start to feel the uneasiness of this pandemic or any situation that seems so hard to overcome, remember take a deep breath and ask yourself "What's Your Plan?" This will all be okay. •

ABOUT THE AUTHOR:

Julia Terrell is the Community Relations Director for The Sturge-Weber Foundation. She currently lives in Southern New Jersey with her husband, Scott, and their daughter, Marissa. Together they love swimming, playing with their puppy, and planning for their future.

ABOUT THE STURGE-WEBER FOUNDATION:

THE STURGE-WEBER FOUNDATION

The Sturge-Weber Foundation (The SWF) global mission is to improve the quality of life and care for people with Sturge-Weber syndrome and associated Port-Wine Birthmark conditions through tenacious collaboration with clinical partners and pioneers, education, advocacy, research and friendly support. Support, integrity, and vision: These qualities have distinguished the Sturge-Weber Foundation (SWF) since 1987. Thousands of people have been served and continue to be served by the SWF's one on one phone support, family networking program, education, physician referral service, medical education programs and research endeavors. The Sturge-Weber Foundation is a 501 (c) (3) non profit organization with an ever increasing worldwide membership and is funded by corporate and private donations, grants and fundraising activities. In 1992, the mission was expanded to also support and serve individuals with capillary vascular birthmarks, Klippel Trenaunay (KT) and Port Wine Birthmarks.

SOUNDS LIKE A PLAN : PREPARING FOR THE UNKNOWN

So how do we prepare for the unknown? Well, it's a bit of work, but the peace of mind it will bring you is well worth the effort. A plan has many moving parts. When you make a plan, you want to make a plan that is easy, understandable, and to be used over and over again. Let's get started: What do you need to accomplish?

STEP 1:

Define the situation you need to overcome. You can create a plan for anything, including but not limited to virtual school, or in-person classes, which is on everyone's minds right now. The plan could be for a medical plan, or getting a job, going to college and more.

STEP 2:

Make a checklist of what you need. When my daughter had a seizure, and I began to panic, I remembered that, thanks to my doctors, we had a plan in place. It all began with a list in my head of all the things that happened when I called 911 that day. A checklist is so important for many reasons: it will keep you on track, you can add and subtract steps as needed, and you have something tangible that allows you to go on autopilot if you need to. The checklist should be kept readily available for when it is needed.

STEP 3:

Once the checklist is complete, make a list of who needs to be involved in your plan.

STEP 4:

Talk to the new team and set up a time to train them and make sure they understand the importance of their role.

STEP 5:

Make sure you have all the pertinent information and items (such as a binder) in one spot, like on the refrigerator, where everyone knows where it is. You may need several copies as well, depending what your plan is, as well as who are involved. For example, my daughter has her health plan in a bag with her medicine that she carries with her when she is at school, a copy in the nurse's office and in the principal's office.

STEP 6:

Implement your plan and make sure everyone is bought in and understands what is asked of them.

STEP 7:

Check in on your plan periodically throughout the year, to make sure it still makes sense, and update the plan where needed.

STEP 8:

Check in yearly with your medical team, or any team that you work with, to keep the plan up to date and make necessary changes.

STEP 9:

Retrain and refresh the team each year. In the example of a health plan, it is important to train the new teachers, or any time the team changes, so everyone is on board with the plan and understands the expectations.

STEP 10:

Always thank everyone involved for taking the time to be a part of your team.

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

EP's Innovative New Digital Strategy

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

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

We've introduced a range of new content to the website, including In This Issue that highlights selected content from our latest issue, and From Our Contributors, which features the most recent offerings from regulars such as Genetic Alliance and the AADMD.

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

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

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

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

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

FROM OUR FAMILIES… TO YOUR FAMILIES

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By Shelly Huhtanen

ARMY
NAVY
AIR FORCE
MARINES

BUILDING BLOCKS: With attention and a commitment to one another, you and your partner can build a foundation strong enough to weather any challenge while providing you both with a source of happiness and fulfillment.

RELATIONSHIP SUPPORT FOR MILITARY COUPLES

When you are part of a military couple, you and your partner share the pride, benefits and challenges of service. Permanent change of station moves mean you get to experience new parts of the country and world. But these frequent moves can also bring stress. Deployments allow the service member to put their training into practice, but being far from home can be hard on a relationship.

Fortunately, couples counseling and many other free and confidential resources are available to help you and your partner build a relationship that can thrive amid these and other challenges.

EXPERT HELP FOR MILITARY COUPLES

Free and confidential non-medical counseling and other programs provide professional support for military couples with relationship concerns.

- **Non-medical counseling** (www.militaryonesource.mil/confidential-help/non-medical-counseling/military-onesource/free-confidential-face-to-face-non-medical-counseling). You and your partner don't have to figure it out on your own. Talk to someone who understands military life and its unique challenges. Non-medical counselors are experienced professionals who are available through:
  - **The Military and Family Life Counseling Program** (www.militaryonesource.mil/confidential-help/non-medical-counseling/military-and-family-life-counseling/the-military-and-family-life-counseling-program). This program offers both face-to-face and telehealth sessions to individuals and couples on or off the installation. Contact your installation's Military and Family Support Center to connect with a non-medical counselor.
  - **Military OneSource** (www.militaryonesource.mil/confidential-help/non-medical-counseling/military-onesource). Sessions are available face-to-face, by phone and through secure online or video sessions. Call 800-342-9647 to request counseling 24 hours a day, seven days a week. Use one of these international calling options if you are outside the continental United States.
- **Building Healthy Relationships specialty consultations** (www.militaryonesource.mil/confidential-help/specialty-consultations/building-healthy-relationships/building-healthy-relationships?redirect=%2Fconfidential-

help%2Fspecialty-consultations%2Fbuilding-healthy-relationships). These consultations include coaching sessions, practical tools, resources and problem-solving techniques. Consultations are available as specific tracks that focus on the area of your relationship that needs attention. The tracks include:

- Building Healthy Relationships With Your Significant Other. This track targets the common issues military couples face and provides tools to support a strong relationship.
- Communication Refreshers. You and your partner will be given the resources to improve the way you communicate.
- Staying Connected While Away. You and your partner will learn ways to stay close and cope with being apart during deployments and other separations.
- Reconnecting After Deployment. This track is tailored to the period of reintegration after a deployment.

Building Healthy Relationships specialty consultations are available by phone or video by calling Military OneSource at 800-342-9647.

VIRTUAL RESOURCES FOR MILITARY COUPLES

These free tools and resources are available to you and your partner 24/7, on your own schedule.

- **Love Every Day** (**www.militaryonesource.mil/confidential-help/interactive-tools-services/resilience-tools/relationship-tool-helps-you-love-every-day**). Practice your communication skills and grow closer to your partner with this fun and interactive digital tool. You get personalized text messages for 21 days to bring you closer together and rekindle your romance.
- **Relationship webinars** (**www.militaryonesource.mil/leaders-service-providers/military-and-family-life-counseling-program/marriage-and-couples**). You'll find webinars that focus on building healthy relationships, challenges facing dual-military couples and more.
- **Military OneSource Relationships** (**www.militaryonesource.mil/family-relationships/relationships/keeping-your-relationship-strong/how-to-strengthen-your-relationship-14-ways**). Visit the webpage to find resources and articles on a range of relationship topics. Find tips for fortifying your relationship in the article, How to Strengthen Your Relationship: 14 Ways (**www.militaryonesource.mil/family-relationships/relationships/keeping-your-relationship-strong/how-to-strengthen-your-relationship-14-ways**). Learn about marriage enrichment programs (**www.militaryonesource.mil/family-relationships/relationships/keeping-your-relationship-strong/marriage-enrichment-programs?redirect=%2Ffamily-relationships%2Frelationships**) that the service branches offer. Read about these military benefits (**www.militaryonesource.mil/family-relationships/relationships/relationships-benefits**) that can recharge your relationship or address specific concerns.

No relationship is perfect. But with attention and a commitment to one another, you and your partner can build a foundation strong enough to weather any challenge while providing you both with a source of happiness and fulfillment.

– Military One Source

GETTING HELP FOR DOMESTIC ABUSE

MILITARY PROTECTIVE ORDERS CAN INCLUDE PETS

Safety Alert: *Computer use can be monitored and it is impossible to completely clear your browser history. If you are afraid your internet usage might be monitored, call the National Domestic Violence Hotline at 800-799-7233 or 800-787-3224 en Español.*

GET HELP TODAY — DON'T WAIT

- Call 911 in an emergency.
- Contact your FAP victim advocate for help with reporting and requesting a Military Protective Order.
- Call the National Domestic Violence Hotline at 800-799-7233 for 24/7 help.

Our pets provide us with great comfort, cuddles and company. They offer and inspire unconditional love. Unfortunately, that love between a family and pet may be used by an abusive partner to inflict emotional abuse, manipulate and control their partner.

A military protective order is the military version of a restraining order. Once a victim elects to make an unrestricted report of domestic abuse, a military commander can issue an MPO. Within the MPO form, the victim may request to include their pet in the protection order. There is space to include what threats or abuse have occurred toward a pet in addition to those made toward the victim.

Another resource available is the National Domestic Violence Hotline. A trained advocate is available to speak with anyone in need of support 24/7. Call the National Domestic Violence Hotline at 800-799-7233 to report animal and intimate partner abuse. Individuals may access support for:

- Crisis intervention
- Safety planning so they and their pet can remain safe
- Referrals to local service providers

If you find yourself or someone you know in immediate danger, call 911.

– Military One Source

Coronavirus.org

Artwork by Shepard Fairey | Amplifier.org

ad COUNCIL

PARENTING YOUTH AND TEENS
THE ESSENTIALS

As a parent, one of your important jobs is to raise children and teens prepared to cope in healthy ways to changing circumstances like deployments, moves and new schools.

Military OneSource is there to help you parent at every stage, offering guidance on making moves easier for your kids, helping you support your child at school and encouraging you to talk to your teens about important topics like substance abuse and managing stress. You're already a guardian of our country, the following can help you be an even better guardian to your kids.

TAKE ADVANTAGE OF MILITARY KIDS CONNECT

Service families have access to this engaging website that helps children connect to an online community of other military kids, prepare for upcoming moves and have fun with lots of tools and games. Military Kids Connect also has great information to help adults understand what it takes to support military children at home and at school. Check out the ways your children can connect with others who've been there.

Relevant Articles:

- Getting the Most from Military Kids Connect
  www.militaryonesource.mil/family-relationships/parenting-and-children/parenting-youth-and-teens/getting-the-most-from-military-kids-connect
- Deployment Resources for Families
  www.militaryonesource.mil/family-relationships/parenting-and-children/parenting-through-deployment/deployment-resources-for-families

Relevant Resources:

- Military Kids Connect
  https://militarykidsconnect.health.mil/Caring-for-Our-Youth/Parents
- Military Kids Connect Teen Tours
  www.youtube.com/playlist?list=PL1aN3lHj22aHHsryACcKaL10StT7mKFfY

SUPPORT YOUR KIDS IN SCHOOL

You want to give your kids a head start in their education, and safely navigate them through the sometimes-tricky terrain of grade school. Military OneSource can support you in supporting your child by providing guidance on a successful transition to a new school, connecting you with tutoring information or helping you navigate standardized tests in high school.

Relevant Articles:

- Ways to Support Your Kids in Grade School
  www.militaryonesource.mil/family-relationships/parenting-and-children/parenting-youth-and-teens/ways-to-support-your-kids-in-grade-school
- Helping Your Children Change Schools
  www.militaryonesource.mil/family-relationships/parenting-and-children/parenting-youth-and-teens/helping-your-children-change-schools

Relevant Resources:

- Military OneSource education consultations
  www.militaryonesource.mil/confidential-help/specialty-consultations/education/plan-your-future-with-a-military-onesource-education-consultant
- MWR Digital Library Fact Sheet
  www.militaryonesource.mil/products#!/detail/399
- Building a Strong Relationship With Your Child's School Podcast
  www.militaryonesource.mil/training-resources/podcasts/building-a-strong-relationship-with-your-child-s-school

HELP YOUR KIDS MANAGE STRESS

Teenage life can be very stressful. There are many things to juggle: fitting in at school, managing classwork and clubs, and a changing body and hormones. Your job is to help steer them through these tricky years. We offer tips for recognizing stress in your teen – and ways to help your adolescent manage emotions. You also can find help through Military OneSource or through hotlines if stress leads to more serious problems.

Relevant Articles:

- Helping Your Teen Manage Stress
  www.militaryonesource.mil/family-relationships/parenting-and-children/parenting-youth-and-teens/parenting-and-teen-stress

Relevant Resources:

- Chill Drills
  www.militaryonesource.mil/products#!/detail/55
- Military and Family Life Counseling Program
  www.militaryonesource.mil/confidential-help/non-medical-counseling/military-and-family-life-counseling
- Build Knowledge of Parenting and Child Development Podcast
  www.militaryonesource.mil/training-resources/podcasts/build-knowledge-of-parenting-and-child-development

TALK TO YOUR KIDS ABOUT DIFFICULT TOPICS

It's important to keep communication open with your teen about topics like substance abuse and dating violence. Review our guidelines on addressing those important issues with your adolescent and where you can go for some extra support if you need it.

Relevant Articles:

- Talking to Your Military Teen About Substance Abuse
  www.militaryonesource.mil/family-relationships/parenting-and-children/parenting-youth-and-teens/talking-to-your-teen-about-substance-abuse
- Understanding Dating Violence
  www.militaryonesource.mil/family-relationships/parenting-and-children/parenting-youth-and-teens/understanding-teen-dating-violence

Relevant Resources:

- Military and Family Life Counseling Program
  www.militaryonesource.mil/confidential-help/non-medical-counseling/military-and-family-life-counseling •

– Military One Source

SHELLY HUHTANEN

What Team are You On?

I'm on everyone's team. We're writing the parenting manual as we go, and the only way we can ensure that we are doing the best we can is to listen to our heart, our gut, and be cognizant of what our child is trying to communicate to us may it be through words or behavior.

Parenting is hard. Especially when your child doesn't come with a manual. Believe me, I've asked a few parents if they received a cheat sheet that somehow Mark and I didn't get when our children were born. Some parents seem to have all the answers and some are pretty honest about not having any answers at all. A friend of mine whose children are in college said, "I have no idea how they got to college and stayed out of trouble. I think it's luck. I have no advice for you." Her brutal honesty was a godsend, but then, there are also parents out there that think it is their duty to call out other parents if they think they do not agree with their parenting style or disagree with the choices they are making for their child. Add COVID-19 or, as my sister-in-law would say, "the Rona" into the mix, and it's like throwing a barrel of gasoline onto the fire.

Raising our typical child, I'm used to the usual conversations that give other parents an idea of what sort of "team" you are on. Do we homeschool? Do we do private or public school? Are we strict with electronics, or are we hands-off with electronics? Snapchat or no Snapchat? The list goes on and no. Eventually, based on the answers, parents will file you in their minds on what "team" you are on. While doing this sort of dance, each parent is either feeling extremely guilty about their choices because they don't measure up to the other high achieving parents, or they are feeling quite proud of themselves by making it to the "high achieving team". Either way, one thing is certain – parents want to feel support from other parents and be assured that what choices they are making are good enough. That's what we all want but, for some reason, playing this game while raising our child with autism feels different. It hurts more because I seem to feel more of a sense of desperation and a lack of patience while listening to the other side of the debate. "Are you kidding me? You don't get to judge me. I've walked through fire."

GAME PLAN: "I read quite a few articles from people who were for and against ABA. Frankly, I knew there was a vocal movement that is against ABA and the comments defending their opinion were very passionate, but a response from a parent made me stop and reflect. 'What do we do for our child then if ABA is not the answer?'"

Last week, Mark and I had a parent conference with our son's behavioral therapist to discuss his progress and the way ahead. I noticed some of her techniques helping Broden's attention at the table were really creative and helpful, but I had not seen a BCBA use that approach before. She agreed, "It works for Broden, so I'm open to it. I've been reading a lot of blogs about parents who are against ABA. I'm really taking a lot of time to understand where they are coming from because they deserve to be heard."

She also told me there were quite a few people with autism that have been vocal about how ABA can be considered inhumane to the child. At the end of the parent session, she said, "This is what I do. I believe in it, but I also am willing to listen and learn. My goal is to work with Broden and take time to realize what he is telling me even if he isn't using words." I liked what I heard and reiterated my opinion about making sure the team that works with your child is the right fit. I've told her I'm "that crazy obsessive mom" and she continues to work with me anyway.

Later that day after our parent session, I visited quite a few blogs and read articles from people who were for and against ABA. Frankly, I knew there was a vocal movement that is against ABA and the comments defending their opinion were very passionate, but a response from a parent made me stop and reflect. “What do we do for our child then if ABA is not the answer? We were always told that ABA was what our child needed. Now you’re telling me we are hurting our child. What do we do then? Our child needs help.”

This response hurt because I could feel his desperation. It’s tough enough being a parent, but raising a child with special needs is beyond tough. You research, you put a plan in place, hoping for the best to only be told that your plan wasn’t the right choice. You’re racing against the clock because you’re also told that early intervention is key. Then you’re told that you chose the wrong path. You can’t go back in time. You can only move forward. I felt for this parent. I rested my elbows on the desk and put my hands on my face. He doesn’t need to be told he did it wrong. He needs to be reassured that he has the power to make sure it’s right for his child. We need to stop judging each other and instead, reinforce the fact that we all need to keep doing the best we can as parents.

> “I felt for this parent. He doesn’t need to be told he did it wrong. He needs to be reassured that he has the power to make sure it’s right for his child. We need to keep doing the best we can as parents.”

As far as ABA is concerned, if it works for your child, then keep your child in the program. If it doesn’t work for your child, then either continue to look for an ABA program that will work with you and your child, or reach out to parent support groups that can provide some other options. ABA can work if your child is thriving and you are involved in the process every step of the way.

What team am I on? I’m on everyone’s team. We’re writing the parenting manual as we go, and the only way we can ensure that we are doing the best we can is to listen to our heart, our gut, and be cognizant of what our child is trying to communicate to us, may it be through words or behavior. I don’t care what anyone else says, we know our children better than anyone and we, as their parents, have their best interest at heart, autism or not. •

PUZZLES & CAMO

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

ADAPTIVE/SPECIAL NEEDS BEDS

KAYSERBETTEN

P: 800-574-7880
E: ruthann@kayserbettenus.com
W: www.kayserbettenus.com
KayserBetten beds ensure special needs children are in a safe secure adaptive health care special needs bed.

CHILD CARRIERS

FREELOADER CARRIERS

W: www.myfreeloader.com
E: contact@myfreeloader.com
Lightweight, compact & portable, these child carriers allow parents to hike, travel, adventure and enjoy parenthood without boundaries.

CLEANING/SANITIZING SOLUTIONS

BANTEC SANITIZING

www.bantec.store.com
Easy to use disinfecting products and safe, environmentally friendly hygiene strategies that are efficient and cost effective.

FINANCIAL PLANNING/ ESTATE PLANNING/ INSURANCE

MASS MUTUAL SPECIALCARE

www.massmutual.com/specialcare
Financial planning products and services by a company that cares.

FINANCIAL PLANNING/ EDUCATION

THE AMERICAN COLLEGE OF FINANCIAL SERVICES

www.theamericancollege.edu
A private college focused on professional training for financial practitioners

NON-PROFIT

IRENE AND ERIC SIMON BRAIN RESEARCH FOUNDATION

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

HOME ADAPTATION/DESIGN

LJS ELECTRIC

www.ljselectric.com
Home automation products and devices professionally installed.

SCHOOLS/CAMPS/RESIDENCES

THRESHOLD PROGRAM AT LESLEY UNIVERSITY

Cambridge, MD
W: www.Lesley.edu/threshold
P: 800-999-1959 ext. 8181; or 617-349-8181
E: threshold@lesley.edu
A two-year, on-campus college experience for students with diverse learning challenges.

SUPPLEMENTS

AVMACOL

P: (888) 886-6442
E: media@nutramaxlabs.com
W: www.Avmacol.com
Avmacol's exclusive Sulforaphane Production System® delivers the support your immune and detox systems need to thrive in the modern world.

SPECIALIZED MUSIC PROGRAM

PIANO FOR SPECIAL NEEDS

W: www.pianoforspecialneeds.org
E: QandA@pianoforspecialneeds.org
Piano for Special Needs is a unique and simple program of math based tonal sequences played on a piano or electronic keyboard. Exceptionally beneficial for children and adults of all ages.

Coronavirus Disease 2019

COVID-19

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

How Do You Practice Social Distancing?

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

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

www.tricare.mil/coronavirus