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MAGAZINE
JUNE 2020
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EP's SUMMER ISSUE:

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RICK RADER, MD:

THE RITES *and* RIGHTS OF SUMMER

RYAN NIEMILLER, THE CRIPPLE THREAT:

A POSITIVE & FUNNY GUY

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Information and Support for the Special Needs Community

VOLUME 50 ISSUE 6 ▪ ESTABLISHED 1971

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

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or toll free: 800-372-7368 ext. 234

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

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

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— Rick Rader, MD

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CARRY THAT WEIGHT: A photo taken at Camp Jened in a scene from *Crip Camp: A Disability Revolution.* The camp became the incubator for social change, social justice, and social inclusion.

The Rites and Rights of Summer

The disability leaders who got their first taste of "so this is what it feels like" at Camp Jened were motivated to change the world. And though it took almost two decades of persistence, fortitude, and a "storm the castle" backbone, it resulted in the passage of the Americans with Disabilities Act.

"The summer sun was not meant for boys like me. Boys like me belonged to the rain."

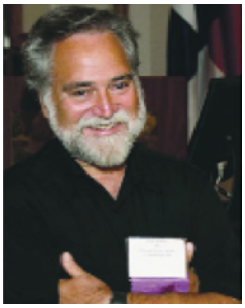
– Benjamin Alire Saenz

Growing up as a kid in Brooklyn it seemed I always worked.

Right up through high school I had jobs as a baby-sitter, I shoveled snow in the winter, made coffee runs at a beauty parlor, bused tables at a delicatessen, worked behind the grill at a hotdog stand (acne came as an occupational hazard), and sold used comic books at our bungalow colony.

In college my horizons blossomed. I cleaned jet planes at Kennedy Airport, stocked the vending machines at our college snack bar, trekked out to San Antonio, and worked at their World's Fair (Hemisphere 68) at a Belgium waffle stand, and conditioned leather saddles and bridles at a local riding academy.

But when it came to me, the summers were the sweet spot for work. There was this great opportunity to spend the summer at an idyllic, serene, lakeside setting, meet girls, play sports all day, and get a bed and food thrown in – all in the hope of getting a nice tip at the end. It was summer camp, and not just "camp," but "sleep-away camp." We got paid about $80 for spending two months as counselors in a number of camps in "upstate" New York. We lived in wood bunks with about 12 "campers." We were responsible for supervising, coaching, disciplining, counseling, overseeing hygiene, insuring letters were written home, and making sure everyone got to play.

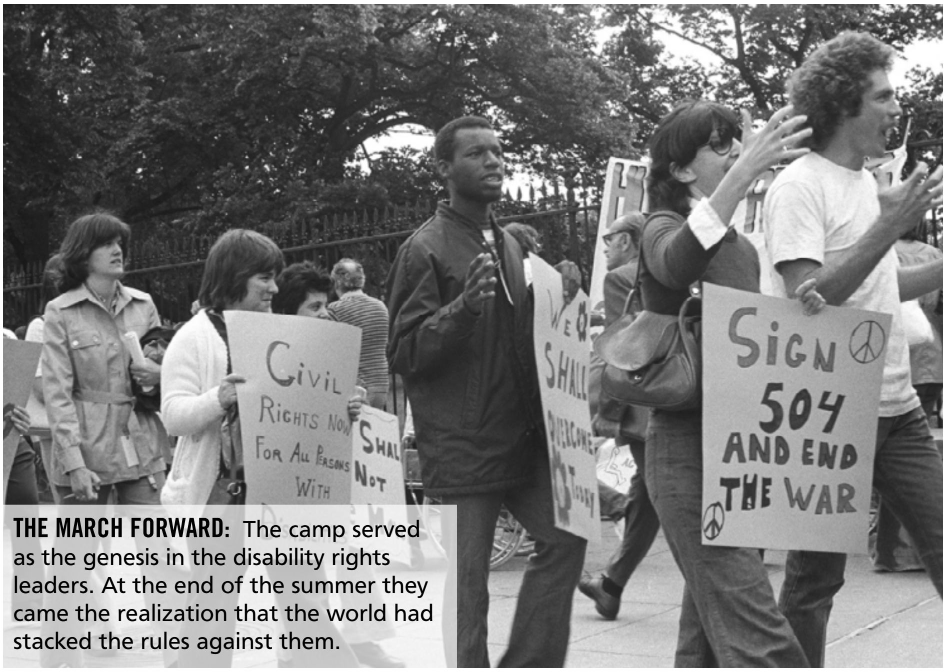


The "sleep-away camp" movement had its origins in the 19th century social reformers seeking to give a reprieve to children living in the squalid conditions of industrializing cities. According to Jeri Zeder, "These fresh-air programs blended spiritual, educational, and recreational components." The camp movement flourished and specialty camps sprang up. There were Christian camps, Jewish camps, sports camps, Boy Scout camps, sailing camps, science camps, equestrian camps, YMCA camps, arts/ music/drama camps, language camps, and space camps.

The names of the camps, their reputations, their accommodations and supporters began to replicate the competition and prestige of elite colleges. Many of the camps were operated by the same families for generations. There was Camp Unirondack, Camp Kinder Ring, Camp Pathfinder, Camp Beaverbrook, Camp Agawam, Camp Tecumseh, Camp Wyandot, Camp Delmont, and hundreds of others.

As counselors, we were often given special instructions by the parents on the day the kids were dropped off at the beginning of the camp season. "Be sure he learns how

PHOTO COURTESY STEVE HONIGSBAUM/NETFLIX



THE MARCH FORWARD: The camp served as the genesis in the disability rights leaders. At the end of the summer they came the realization that the world had stacked the rules against them.

to swim," "We would like him to get out of his shell," "Make sure he stops biting his nails," "See if you can keep him from squeezing his pimples," "He needs to lose weight," "He should learn to dance," "He won't tell you but he hates playing the outfield." One of the main messages we got was the subtle message of "Please make sure our child is included." And, to the best of our 18- and 19-year-old maturity, we did. After all, we were looking forward to "Palm Sunday," the last day of Camp when the parents would show their appreciation for our mentoring.

Looking back at those several camping seasons, I don't recall any of the campers having any disabilities. The only assistive medical devices we saw were eyeglasses, braces on teeth, and the occasional sneaker insoles. A few of the campers had bee-sting allergies and one would stutter if he became nervous. No one had diabetes, no one had movement disorders, sensory disorders, emotional or behavioral disorders (other than being spoiled rotten and entitled), communication deficits, there was not a wheel chair in sight, no seeing-eye-dogs, canes, crutches, walkers or anything that was employed to assist in inclusion. Just bunks of healthy city kids…challenged with having the time of their lives.

Nothing about the camps I worked at compared to Camp Jened.

Camp Jened was a ramshackle camp in the Catskill Mountains outside of New York City. It was a camp for the "handicapped." a camp staffed by long-haired, pot-smoking hippies who didn't have a clue about people with disabilities. A camp staffed by guys and girls who needed a summer job. A staff that had no specialized training, no preconceived impressions or expectations, a staff that had one goal, which was to give the campers the time of their lives (the same goal that every counselor at every camp had). In addition to a memorable summer vacation for campers with a multitude of disabilities, the camp became the incubator for social change, social justice, and social inclusion.

Crip Camp: A Disability Revolution is a documentary film about the 1971 camp season at Camp Jened. It shares the daily activities, relationships, awakenings and resolutions of both the campers and the counselors. It shows how untrained teenagers (the counselors) relied on their sense of fair play, equality, intuition, and values changed the way people with disabilities could and should be viewed.

The campers were held to high standards by the staff (who apparently lived their own lives with high standards). If they got tagged out running or crawling to first base, they were out; no do-overs. If their marshmallow fell off of the stick and into the fire, they had to wait to see if there was another one, or get one from a friend. If a girl refused to dance with them, they had to suck it up. Inclusion didn't always look like a Hallmark card. The campers had the freedom and the opportunity to bitch about their parents being overprotective, trying new things and failing and, most of all, calling the shots on how they wanted to spend their time and with who… a concept we call "choice," that has historically been denied to people with disabilities.

Crip Camp served as the genesis for leaders in the disability rights movement. At the end of the summer came the realization that this camp, this "carve out camp" which gave them the taste of how life could and should be, would not follow them back into the city. Back to the world where they would not have a "choice," and that society had stacked the rules against them.

The disability leaders who got their first taste of "so this is what it feels like" at Camp Jened were motivated to change the world. And though it took almost two decades of persistence, fortitude, and a "storm the castle" backbone, it resulted in the passage of the Americans with Disabilities Act.

While I am not the first to celebrate the work, accomplishments and outcomes of these untrained staff, it comes with the realization that, at the time, there were no trained and educated disability support staff.

Their preparation for their success came from the way they lived their own lives, in a natural, open-horizons, self-determined path. So while I continue to create training curriculum, spend countless hours training new and seasoned staff, and evaluate the data resulting from ongoing training programs, perhaps we need to incorporate a bit of their ownership of simply thinking, "Let's give them the time of their lives."

My own take-home message from Crip Camp is, marshmallows are bound to fall off the stick; make sure the stick is sharp! •

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

PHOTO COURTESY HOLLYNN D'LIL/NETFLIX

WHAT'S HAPPENING

YOUTH WHO UNDERSTAND MENTAL ILLNESS MORE LIKELY TO ASK FOR HELP LATER

Research suggests destigmatizing mental illness in schools could increase the likelihood of treatment-seeking for youth who need it.

Because attitudes toward mental illness are typically formed early in life, ensuring youth receive education about mental illness and stigma could also be key to ensuring they pursue treatment for their own mental-health problems.

With this in mind, a team of researchers led by Bruce Link, a professor of sociology and public policy at the University of California, Riverside, has developed and tested a new curriculum for sixth graders geared toward destigmatizing mental illness.

The curriculum has shown promising results, suggesting that improving how youth view mental illness could have positive effects on how likely they are to seek mental-health treatment.

In an article published this month in the journal Pediatrics, the researchers discussed the findings of an evaluation of the curriculum's efficacy during a two-year, randomized trial involving 416 sixth graders in 14 schools across an urban district in Texas.

The curriculum, called Eliminating the Stigma of Difference, or ESD, consisted of three modules delivered over three hours in one week, with each module comprising a didactic component, group discussion, and homework exercises.

The first module broaches the concept of stigma, its consequences, and how to end it. The second and third modules introduce specific mental disorders, including attention-deficit hyperactivity disorder, anxiety disorders, depression, schizophrenia, and bipolar disorder.

"The intervention was developed for ease of use by teachers in school settings so that it can be used anywhere there are schools," Link said of the curriculum. "It emphasizes increasing knowledge about mental illnesses and increasing empathy for people who are different in any way, including those who have a mental-health problem."

Students in the researchers' trial received the ESD curriculum from their physical education teachers in 2011-12, with the researchers conducting follow-up assessments at six-month intervals over 24 months.

They compared the impacts of ESD with those of a no-intervention control and two other interventions — one involving in-class presentations by two young adults with their own histories of mental illness, and one that saw the sixth graders read anti-stigma printed materials.

When comparing their ESD curriculum with the control and two other interventions, the researchers found exposure to ESD significantly boosted students' knowledge of and attitudes toward mental illness. Exposure to the curriculum was also associated with a decrease in "social distance," meaning youth reported being more willing to interact with someone identified as having a mental illness.

PROBLEM SOLVING: "This study shows that a school-based intervention in sixth-grade youth can improve attitudes towards mental illness and increase appropriate treatment-seeking in youth with mental-health problems," said Bruce Link.

Perhaps most important, receipt of ESD was associated with an increased likelihood of treatment-seeking for youth with high levels of mental-health symptoms. The same result, however, was not found for youth with lower levels of symptoms.

"The stigma of mental illness is a powerful barrier keeping children from receiving the help they need," Link said. "This study shows that a school-based intervention in sixth-grade youth can improve attitudes towards mental illness and increase appropriate treatment-seeking in youth with mental-health problems."

*Click here to read the full story (*a PDF of the Pediatrics article is available upon request*):* **https://news.ucr.edu/articles/2020/05/26/youth-who-understand-mental-illness-more-likely-ask-help-later**

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WHAT'S HAPPENING

BOKS AND SPECIAL OLYMPICS PARTNER TO ENHANCE PHYSICAL ACTIVITY FOR CHILDREN OF ALL ABILITIES

BOKS, an initiative of the Reebok Foundation, and Special Olympics, have announced a multi-year collaboration to enrich BOKS' physical activity program with inclusive strategies for kids engaged in physical activity and fitness. This collaboration will allow Special Olympics and BOKS to get more kids active and improve their physical and emotional well-being.

Globally, 16% of Special Olympics athletes eight to19 years old are obese and 15% are overweight. In the United States, 32% of Special Olympics athletes eight to 19 years old are obese and 15% are overweight. The obesity rate of Special Olympics athletes in the US is nearly twice that of the obesity rate in the general population among children and adolescents of the same age. Due to a lack of training and knowledge of working with people with ID among health and fitness professionals, these children might be overlooked when it comes to having the opportunity for fitness and play. BOKS and Special Olympics have joined forces with a shared vision to get youth with and without intellectual disabilities (ID) more active and establish a lifelong commitment to health and fitness.

ON THE MOVE: "This is a wonderful opportunity to encourage inclusion and get youth with and without intellectual disabilities moving and beginning a lifelong commitment to their health," said Dr. Alicia Bazzano, Chief Health Officer of Special Olympics.

To celebrate this collaboration, in May, Special Olympics athletes joined BOKS in its efforts to deliver at-home physical activity to families and kids during COVID-19.

Britney Bautista, Special Olympics United States Youth Ambassador shared her excitement for the new partnership, "Our partnership with BOKS allows more youth to have the chance to be physically active. Inclusive physical activity opportunities are important to me because they can strengthen relationships with families, athletes and teammates. Daily exercise can improve your energy level, help you stay more focused in school, and help build a more positive mindset. The most important part of inclusion is allowing Special Olympics athletes to be in the spotlight and show his/her capabilities. Everyone should be included and celebrated!"

Special Olympics U.S. Youth Ambassadors are a group of 23 youth leaders with and without intellectual disabilities who are striving to make the nation a more inclusive place for all. These youth leaders act as advocates, share stories, and demonstrate the values of inclusive youth leadership across the country.

BOKS provides a program based in functional fitness and play that anyone and everyone can engage in, regardless of age or skill, and is currently run in many different inclusive environments throughout the United States. Working together with Special Olympics, the team will offer this programming as an additional fitness opportunity in 7,600 Special Olympics Unified Champion Schools® (SOUCS), especially the elementary schools. SOUCS is a program for schools, Pre-K through university, that intentionally promotes meaningful social inclusion by bringing together students with and without intellectual disabilities to create accepting school environments.

Special Olympics improves the fitness of athletes by providing tailored tools for individuals, families, and Special Olympics Programs. Physical activity, adequate nutrition and hydration enhance athletes' performance and improve health and overall quality of life. By working with BOKS and incorporating facets of their movement skills and nutritional tidbits into what already exists, the two programs become even stronger together.

"We don't have many fitness opportunities specifically targeted to elementary school students, outside of our Young Athletes program, which is an early childhood play program geared to children with and without intellectual disabilities aged two to seven years old." said Dr. Alicia Bazzano, Chief Health Officer, Special Olympics. "By partnering with BOKS, we are continuing to expand the reach of our fitness and physical activity opportunities offered in schools to youth around the world and are able to reach their network of 5,500 schools with a curriculum that is more inclusive of all students. This is a wonderful opportunity to encourage inclusion and get youth with and without intellectual disabilities moving and beginning a lifelong commitment to their health."

To sign up to receive the full inclusive BOKS curricula enroll here:
www.bokskids.org/enroll-school

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

NEW PRODUCTS

SUMMER DAYS

WEIGHTED DISC BLANKET

The Weighted Disc Blanket is a colorful, easy to clean weighted blanket. It is a sensory tool for classrooms and clinics that can be wiped clean between uses. Users can drape it across the lap, back or trunk while sitting, reading, doing school work, or during therapeutic activities. The weight has a grounding effect, helping to calm, focus or increase alertness. Pellet-filled discs are sewn together for uniform weight. This weighted blanket provides proprioceptive input to body and joints to help children calm and attend. Supports children with autism, ADHD, and sensory integration disorder. Suitable for children weighing 80 pounds. Dimensions: 30 inches x 30 inches. Weight: 8 pounds. Made of polyurethane fabric, weighted with polypropylene pellets. Colors: red, orange, yellow, green, blue, and purple.

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Feel Good Glenn is a singing teddy bear who makes everyone feel better by singing and dancing to the song “I Feel Good” when users activate their capability switch. It is designed to increase visual attention, and teach cause and effect. Glenn comes dressed in hospital scrubs with an embroidered stethoscope. Works with or without a switch. Size: 8 inches x 9 inches x 11 inches. Weight: 1 pound. Battery requirement: 3 AAA.

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The Disney Mickey Mouse ABC-123 Nesting & Stacking Blocks features brightly colored Disney characters that illustrate numbers, letters, and words on sturdy cardboard blocks. These 10 nested blocks fit into a durable case. When stacked, these blocks form a tower nearly 3 feet high! The blocks feature letters, numbers, and full-color artwork. The reusable storage box can also be used for stacking. This set of stacking block promotes fine motor skills, number and letter recognition, and matching and sorting skills. Suitable for ages and 2 and up.

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NEW PRODUCTS

BRODA ASPIRE PEDIATRIC GLIDER

The Broda Aspire Pediatric Glider is designed for the seating and behavioral needs for children ages 3 and up who require sensory input and special assistance for learning, focus, and behavioral issues. The Aspire helps enhance children's ability to learn and safely engage in activities by providing a soothing gliding action for reduced anxiety, increased concentration, and better overall contentment to help children achieve success. It is designed for active or calming seating. The gliding movement provides sensory stimulation when desired or it can be utilized to soothe when the child needs a break. The Comfort Tension Seating® contours to the body for an individualized fit combined with soft foam padding that gently cradles each child providing a comforting effect. A stable base combined with an auto-locking feature provides user safety and caregiver peace of mind. Can be used for classrooms, multi-sensory or quiet rooms, therapy centers, hospitals, outpatient, or home use.

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SPINNYPINS

SpinnyPins is a game for young children that encourages fine motor skills, sensory exploration, early experimentation. This game features wobbly bowls with slots for sorting textured, wobbly pins. The pins fit into bowl either upside down or right side up. The pins feature two types of surfaces: smooth and coated with unique textures. Each of the five colorful pins features fascinating textures to feel plus a weighted base that wobbles wonderfully. Fit them into the slots of the big bowl either upside down or right side up, matching the colors. On the bottom of the bowl is a bump that keeps it constantly tilted and inside is hidden a delightful chime. Set includes 5 pins and a bowl. The pins measure 3. 75 inches tall, 2 inches in diameter. The bowl measures 7.5 x 7.5 x 3.25 inches.

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

Are You at Higher Risk for Severe Illness?

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

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

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

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

Here's What You Can do to Help Protect Yourself

Stay home if possible.

Wash your hands often.

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

Clean and disinfect frequently touched surfaces.

Avoid all cruise travel and non-essential air travel.

Call your healthcare professional if you are sick.

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

cdc.gov/coronavirus

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HEARTSIGHT CHRISTINA LLANES MABALOT

Advocacy During Covid-19

Promote collaborative engagement and act now. Get and keep connected with as many people, organizations, and groups as you can handle.

By the time this column is published, it will have been three months since the Centers for Disease Control and Prevention (CDC) released the guidelines for isolation and social distancing. While I wish this period is just a nightmare from which we can all wake up, or a free trial for quarantine which we can cancel, our current situation, perhaps with some modifications, could be our "new normal."

Several good things have resulted from our strange situation, don't get me wrong. Most of society has united to fight the virus. Families enjoy more bonding time, and parents are once again the decision-makers for their children's education. The air is cleaner. There is a substantial amount of home improvement. Our resilience has increased, as evidenced in a lot of recent comic relief posts and videos on social media. Most impressive is the reinvention of socialization and events. Students study and interact in visual classrooms. Newborns are introduced to the family through video chats. Weddings and special events are conducted live on Facebook, family reunions on Zoom, and so on and so forth.

These marvels pale, however, in comparison to the ravages of the pandemic. Unimaginable tragedies include numerous Covid-19 cases and deaths, a global recession, political upheavals, an astounding increase of psychological and mental cases, domestic violence, divorce, and others. Overlooked in the chaos is our special needs community, stuck in a mire, unable to move to the so-called new normal, and regressing, in our vision, towards our goal full inclusion.

The following is some disturbing information I've gathered over the past months.

Employment: Several people with special needs have lost their jobs. Since small businesses and non-profit organizations are mostly closed, their employees with disabilities have been furloughed indefinitely. I know a blind person with some health complications who was honorably dismissed by his employer of 15 years due to his vulnerability to Covid-19.

While the loss of employment is a situation that is normal across the board, society needs to understand that our circumstances can be more complicated. People with disabilities are one of the most marginalized minority groups in terms of employment numbers. Competing with the 28 million unemployed people without disabilities to land a job during this pandemic would be practically impossible for our sector. Individuals who were allowed to work from home seem to have been blessed. Still, at such short notice, workers with disabilities haven't been effectively set up and transitioned for remote work. Consequently, several employees don't have adequate support and resources that used to be available in the office. Such needs may include adaptive technology and equipment, office modifications, or a safe and operational space for optimum productivity.

> "Overlooked in the chaos of this coronavirus pandemic is our special needs community, stuck in a mire, unable to move to the so-called new normal, and regressing, in our vision, towards our goal of full inclusion."

Social distancing and isolation: In general, the guidelines on social distancing have not been reasonable for the majority of persons with special needs. For example, a person with intellectual or behavioral disabilities who can't get a hug of affirmation from a personal caregiver may develop anxiety. It is also challenging for them to understand all the new rules and changes that are suddenly imposed. Among adults living by themselves, loneliness is predominant, and video-conferencing with a therapist or a family member may just not provide consolation.

The life-sustaining, hands-on assistance is suddenly limited or unavailable to several individuals who rely on it. This may be caused by a variety of reasons related to the pandemic, such as the person may be infected, or transportation isn't available, or the staff is no longer allowed to provide personal care. Unfortunately, setting up services with an alternate caregiver would take forever because of system policies. Another factor to consider is the difficulty in maintaining standards of hygiene during home visits to protect both the staff and the individual.

We, the blind or visually-impaired, have lost our freedom to touch and carry on decent conversation with the six feet distance requirement between individuals. I'm not even allowed to hold on to my husband's arm in public. The fear of missing out might get us before the virus does.

Hearing-impaired individuals can no longer lip-read, with masks or respirators covering a person's mouth. With the lockdown, interpreters wouldn't be readily available when they're needed.

Transportation: Limited or unavailability of public transportation has far-reaching consequences for the majority of the non-driving people with special needs and care providers. Mobility to places for doing essential business isn't accessible, posting a threat to survival. Neighbors are less likely to offer transportation, and ride-sharing—which easily became the most accessible transportation for people with disabilities—has become scarce, expensive, and risky.

CHORUS FOR CHANGE: At this crucial time, our greatest strength is our community, and advocating together should be the order of business to get people with disabilities unstuck. While one voice can make a difference, many voices together can create a movement for change.

Education: Overall, families of children with special needs are overwhelmed with the changes and disruptions. With schools, service providers, and support systems closed, parents find themselves assuming multiple full-time roles of special education teachers, caregivers and therapists, on top of their jobs, that is, if they still have one. Throw into this confusion crucial responsibilities like running to the grocery stores to stock up on essentials, making sure medications are adequate for a good while, setting up online learning, household management, and protecting the family from the virus. Students are sent home with their learning packets, but for the most part, parents of children with IEP or 504 plans barely have support and resources to conduct the lessons. Eventually, the children may lose the knowledge and skills they worked so hard to gain. Individuals who rely mainly on routine and structure, like those with autism spectrum disorders, may have more frequent meltdowns, consequently escalating emotional problems. On the other hand, parents with special needs may not be technologically equipped to guide their children through virtual classes at home.

Healthcare, service providers and congregate facilities: Generally, health and wellness support systems are not available during the lockdown, and may not be feasible to be conducted through the phones or the internet. Several group homes and residential institutions have closed, thus sending residents back to their families who don't have the time or means to properly care for them. This situation posts the potential breakdown of household units. Meanwhile, residents of institutions that have remained operational are exposed to higher risks of contracting the virus.

Civil rights violations: The ugly reality is that some individuals with special needs who have contracted the virus have been denied the treatment they deserve because of medical rationing. In hospitals where there are more Covid-19 patients than can be attended, healthcare practitioners follow guidelines as to who gets care first, and persons with disabilities are not in the list. Hospitals implement a "no visitors" policy, and there are no accommodations for the unique needs of patients with disabilities, like interpreters, sighted guides, readers, note-takers, or personal care providers, which are vital to medical visits.

These are just a few among thousands of paralyzing situations in our new normal, and we cannot go on this way. Unfortunately, our government and private voluntary organizations, also swamped with never-ending emergencies and crisis-management tasks, may not be there to help alleviate our situation.

OUR BROTHER'S KEEPER

At this crucial time, we are our brother's keeper, and our greatest strength is our community. Advocating together should be the order of business to get people with disabilities unstuck. The word "advocacy" is derived from the Latin words ad and voce, meaning towards having a voice. While one voice can make a difference, many voices together, in harmony, can create a movement for change. Since not every individual with special needs can speak up, I appeal to those who can, whether for yourself or for a family member, to help the rest of the community navigate to the future we face. Socrates said, "The secret to change is to focus all of your energy, not on fighting the old, but on building the new."

The first step is to know your rights, don't just accept what institutions tell and give you. However, you can't advocate for something you don't know. Look into **www.ndrn.org** where you'll find disability rights for every state about healthcare, education, employment, and those relevant to this pandemic for persons with special needs. Be alert and report discriminatory practices that impact people with disabilities. If you see something, say something. Email your state advocate, congress representative, senator, and everyone in your network who needs to know your situation.

Get informed and share information. Check into all websites for your specific disability. For the blind and visually impaired, the sites are **NFB.org**, **ACB.org**, and **AFB.org**. If you can, listen to podcasts. I recommend Disability Matters with Joyce Bender, where I get a lot of information.

Promote collaborative engagement and act now. Get and keep connected with as many people, organizations, and groups as you can handle. Groups don't need to be formally organized. You can set up a group chat with parents, families, and other individuals with disabilities. Make it a communication hub to check on and encourage each other, share information, issues, or challenges, mobilize support, and promote possible changes. For example, if you know of a software, an app, learning resources, or adaptive equipment that would be helpful, put out that information. Set up a watch party for videos while interacting with your network. If you, or someone has an idea to create something, solicit the support necessary to develop this innovation. Inspire everyone to do a little bit more for the community every day, even if it is simply sharing cheer, or a new teaching trick, or a reward system you've discovered that works for your child.

Community members who are unemployed might want to look ahead in building the new technology-based society. If there's one thing that's certain during this unchartered time, it is our world abruptly transitioning to a virtual one. If your expertise is Information Technology, then, you're almost there. Look for a niche and develop new services you can offer. If you're not technologically adept, now is a good time to learn. Search for gaps that you can fill, or why not start in the special needs community? Some suggestions are: the virtual transformation of community-based activities, making materials accessible online, interactive learning videos or games, tutorials for parents and children, homeschooling tips, videos for physical, mental and emotional wellness, circle time activities relevant to distance learning, and calming or relaxation activities for parents and children. Another suggestion is partnering with agencies to start a hotline for various situations and counseling.

> "Inspire everyone to do a little bit more every day, even if it is simply sharing cheer, a new teaching trick, or a reward system that works for your child."

There's also a variety of business opportunities for people who are gifted with arts and crafts. Look along the line of masks, gloves, protective apparel, and accessories that would help people avoid contact with others while conducting daily transactions. Meanwhile, diligently search for openings in the job market and consistently submit applications, at least two every week. While searching, identify a field that is on demand and, if possible, get certified for the necessary skills.

For parents, take time to help your child understand the changes as well as the new rules for hygiene and social distancing. Introduce a structure or routine for your kids to settle in the new normal. If teachers aren't able to provide a system of delivering accessible content online, work instead on projects or activities that you and your child will enjoy doing together. You know how your child learns best, so use learning methods that have worked in the past. In fact, your child might enjoy self-learning and reading on things that interest him. Keep in mind that maintaining emotional health and essential skills are the immediate priority. Don't allow yourselves to get a caregiver burnout. Set up regular schedules for breaks and relaxation. You need to maintain wellness to properly care for your child. Identify a mentor or someone to whom you could vent your frustrations.

Individuals who need direct support care workers should reach out to their local centers for independent living. They can also ask family members or friends who are willing to provide support. Think of other ways your needs can be met. Also, always set up a back-up plan in case all else fails.

In the meantime, don't stop corresponding with your local, state and federal authorities. We who have less privileges in society should have more laws in place. Let's take courage to face this global catastrophe. After all, there's no telling when or if this will ever be over. We do not know what recovery will look like. Everything's uncertain, except what we choose to focus on. A crisis always brings out the worst and the best in human beings. If we focus our energy on opportunities for growth, we would have reset for the better when the disruption is over (or if it becomes the new normal). We all cope differently, but we can move forward together if the strong among us support the weak. We are a resilient people and adaptable to trying times, because this has always been the story of our lives. Let us strive to be the voice of our special needs community.•

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. Visit leadershiptovision.com

What Are We Learning?

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

WHAT WILL HAVE BEEN LEARNED ABOUT INDIVIDUALS WITH SPECIAL NEEDS IN A WORLD OF COVID-19?

> *"The COVID-19 crisis (has) a potentially far-reaching, long-term negative impact on children around the world. More than 1.5 billion students (are) out of school. Widespread job and income loss and economic insecurity among families (are) likely to increase rates of child labor, sexual exploitation, teenage pregnancy, and child marriage. More than 91 percent of the world's students (are) out of school, due to school closures in at least 188 countries. Experts estimate that the global total of COVID-19 deaths could eventually (reach) 10 to 40 million, which inevitably (will leave) many children without one or both parents or other caregivers."*[1]
>
> *"While social distancing (has) been widely promoted as the best strategy to avoid transmission, that advice may not (be) realistic for people who care for children and youth with disabilities who may require therapy or assistance with daily tasks. Meanwhile, children's clinical services and other treatments (are) being disrupted with the closures of schools, medical settings and caregiving agencies. Families' ability to obtain critical medical supplies (are) difficult as resources (are) scarce."*[2]

In addition, while children overall seem to be less likely to show symptoms of COVID-19, those with disabilities may fall into the category of 'high risk' due to secondary health conditions; further adding to caregiver stress related to fears of infection and contagion. Should a child with a disability become sick or need medical care during the pandemic, many parents worry about rationing of care and supplies as another threat to their child's safety. [3]

As the COVID-19 pandemic unfolds, the virus sickens and kills people of all ages, races, income levels and levels of underlying health. Public health officials continue to stress that seemingly young and healthy people are vulnerable to the virus while acknowledging that it is especially deadly for older people, people with chronic illnesses and **people with disabilities.** [4] For example:

1. People with Down syndrome who have certain underlying conditions may be at risk for a more serious course of COVID-19, which can cause symptoms such as: loss of taste and smell, shortness of breath, fever, cough and digestive issues. Higher risk underlying conditions include:

- Having a hole in the heart that has not been repaired or other heart issues. (Those who have had a heart repair and are currently doing well don't seem to be as high-risk.)
- Lung or breathing issues, including asthma.
- Compromised immune system, or frequent respiratory infections, ear infections or pneumonia.
- Diabetes. [5]

2. Parents of children with disabilities are worried that federal officials would give districts claiming coronavirus hardships significant leeway to sidestep laws that ensure their children have access to education that's appropriate for their needs. [6]

3. In the time of the coronavirus pandemic, parents across the country are learning to cope with remote schooling. For parents of children with special needs, the challenges can be impossible. [7]

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.

NO ONE SPARED: Public health officials continue to stress that seemingly young and healthy people are vulnerable to the virus while acknowledging that it is especially deadly for older people, people with chronic illnesses and people with disabilities. Numerous guidelines have been put forward for public health planners, but they have not specified steps to include people with disabilities in their planning.

4. A third of the global population is on COVID-19 lockdown, and school closures are impacting more than 1.5 billion children. Movement restrictions, loss of income, isolation, overcrowding and high levels of stress and anxiety are increasing the likelihood that children experience physical, psychological and sexual abuse at home – particularly those children already living in violent or dysfunctional family situations. While online communities have become central to maintain many children's learning, support and play, it also increases their exposure to cyberbullying, risky online behavior and sexual exploitation.

The situation is aggravated by children and adolescent's lack of access to school friends, teachers, social workers, the safe space, services and reports of abuse that schools provide. The most vulnerable children – including refugees, migrants, and children who are internally displaced, deprived of liberty, living without parental care, living on the street and in urban slums, **with disabilities,** and living in conflict-affected areas – are a particular concern. For many, growing economic vulnerability increase the threat of child labor, child marriage and child trafficking. [8]

SO, WHAT ARE WE LEARNING?

> *"Beyond the threat presented to the general population, pandemic influenza poses a substantial risk to people with a disability because of (1) a lack of epidemiological data on which to base preparedness plans and evaluate responses; (2) a lack of detailed emergency preparedness plans at all governmental levels with regard to people with disabilities; (3) disability-related factors that increase risk for exposure, complications, and death from pandemic influenza; (4) inaccessibility of risk communication; and (5) ethical issues surrounding priority vaccination and treatments that affect the disability community.* [9]

There are little if any population-based data on the experiences of **people with disabilities** during emergency situations. In addition, there are sparse data on the impact of seasonal influenza and no data on the impact of previous influenza pandemics on this population. Further, while there is extensive demographic and geographic (e.g. nationally, region, state and county) information available for the **424,653 children in foster care in 2018, there are no population-based data available regarding the number of individuals with disabilities.** [10]

Without the capacity to identify people with disabilities in emergency management surveillance systems, these populations may be overlooked when interventions are planned and evaluated. However, in the past, a somewhat higher percentage of people with disabilities (36.5%) reported getting annual immunizations for seasonal influenza than did people without disabilities (32.2%). [9]

Federal agencies have conducted a review of emergency plans across the nation and found major fragmentation, inconsistencies, and critical gaps regarding populations with disabilities. Few plans or guidelines provide details about how emergency planners can meet the needs of people with disabilities before, during, and after an emergency. Current plans tend to delegate critical responsibilities regarding disability to third parties or make scattered references to people with disabilities.

The risks are greatest among:

- *Persons with severe disabilities who may rely routinely on assistance from others to perform basic activities of daily living. Many of these individuals reside in institutional settings such as nursing homes or receive support services in their homes. Such persons would face substantial difficulties when these support services would be disrupted during an influenza pandemic. (Note: According to the 2000 US Census, nearly 29% of American families include at least one person with a disability.)*
- *Residents of group homes operated by state and nongovernmental agencies.* [9]

The reality is that numerous recommendations and guidelines have been put forward for emergency and public health planners, but they have not specified steps to include people with disabilities in their planning. Such action is needed, particularly at the local level.

> “Public health planning needs to include the involvement of people with disabilities to ensure that the plans minimize preventable exposure, communicate risks effectively, and ensure continuity of essential services.”

Recommendations are available to strengthen pandemic influenza planning and response that will reduce the risks posed to populations with disabilities. They include:

- *Indicators of disability status are needed in all public health surveillance systems to assess the impact of public health threats and events on populations with disabilities so that effectiveness of planning and response can be assessed.*
- *People with disabilities, their advocates, and service providers such as home health care agencies, should be included in planning for pandemic influenza to inform emergency planners of the need for and resources to ensure adequate provisions for effective risk communication.*
- *Questions that identify people with disabilities should be included routinely in all data collection related to pandemic influenza and preparedness activities.*
- *Specific contingency plans need to be developed to ensure continued staffing for in-home and personal assistance services and congregate care supervision and care.*
- *National pandemic influenza program managers need to continue to evaluate and provide detailed feedback to state, territorial, local, and tribal emergency planners on performance with regard to their preparations for all at-risk populations.*

“Public health planning for pandemic influenza needs to include the involvement of people with disabilities to ensure that plans adequately anticipate and address these needs to minimize preventable exposure, communicate risks effectively, and ensure continuity of essential services.” [9]

REMEMBER

“1. COVID-19 deaths will likely be more prevalent among those with intellectual and developmental disability (IDD).

2. Death rates from pneumonia are between 2.2 times and 5.8 times higher among individuals with an IDD than among those without IDD, giving us a clear warning of the severity of COVID-19 among people with IDD.

3. Underestimation of COVID-19 deaths is potentially more severe for those with IDD.” [11]

WE STAND WITH YOU!

The American Academy of Developmental Medicine and Dentistry (AADMD) is a leading organization for the advocacy of people with intellectual and developmental disabilities; as well as for the education and training of their health care professionals. In the current Covid-19 crisis, two major issues have surfaced that demand immediate action to protect the health and safety of this medically underserved and marginalized population – equal access to ventilators and the ability to have a caretaker accompany them to emergency rooms. The following two policy statements will be of value for our readership, family members, advocates and health care providers in their efforts to secure needed assistance for the children and adults with special health care needs. For details on this, visit EP’s May issue: **https://reader.mediawiremobile.com/epmagazine/issues/206098/viewer?page=19** •

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COVER STORY

Ryan Niemiller says:
“Stop focusing on what you can’t do and focus on what you can do better than anyone else.”

A POSITIVE & FUNNY GUY

BY LEN HARAC, PHD

Ryan Niemiller is an impressive man and, in this author’s opinion, an inspiration to others in and out of the special needs community. Ryan, known professionally as The Cripple Threat, came to my attention after I saw him on NBC’s flagship summer series, America’s Got Talent. *I was impressed by that way he joked about his disability in such a positive way. Talking with Ryan, it became apparent that he never let his disability hold him back from anything.*

PHOTOS PROVIDED BY RYAN NIEMILLER

A Stand-Up Guy

Growing up, Ryan played baseball and football and enjoyed his self-selected role as class clown. When I asked him if he was ever bullied because of his disability, he said not really – primarily because he made jokes first and got out in front of potential comments. Although he liked the attention, he admitted that it was a double-edged sword because self-deprecating jokes had a way of hurting his self-esteem by constantly reminding him of his disability. He found it somewhat hard to deal with unwanted attention due to his disability and therefore focused on other things.

He grew up in a small farming town in Indiana. He didn't want special attention, and although it was offered in school, he preferred to work things out on his own. He took less assistance than was offered. He is a genuine, nice guy. He talked about the common practice of people offering unsolicited help because of his disability. He explained that assuming someone wants or needs assistance can be insulting. He suggested asking rather than assuming.

Ryan's entertainment career began when he was a junior at Indiana State University and took a course called Intro to Theatre. He wanted to be a professional wrestler and he thought his theatre experience would contribute to that aspiration. He found professional wrestling too physically challenging and stressful on his body, though he said disability was not a factor. After college, Ryan moved to Los Angeles where he took a class at the Ice House and learned about stand-up comedy as a possible career. That course gave Ryan the impetus to give stand-up a shot. He performed wherever he could. He stayed in L.A. for three years to hone his craft. After that, Ryan moved back to Indiana where he continued to promote his act. He worked as a stand-up for 12 years, frequently driving 12-15 hours for a gig.

Talent Revealed

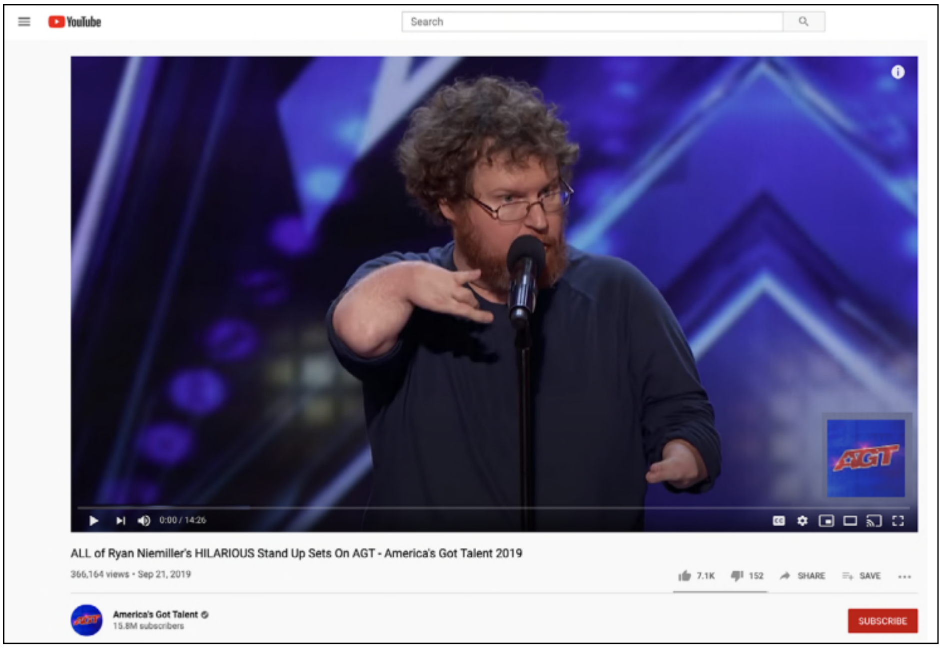
Ryan found audiences to be accepting, while bookers were reluctant due to his disability. He didn't want to be labeled a disabled comic but rather thought of as a comic with a disability. His time on the road showed him that he was genuinely funny, and audiences liked him. During most of his time as a stand-up, he had to support himself with what he describes as boring day jobs. He tried to get on *America's Got Talent (AGT)* for five years and finally got his break in July of 2019. The rest is history.

The Cripple Threat of Comedy

Despite being born with a disability in both arms, Ryan Niemiller, the self-proclaimed "Cripple Threat of Comedy" shares his views of the world from the perspective of the handicapped.

UPCOMING SHOWS

JUN 04 8:00 PM 26 ACRES BREWERY CONCORD, NC
JUN 05 8:30 PM COMEDY SHOPPE – MT. ARLINGTON MT. ARLINGTON, NJ
JUN 06 6:00 PM COMEDY SHOPPE – NEWTOWN NEWTOWN, PA



ALL of Ryan Niemiller's HILARIOUS Stand Up Sets On AGT - America's Got Talent 2019

366,164 views • Sep 21, 2019

America's Got Talent
15.8M subscribers

WELCOME SUMMER WITH LAUGHTER: Ryan's website (www.cripplethreat.com) and Youtube channel (https://youtu.be/e3KcqK-8bD8) help to keep him connected with his audience and update his fans with his touring schedule and appearances.

His tenacity is admirable. There is no quit in Ryan. His five years of calls to *America's Got Talent* took him to various locations, but it was a video submission that got him his first at bat. Interestingly, it was a video he did for a Fox show called *Laughs*. Ryan describes auditions on *AGT* as different for him because he was used to working off the energy of a crowd. The *AGT* audition had no audience but clearly, he impressed the casting director. Aside from being talented, he is an extremely positive and likable guy.

A Dream Realized

After his first show aired, his life changed. He became famous overnight. Ryan is proud to say that his family supported him throughout his career, so sharing the *AGT* success was that much sweeter. Ryan managed himself until *AGT* but with his new found fame, agencies and managers sought him out. He signed with an agency and hired a manager who was a long-time supporter. The *AGT* family image is real, with Ryan describing it as a family of sorts.

Ryan now performs all over the country and in Canada. He says being on the road is tough but rewarding. It is his dream come true.●

ABOUT THE AUTHOR:

Len Harac, PhD, is the Publisher of EP Magazine.

SUMMER
EP's ANNUAL EDITION

EXTENDED SCHOOL YEAR AND COMPENSATORY SERVICES: SPECIAL EDUCATION DURING THE COVID-19 PANDEMIC

Many families and districts are struggling with the uncertainty regarding the availability of special education services in schools this summer, or even fall. Safeguards are in place for students with disabilities during this trying time.

BY LAUREN AGORATUS, M.A.

Extended School Year and Coronavirus

At the time of publication of this issue of *Exceptional Parent*, it is unknown if any districts will be open for extended school year services during the summer. However, students with disabilities whose IEP includes Extended School Year (ESY) services should continue to receive virtual learning services, even if school buildings remain closed. The U.S. Department of Education made it clear that, "If a student who has an individualized education program (IEP) through the Individuals with Disabilities Education Act, or is receiving services under Section 504, is required or advised to stay home by public health authorities or school officials for an extended period of time because of COVID-19, provision should be made to maintain education services."[1] This includes extended school year.

If Schools Are Still Closed in Fall

There is the possibility that not all school districts will be open at once, especially in the hardest hit states like New York and New Jersey. Again, the Department of Education specified that, "To be clear: ensuring compliance with the Individuals with Disabilities Education Act (IDEA), Section 504 of the Rehabilitation Act (Section 504), and Title II of the Americans with Disabilities Act should not prevent any school from offering educational programs through distance instruction."[2]

What Families Can Do Now to Prepare

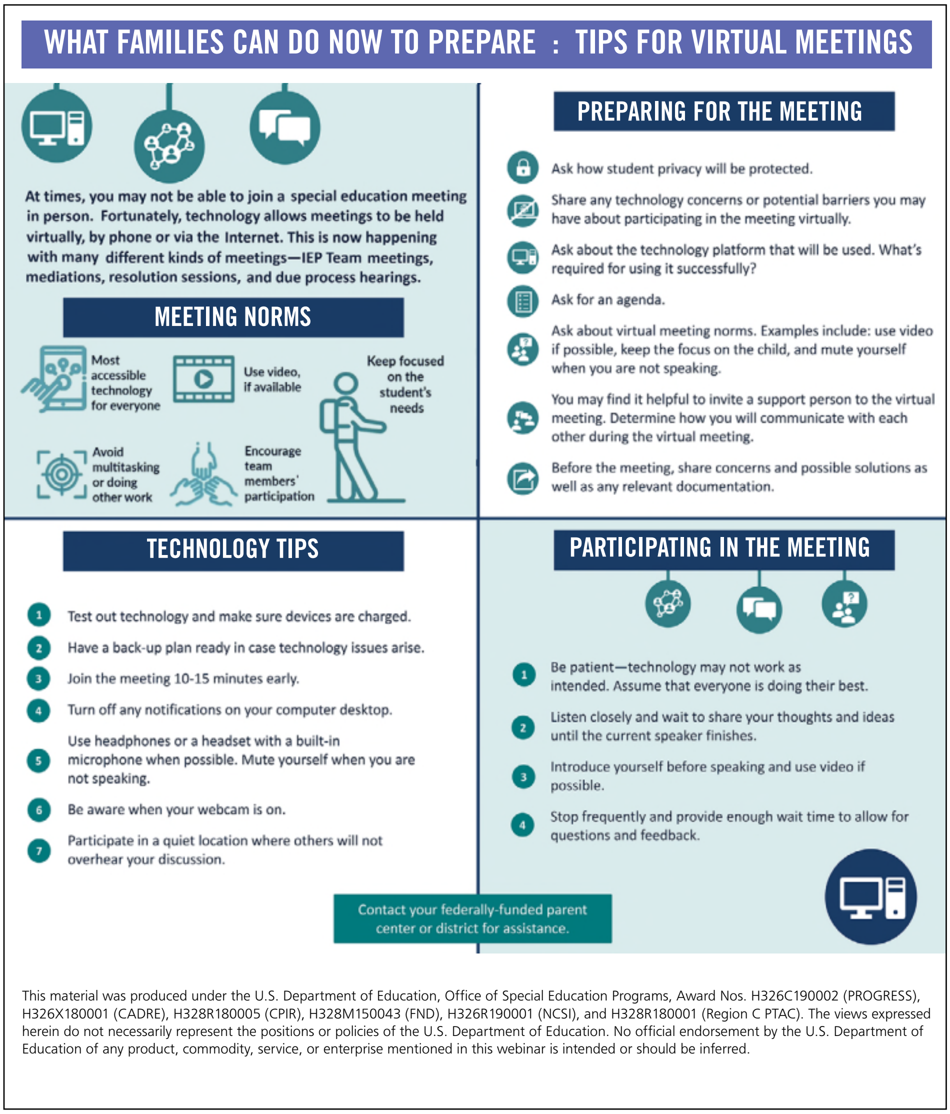
Tips for distance learning: Parent Centers throughout the country have been hearing from families on difficulties their children are having with distance learning, including regression. Some strategies include:

- ✓ *Consistent home/school communication*
- ✓ *Requesting technology devices and connectivity from the district, if unavailable at home*
- ✓ *Supporting challenging behaviors at home using positive behavioral support*
- ✓ *Identifying and using strategies to motivate the student to maximize their learning*

For more information, see Resources at the end of this article.

Tips for virtual IEP meetings: Some advocates are suggesting that families should not request formal IEP meetings because there is the risk of not obtaining services in the current IEP when schools open for in-person instruction or losing the opportunity to request compensatory services. To address this concern, parents can request a meeting to discuss temporary services that can be attached to the current IEP that contain an explicit statement that the current IEP remains in effect and that these services are merely stopgap measures to maximize the student's learning during the period of school closures. For students whose IEP dates are due for services to start in the fall, the Center for Parent Information and Resources has tips on virtual IEP meetings including:

- ✓ Sample IEP meeting agenda
- ✓ Technology help
- ✓ Tips for hosting/participating in a virtual meeting
- ✓ Infographics, including preparing for the meeting



WHAT FAMILIES CAN DO NOW TO PREPARE : TIPS FOR VIRTUAL MEETINGS

At times, you may not be able to join a special education meeting in person. Fortunately, technology allows meetings to be held virtually, by phone or via the Internet. This is now happening with many different kinds of meetings—IEP Team meetings, mediations, resolution sessions, and due process hearings.

MEETING NORMS

- Most accessible technology for everyone
- Use video, if available
- Keep focused on the student's needs
- Avoid multitasking or doing other work
- Encourage team members' participation

PREPARING FOR THE MEETING

- Ask how student privacy will be protected.
- Share any technology concerns or potential barriers you may have about participating in the meeting virtually.
- Ask about the technology platform that will be used. What's required for using it successfully?
- Ask for an agenda.
- Ask about virtual meeting norms. Examples include: use video if possible, keep the focus on the child, and mute yourself when you are not speaking.
- You may find it helpful to invite a support person to the virtual meeting. Determine how you will communicate with each other during the virtual meeting.
- Before the meeting, share concerns and possible solutions as well as any relevant documentation.

TECHNOLOGY TIPS

1. Test out technology and make sure devices are charged.
2. Have a back-up plan ready in case technology issues arise.
3. Join the meeting 10-15 minutes early.
4. Turn off any notifications on your computer desktop.
5. Use headphones or a headset with a built-in microphone when possible. Mute yourself when you are not speaking.
6. Be aware when your webcam is on.
7. Participate in a quiet location where others will not overhear your discussion.

PARTICIPATING IN THE MEETING

1. Be patient—technology may not work as intended. Assume that everyone is doing their best.
2. Listen closely and wait to share your thoughts and ideas until the current speaker finishes.
3. Introduce yourself before speaking and use video if possible.
4. Stop frequently and provide enough wait time to allow for questions and feedback.

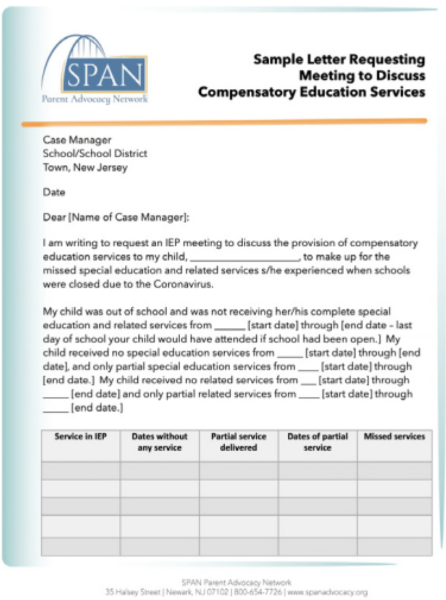
Contact your federally-funded parent center or district for assistance.

This material was produced under the U.S. Department of Education, Office of Special Education Programs, Award Nos. H326C190002 (PROGRESS), H326X180001 (CADRE), H328R180005 (CPIR), H328M150043 (FND), H326R190001 (NCSI), and H328R180001 (Region C PTAC). The views expressed herein do not necessarily represent the positions or policies of the U.S. Department of Education. No official endorsement by the U.S. Department of Education of any product, commodity, service, or enterprise mentioned in this webinar is intended or should be inferred.

What are Compensatory Services?

If a school district does not provide the instructional and/or related services in a child's IEP, teams should convene to discuss the possible need for compensatory services. Compensatory services are provided to students with disabilities to make up for services that were lost due to failure to provide those services. (This also includes early intervention.)[3]

The IEP team, or the personnel responsible for ensuring FAPE (free, appropriate public education) to a student for the purposes of Section 504, would be required to make an individualized determination as to whether compensatory services are needed under applicable standards and requirements. You can access sample letters to request meetings to discuss compensatory services at:



Sample Letter Requesting Meeting to Discuss Compensatory Education Services

Case Manager
School/School District
Town, New Jersey

Date

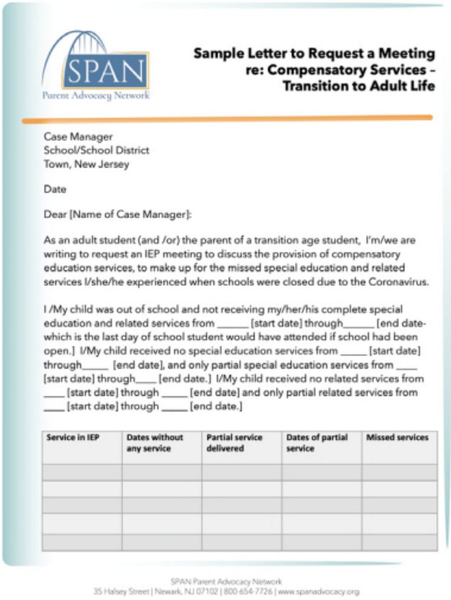
Dear [Name of Case Manager]:

I am writing to request an IEP meeting to discuss the provision of compensatory education services to my child, ____________________, to make up for the missed special education and related services s/he experienced when schools were closed due to the Coronavirus.

My child was out of school and was not receiving her/his complete special education and related services from ______ [start date] through [end date - last day of school your child would have attended if school had been open.] My child received no special education services from _____ [start date] through [end date], and only partial special education services from ____ [start date] through [end date.] My child received no related services from ___ [start date] through _____ [end date] and only partial related services from ____ [start date] through _____ [end date.]

Service in IEP	Dates without any service	Partial service delivered	Dates of partial service	Missed services

SPAN Parent Advocacy Network
35 Halsey Street | Newark, NJ 07102 | 800-654-7726 | www.spanadvocacy.org



Sample Letter to Request a Meeting re: Compensatory Services - Transition to Adult Life

Case Manager
School/School District
Town, New Jersey

Date

Dear [Name of Case Manager]:

As an adult student (and /or) the parent of a transition age student, I'm/we are writing to request an IEP meeting to discuss the provision of compensatory education services, to make up for the missed special education and related services I/she/he experienced when schools were closed due to the Coronavirus.

I /My child was out of school and not receiving my/her/his complete special education and related services from ______ [start date] through______ [end date-which is the last day of school student would have attended if school had been open.] I/My child received no special education services from _____ [start date] through_____ [end date], and only partial special education services from ____ [start date] through____ [end date.] I/My child received no related services from ____ [start date] through _____ [end date] and only partial related services from ____ [start date] through _____ [end date.]

Service in IEP	Dates without any service	Partial service delivered	Dates of partial service	Missed services

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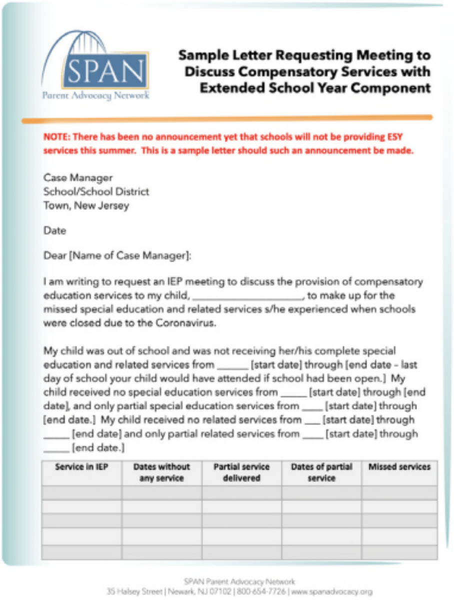

Sample Letter Requesting Meeting to Discuss Compensatory Services with Extended School Year Component

NOTE: There has been no announcement yet that schools will not be providing ESY services this summer. This is a sample letter should such an announcement be made.

Case Manager
School/School District
Town, New Jersey

Date

Dear [Name of Case Manager]:

I am writing to request an IEP meeting to discuss the provision of compensatory education services to my child, ____________________, to make up for the missed special education and related services s/he experienced when schools were closed due to the Coronavirus.

My child was out of school and was not receiving her/his complete special education and related services from ______ [start date] through [end date - last day of school your child would have attended if school had been open.] My child received no special education services from _____ [start date] through [end date], and only partial special education services from ____ [start date] through [end date.] My child received no related services from ___ [start date] through _____ [end date] and only partial related services from ____ [start date] through _____ [end date.]

Service in IEP	Dates without any service	Partial service delivered	Dates of partial service	Missed services

SPAN Parent Advocacy Network
35 Halsey Street | Newark, NJ 07102 | 800-654-7726 | www.spanadvocacy.org

MEETING OF THE MINDS: You can access sample letters to request meetings to discuss compensatory services. *(Above, left to right)*: Sample Letter Requesting Meeting to Discuss Compensatory Education Service: **https://spanadvocacy.org/wp-content/uploads/2020/05/Sample-Letter-Comp-Svs-GENERAL.pdf** ; Sample Letter to Request a Meeting re: Discuss Compensatory Services - Transition to Adult Life: **https://spanadvocacy.org/wp-content/uploads/2020/05/Sample-Letter-Comp-Svs-Transition.pdf** and Sample Letter Requesting Meeting to Discuss Compensatory Services with Extended School Year Component: **https://spanadvocacy.org/wp-content/uploads/2020/05/Sample-Letter-Comp-Svs-ESY.pdf**

Students with special needs are entitled to a free, appropriate public education. FAPE includes consideration of extended school year as well as compensatory services as applicable. •

References

1. https://www2.ed.gov/about/offices/list/ocr/docs/ocr-coronavirus-fact-sheet.pdf
2. https://www2.ed.gov/about/offices/list/ocr/frontpage/faq/rr/policyguidance/Supple%20Fact%20Sheet%203.21.20%20FINAL.pdf
3. https://sites.ed.gov/idea/idea-files/q-and-a-providing-services-to-children-with-disabilities-during-the-coronavirus-disease-2019-outbreak/#Q-B-2

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

MEETING THE CHALLENGE : DISTANCE LEARNING AND COMPENSATORY SERVICES RESOURCES

U.S. DEPARTMENT OF EDUCATION

https://www.ed.gov/coronavirus

COMPENSATORY SERVICES

www2.ed.gov/about/offices/list/ocr/docs/ocr-coronavirus-fact-sheet.pdf
www2.ed.gov/policy/speced/guid/idea/memosdcltrs/qa-covid-19-03-12-2020.pdf
www2.ed.gov/about/offices/list/ocr/frontpage/faq/rr/policyguidance/Supple%20Fact%20Sheet%203.21.20%20FINAL.pdf

SPAN PARENT ADVOCACY NETWORK

Early Intervention and Covid-19 Factsheet
https://spanadvocacy.org/wp-content/uploads/2020/05/Early-Intervention-Factsheet.pdf

Distance Learning Factsheet
https://spanadvocacy.org/wp-content/uploads/2020/05/SFS-018-20-Distance-Learning.pdf

Understood
for learning & attention issues

UNDERSTOOD.ORG

School Closing and Distance Learning
www.understood.org/en/school-learning/coronavirus-latest-updates

CENTER FOR PARENT INFORMATION AND RESOURCES

Virtual IEP Meeting Tips
www.parentcenterhub.org/virtual-iep-meeting-tip-sheets

Schooling at Home
www.parentcenterhub.org/cv19-schooling-at-home

Supporting Challenging Behaviors at Home
www.parentcenterhub.org/wp-content/uploads/repo_items/supporting-families-pbis-at-home-final.pdf

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4 Tips for Families from Occupational Therapists During the Summer of COVID-19

CONTRIBUTED BY AOTA

"The spread of coronavirus (COVID-19) has caused all of us to change routines in order to keep ourselves and loved ones safe and healthy. For parents, the challenge may be greater—juggling working from home with providing children's educational or basic needs can cause stressful situations. Fortunately, the foundation of occupational therapy, which is the promotion of engagement in daily activities for mental and physical well-being, can help families adapt and thrive.

"As we all adjust to a new 'normal,' occupational therapy is serving a critical and unique role in supporting families' adjustment to disruptions in routine and daily life," said Kelly Tanner, PhD, OTR/L, BCP, an occupational therapist at Nationwide Children's Hospital in Columbus, Ohio. "The distinct value of occupational therapy lies in the ability of practitioners to help children and their families design solutions for the challenges of everyday living."

Occupational therapy practitioners can help children and families navigate disruptions to their daily routine due to COVID-19. Here are some of the strategies that pediatric occupational therapists, including Tanner and her colleagues Grace Sagester, OTD, OTR/L, and Sara O'Rourke, MOT, OTR/L, BCP, at Nationwide Children's, recommend:

1. Participate In Meaningful Activities.

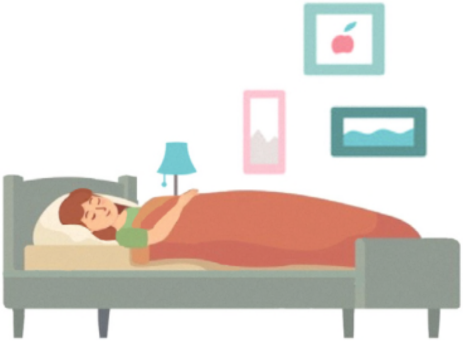
While screen time can be a valuable tool for educational purposes, remaining socially connected, and keeping in touch with family and friends, it is important to help children to build healthy habits and routines. "Take some time to do things you enjoy as a family that do not involve screens," said Sagester. "For younger children, take some time to play on the floor with them using toys they are interested in." For older children, try a family board game night or start a puzzle together.

2. Rely on Familiar Routines.

Children thrive on consistency and clear expectations. "While your day-to-day life might currently look different as a family, consider identifying or creating small, predictable routines throughout your day," says O'Rourke. "For most families, it is not feasible to try to provide your children structure throughout their entire day, as many parents continue to work from home and frequently have other roles they are balancing. Rather, try to build a familiar, comforting routine around one daily activity, such as getting ready in the morning, mealtime, or the transition to bedtime." Consider asking your child to identify what is meaningful to them during these routines, such as reading a story, helping to prepare a meal, or cuddling on the couch before breakfast.

Occupational therapy is a skilled service that focuses on facilitating development, enhancing function, and maximizing independence in all daily life activities. For children, the word "occupation" refers to play, self-care, schoolwork, and other activities that occupy a child's time.

For more information about how occupational therapy can help families, and for more tips for navigating routines, visit: **www.aota.org/About-Occupational-Therapy/Patients-Clients/ChildrenAndYouth.aspx** •



3. Take Time for Rest and Sleep.

Sleep is important for both mental and physical health. "While it may be tempting to stay up late and let everyone sleep in, try to keep your family members' bedtime and wake-up times similar from day to day," says Tanner. "If you or your children are having trouble falling asleep, consider introducing a relaxing bedtime routine." It can be as simple as "bath, brush teeth, book, bed." And remember, viewing screens before bedtime (even for "relaxing" shows) can make it harder to fall asleep.

4. Be Gracious with Yourself.

It may be easy to feel guilty as a parent for the sudden increase in screen time or lack of structure throughout your day. It is important to acknowledge that this is a challenging time for everyone, and that each family is doing their best. "Consider setting one achievable goal for the day such as going for a walk as a family, or providing words of encouragement to each child," says Sagester. "Take time to think about what went well during your day and acknowledge moments of joy as you experience them."

ABOUT THE AMERICAN OCCUPATIONAL THERAPY ASSOCIATION:

Founded in 1917, the American Occupational Therapy Association (AOTA) represents the professional interests and concerns of more than 213,000 occupational therapists, assistants, and students nationwide. Occupational therapy practitioners facilitate participation in everyday living for people of all ages. The Association educates the public and advances the profession of occupational therapy by providing resources, setting standards including accreditations, and serving as an advocate to improve health care. Based in North Bethesda, MD., AOTA's major programs and activities are directed toward promoting the professional development of its members and assuring consumer access to quality services so patients can maximize their individual potential. For more information, visit **www.aota.org**

Fun Summer Activities with the American Kennel Club!

BY ASHLEY JACOT

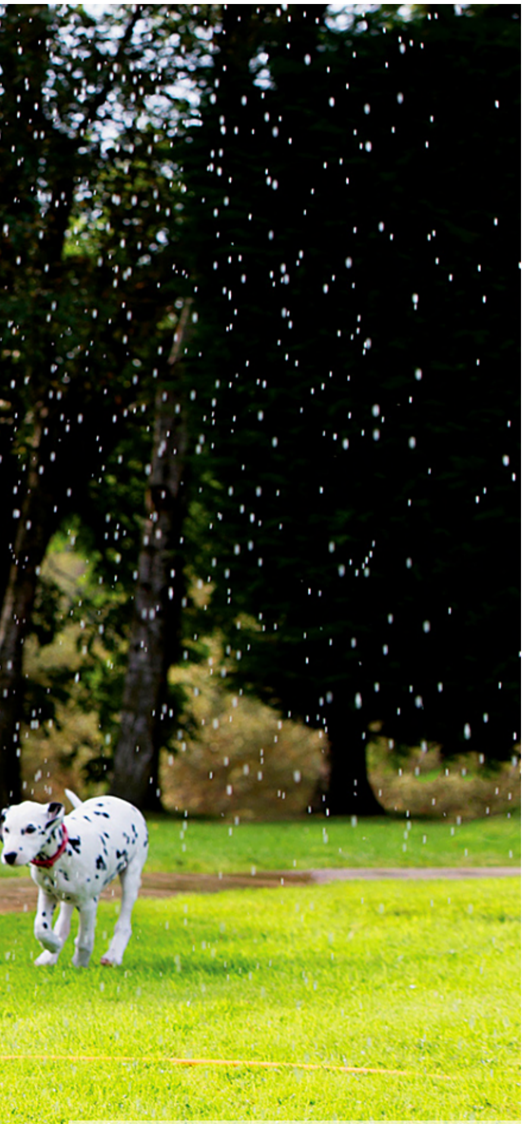
We are living in unprecedented times right now. Most of the country continues to shelter in place and we know that it can be very difficult to keep children engaged. The American Kennel Club (AKC) recognized that challenge and wanted to help parents with fun and educational tools for the young dog lover(s) in their lives.

From crafts to books to song and dance, there is something for everyone. We have even included a schedule for parents trying to keep structure and consistency throughout the day. Additionally, we have created lessons to go along with some dog related books for younger readers.

There are so many activities on the American Kennel Club's website, and they are geared to both children and young adults and are modified to accommodate a great number of special needs, including ADHD, autism spectrum disorder, and a variety of developmental delays.

We in the AKC Education department spent several years as classroom teachers prior to joining the American Kennel Club, so we know first-hand how difficult it can be to find engaging lessons and activities for exceptional learners. A vital aspect of our mission is to help people understand the value of the human-canine bond. The entire AKC Public Education team knows the special bond between children and dogs and we have carefully considered that while creating these quality education activities.

All of the activities and lessons can be modified, and we provide suggestions for teachers – and now parents – to do this. We have a resource that gives general tips and tricks that can be used to modify any lesson for exceptional learners. These are all strategies that we used during our time as classroom teachers.



PLAYING IT COOL: For those kids who have dogs, there are lots of ways to be active with your dog while staying home, and it's very important to spend quality time with them.

The traditional educational activities that we to offer can be done at home, and you don't need to be a dog owner to do them. They are all fun and will delight the dog lovers in your house!

- *AKC Kids News is great new initiative for which to enroll your child, especially during this difficult time. It is a quarterly newsletter that features a variety of learning activities for students. Each newsletter is themed. We provide a version specially designed for exceptional learners.*
- *Another great thing to check out with your children at home is the Article of the Week. It is a resource center of dog-related articles that feature close reading and annotation activities, which are helpful with comprehension. They also feature discussion questions that are scaffolded to meet the learner where they are.*
- *A new activity that we recently designed is the AKC Breed of the Week. This introduces children to a new breed each week through fun, interactive activities. Once they have learned about the breed, they earn a virtual sticker for the virtual sticker book. We provide a version that is designed for exceptional learners, as well.*
- *The AKC Virtual Patch Program is an at-home twist on our wildly popular AKC Patch Program that typically takes place at dog shows and dog events. The AKC Virtual Patch Program is an activity designed for children to learn about purebred dogs and the sport of purebred dogs through a virtual scavenger hunt. Once they have completed it, they earn a patch! We have a version specifically designed for exceptional learners.*

We also provide lesson plans for K-12 in the areas of math, language arts, science and social studies. The lesson plans have modifications for exceptional learners so that the teacher can provide the student what they need based on their own learning abilities.

Dogs & Kids at Home

For those kids who have dogs, there are lots of ways to be active with your dog while staying home, and it's very important to spend quality time with them. Here are fun ways to do that!

- *Have your kids bring out their inner artist and create a portrait of your dog. Try focusing on just your dog's face or play with different media. You can do one in pencil and then the next one in marker or crayon. The options are endless!*
- *Create a dog picture using geometric shapes: different-sized circles, ovals, triangles, squares and rectangles. You can cut out these shapes from paper or use your computer. There are YouTube videos you can watch to help.*
- *Song and dance are great ways to exercise with your dog and also practice some commands. You can make up a dance routine with your dog! Check out this fun freestyle video, Musical Dog Freestyle, on AKC.TV and then practice teaching your dog to jump, spin and wiggle to your favorite song! Training is a wonderful way to spend quality time with your pup, while keeping him or her mentally stimulated. Another fun idea is to change a pop song you like so the lyrics are about your dog. Put on a show for your family and perform your new song!*
- *Create a map of your neighborhood and include your dog's favorite places to sniff and play.*
- *Agility is a dog sport that is fun, fast-paced, and includes different obstacles for your dog such as jumps, tunnels, weave polls and more. You can create your own Agility jump for your dog. Using household items such as a broom pole and chairs as anchors, place the pole between the two anchors. Practice introducing your dog to the jump first, then guide them over the jump with their favorite toy or treat! Before you know it, you'll have an Agility pro!*
- *Make a pawprint finger paint masterpiece! Using non-toxic paint, gently place your dog's clean, dry paw in the paint. Move their paw over to the paper and lightly press their paw down. Use different colors to make a true doggie creation! After you are done, wash your pup's paw off using warm water and their favorite dog shampoo. You can even make your handprint alongside your dog's pawprint!*
- *Caring for your dog is very important, and getting children involved in the dog's daily routine is beneficial and helps teach kids responsibility. Help them practice good hygiene with the pups. Take the time to have kids help you wash their bowls and toys using warm soap and water. Make sure to include them in brushing your dog every day to keep their fur soft and clean!*
- *You can bake your dog some delicious dog treats with your kids. You can find dog treat recipes on akc.org.*

Keep checking **www.akc.org** for more activities to keep your kids engaged during this challenging time and beyond. •

ABOUT THE AUTHOR:

Ashley Jacot serves as the Director of Education at American Kennel Club. Formerly a classroom teacher and educational researcher, Ashley has worked with diverse learners of all ages. Her research on the effects of educational testing on teacher motivation was published in the peer-reviewed journal Social Studies Research and Practice in 2015.

In recent years, there have been a number of infants and children who have been denied organ transplantation based solely on intellectual disability. This is why we are so heartened to see this recent article – "Children with Intellectual and Developmental Disabilities as Organ Transplantation Recipients" – published by the AAP. The authors, some of whom are expert in working with patients with IDD, helped craft an organ transplant policy that makes sense.

LIFE-ENDING DECISIONS

BY MATTHEW HOLDER, MD, MBA

Everyone knows that physicians take the Hippocratic oath upon graduation from medical school. Paraphrasing the part of the oath that everybody remembers, the prime directive of being a physician is to "do no harm." But, there are different ways that physicians harm their patients every single day.

Most of the time, it is unintentional – the post-op infection or the unanticipated adverse drug reaction – and we, both within society and within the medical profession, have a fair amount of tolerance for harm that occurs unintentionally. The logic goes that the physician could not have known that a bad outcome would occur and, moreover, that the physician was acting with the best, life-improving intentions – so all is forgiven.

But what happens when the intention of the physician is not life-improving, but intentionally life-ending? It is hard to imagine that "do no harm" can lead a physician to making a decision that will hasten the death of somebody. After all, isn't death the ultimate harm? Perhaps that is up for debate. But certainly, death is an outcome that we would surely like to avoid.

In general, life-ending decisions are a last resort, they come when the physician essentially gives up and says to themselves and to the patient "there is nothing more we can do". Such is often the case with terminal cancer. Once certain types of cancer progress to a certain point, the physician knows that there are no other options, so he will refer the patient to hospice care, where they will likely be given comfort measures (e.g. pain medications), but they will often withhold other medications and sometimes food or liquids so as not to prolong the suffering of a natural death.

We accept the physician hastening death in this scenario, because we accept the fact that the physician "knows" that death is imminent. But, what if there was a cure for this terminal condition and the physician just didn't know that it existed? Would we accept it then? What if, but not for their own ignorance, the physician could have known that the patient was not actually terminally ill at all?

In the field of Developmental Medicine, we have unfortunately seen this happen far too often. I am reminded of the case of a 30-something year-old, non-verbal gentlemen with severe cerebral palsy and intellectual disability. After two months of deteriorating mental status changes, decreased appetite and weight loss, the doctors referred him to hospice with the diagnosis of "terminal cerebral palsy." As a technical side note, there is no such thing as "terminal cerebral palsy" in an adult.

As it turned out, the patient had an untreated urinary tract infection that was causing the observed changes. Due to the doctor's inexperience with patients with intellectual and developmental disabilities (IDD), the doctor had just assumed that, because of the severity of the patient's disabilities, it must just be "his time to go" and, he gave up. What saved the patient in this case was insistence from the concerned caregivers that the medical team consult a doctor who knew something about developmental disabilities. The consulting doctor insisted that the UTI be treated. Within a few days, the patient got better and suddenly was no longer classified as terminal. The extra knowledge and experience that the consulting physician had, meant the difference between life and death in this case.

The problem, however, is that across the United States there are very few doctors who know about developmental disabilities – and this likely isn't going to change anytime soon. Recently, the National Council on Disability corresponded with the Liaison Committee on Medical Education (LCME). The LCME essentially sets the standards for medical education in US allopathic medical schools. Despite the mountain of evidence that lack of physician training in this area produces bad outcomes, the LCME refused to specifically address the issues of the IDD population in medical education, because they believe that their long-standing requirements around “disability” are enough. Though, if just focusing on “disability” were enough, of course, the National Council on Disability would not have asked them to address the IDD population specifically.

Medicaid spends more on the care of people of with IDD than it does on the care of people with diabetes. Yet, our medical schools continue to graduate doctors who know nothing about the IDD patient population.

Imagine for a moment that we routinely allowed doctors to graduate from medical school being incompetent in the basics of diabetes management. This would be preposterous, if not from a quality of life standpoint, just from a sheer investment standpoint. Medicaid spends tens of billions of dollars per year in diabetes-related costs. Imagine how bad the patient outcomes would be and how much more money we would spend on diabetes if the doctors who were treating it didn't know anything about it!

But, this is exactly what we do with IDD. Medicaid spends more on the care of people of with IDD than it does on the care of people with diabetes. Yet, our medical schools continue to graduate doctors who know nothing about the IDD patient population. And the results are inefficient care laced with covert bias, discrimination, and inequity.

This discrimination and bias were recently put on full display, thanks to the Coronavirus pandemic. During the pandemic, society was faced with the question “what happens if we run out of ventilators?” What we found out was that many states had ventilator rationing plans that specifically excluded people with IDD. Even in the states that didn't have those plans, it was often suggested that doctors employ the SOFA scoring criteria for determining who would get a ventilator. On the surface, this seemed reasonably objective. However, part of the SOFA score includes parameters that will inherently discriminate against people with mobility, hearing, communication, and social impairments. In fact, it discriminated so much that in some cases, a person with IDD who had a better than 67% chance of survival would be ranked to get a rationed ventilator behind a person without IDD who had less than a 5% chance of survival. Thankfully, we were not faced with ventilator rationing during the first wave of the pandemic, but this issue again illustrates the danger behind allowing uninformed medical personnel to make life-ending decisions for people with IDD.

A few years ago, there was a case involving an organ transplant at a very well-known children's hospital. The patient was, at the time, three years old. She had a rare syndrome that, among other things, resulted in intellectual disability and kidney failure. She needed a kidney transplant. The child's mother was a donor match. But the doctors at the hospital refused to do the surgery. Why? Because their organ transplant guidelines stated that people with IDD should not be the recipient of donor organs. They further argued that the three-year-old child lacked the intellectual capacity to keep up with the complex post-op medication regimens (as if any three-year old child could do so). The doctors were making a life-ending decision for their patient, and they were doing so out of their own bias and ignorance. The mother, however, fought back. She, along with the help of physician advocates, got the medical establishment to pay attention, and the children's hospital reversed its decision. The patient and the mother survived and thrived. But, other children have not been so lucky.

In recent years, there have been a number of infants and children who have been denied organ transplantation based solely on intellectual disability – even when the severity of the disability was unproven, just the specter of disability was enough to cause major medical centers (supported by their so-called “bioethics committee”) to deny the possibility of organ transplantation.

This is why we are so heartened to see this recent article —"Children with Intellectual and Developmental Disabilities as Organ Transplantation Recipients”—published by the American Academy of Pediatrics (AAP). The authors, some of whom are expert in working with patients with IDD, helped craft an organ transplant policy that makes sense. EP Magazine (Exceptional Parent), AADMD, Special Olympics, the Center for Dignity in Healthcare for People with Disabilities, and many others, have been involved in bringing attention to organ transplant issue for almost a decade. We applaud the efforts of the authors to establish the precept that people with IDD should not be denied consideration for organ transplantation simply because they have a disability and that, furthermore, doctors who are expert in the care of people with IDD should be consulted in situations that could result in a life-ending decision being rendered.•

ABOUT THE AUTHOR:

Matthew Holder, MD is recognized as an international leader in the care of individuals with Intellectual and Developmental Disabilities (IDD). Dr. Holder began working on what would result in Developmental Medicine becoming a recognized medical expertise soon after starting his career. In 2002, he took over the American Academy of Developmental Medicine and Dentistry (AADMD). Since then the AADMD has set the curriculum and standards that guide medical students, residents and fellowship-level physicians to better treat and understand patients with IDD. Medical schools and residency programs around the world have implemented curriculum changes based on the work done by Dr. Holder and the AADMD. In 2005 Dr. Holder became Global Medical Advisor for the Special Olympics. Dr. Holder has trained thousands of healthcare providers in addressing the health needs of athletes with IDD.

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CHILDREN WITH INTELLECTUAL AND DEVELOPMENTAL DISABILITIES AS ORGAN TRANSPLANTATION RECIPIENTS

BY MINDY B. STATTER, GAREY NORITZ AND COMMITTEE ON BIOETHICS,
COUNCIL ON CHILDREN WITH DISABILITIES

From Pediatrics *May 2020, 145 (5) e20200625; DOI:* **https://doi.org/10.1542/peds.2020-0625**

ABSTRACT

The demand for transplantable solid organs far exceeds the supply of deceased donor organs. Patient selection criteria are determined by individual transplant programs; given the scarcity of solid organs for transplant, allocation to those most likely to benefit takes into consideration both medical and psychosocial factors. Children with intellectual and developmental disabilities have historically been excluded as potential recipients of organ transplants. When a transplant is likely to provide significant health benefits, denying a transplant to otherwise eligible children with disabilities may constitute illegal and unjustified discrimination. Children with intellectual and developmental disabilities should not be excluded from the potential pool of recipients and should be referred for evaluation as recipients of solid organ transplants.

ABBREVIATIONS

ADA:	Americans with Disabilities Act
HHS:	US Department of Health and Human Services
ID:	intellectual disability
IDD:	intellectual and developmental disability
OPTN:	Organ Procurement and Transplantation Network
ADA:	United Network for Organ Sharing

INTRODUCTION

The American Academy of Pediatrics policy statement "Pediatric Organ Donation and Transplantation" published in 2010 provides recommendations to promote awareness for increased organ donation and the role of organ donation as an integral part of end-of-life care but does not discuss recipient candidacy and eligibility.[1] The demand for transplantable solid organs far exceeds the supply of deceased donor organs. Patient selection criteria are determined by individual transplant programs. Given the scarcity of solid organs for transplant, organs are allocated to those most likely to experience maximal benefit, taking into consideration both medical and psychosocial factors. Historically, patients with intellectual and developmental disabilities (IDDs) have often been excluded as potential recipients of organ transplants. The issue of intellectual disability (ID) in donors is not in the scope of this statement. IDD is defined as "a group of developmental conditions characterized by significant impairment of cognitive functions, which are associated with limitations of learning, adaptive behaviour and skills."[2] Patients with an autism spectrum disorder can also be considered to have an IDD. IDDs may be secondary to genetic syndromes, chromosomal abnormalities, exposures during pregnancy (fetal alcohol syndrome, exposure to teratogenic drugs or toxins), congenital anomalies, intrauterine insult (stroke, placental problems), or postnatal insults (infections, trauma).

Intellectual impairment refers to deficits in general mental abilities, including reasoning, planning, problem-solving, abstract thinking, academic learning, and learning from experience, and is commonly defined as an IQ of ≤70. Adaptive functioning deficits refer to impairments in social, conceptual, and practical skills needed for self-care, self-direction, communication, home living, use of community resources, and functional academic skills.[3] In the case of developmental disabilities, it is recognized that cognitive testing alone is inadequate to characterize a person's level of disability. More important is the individual's level of adaptive functioning, which describes the skills with which an individual lives in his or her environment.[4]

People may function at, above, or below what would be expected on the basis of their cognitive ability, largely as a result of the quality of the environmental supports they receive. In this way, disability is a social construct; people with a physical or cognitive difference are also disabled by the inability of society to support them. Studies that do not take into account adaptive capabilities find a higher prevalence of ID than those taking into account a person's adaptive capability or level of functioning.[5] It is this larger view of adaptive functioning that should be examined as part of the transplant evaluation.

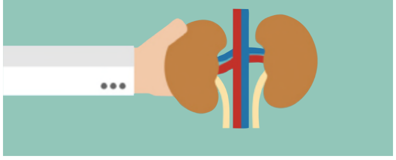
Richards et al[6] highlighted the inconsistencies across major pediatric transplant centers in how the presence of IDD is used as a criterion in the listing decisions for solid organ transplant. Thirty-nine percent of programs stated that they consider IDD "rarely" or "never" in the listing process, whereas 43% of programs "always" or "usually" do. The degree of a patient's delay also affects the listing decision, with 14% of programs reporting mild or moderate IDD as a relative contraindication to listing and 22% reporting that IDD was "irrelevant" to the listing decision. There was also discordance among the solid organ programs (heart, liver, and kidney). Heart programs tend to consider neurodevelopmental status more often in their listing decisions compared to liver and kidney programs, which use IQ more restrictively.[6] The official guidance from the International Society for Heart and Lung Transplantation does specifically mention "mental retardation" as a relative contraindication to heart transplant.[7] The inconsistencies among programs serve to highlight that the use of the criterion of neurodevelopmental delay for listing is heterogeneous, likely reflecting individual programmatic biases.[6]

The Americans with Disabilities Act (ADA)[8] and the Rehabilitation Act[9] prohibit disability-based discrimination by doctors' offices, state-run hospitals, and recipients of federal funding, including health care providers who are paid through Medicaid or Medicare and organizations funded through federal contracts such as the United Network for Organ Sharing (UNOS). The Organ Procurement and Transplantation Network (OPTN) is the nation's organ procurement, donation, and transplant system.[1] It is overseen by the US Department of Health and Human Services (HHS). UNOS is the nonprofit organization that operates the OPTN under a contract from the federal government. All organ procurement organizations and transplant programs in the United States are OPTN and/or UNOS members and follow OPTN policies.[1]

Discrimination under the ADA includes both the refusal to provide services to qualified individuals with disabilities and refusal to make reasonable modifications in policies and practices that are necessary to ensure people with disabilities may access services. When transplant is likely to provide significant health benefits, denying transplant to otherwise eligible people with disabilities may constitute illegal and unjustified discrimination.[8]

In 1995, Sandra Jensen, a 34-year-old woman with Down syndrome and congenital heart disease was initially refused a heart-lung transplant solely because she had trisomy 21 and mental retardation (current terminology at the time). She, with her family and other advocates, mounted a national campaign to protest this discrimination. She subsequently received her transplant on January 23, 1996, and became the first person in the world with trisomy 21 to do so. Dr William Bronston, a state rehabilitation administrator and coordinator of the campaign, in a speech delivered to the National Down Syndrome Society after Sandra's transplant in 1996, said, "Sandra's story has opened a window into the chaos and incompetence of the national transplant system as it currently exists."[10]

Transplant centers contend with conflicting priorities that may affect the evaluation of recipients with IDDs, including the need to have high transplant success rates for accreditation and to remain in payer networks.



STATEMENT OF THE PROBLEM

Transplant centers contend with conflicting priorities that may affect the evaluation and listing of recipients with IDDs, including the need to have high transplant success rates for accreditation and to remain in payer networks. Transplant centers want to allocate limited resources to those most likely to benefit but also want to avoid negative media attention around the perception of discrimination in the referral, acceptance, or listing processes for solid organ transplant.[11]

Among transplant centers, there is inconsistency in defining IDDs, which affects referral and listing and excludes patients from the qualifying pool of recipients. The use of IDD as a medical criterion by transplant centers is inconsistent and varied. When transplant centers use IDD as a social value criterion rather than a medical criterion, they make implicit rationing decisions that favor candidates without an IDD.[12]

The study of "implicit bias" helps us understand how unconscious assumptions about groups of people may influence perception and decision-making.[12] Tests have been designed to assess implicit bias toward individuals with developmental disabilities,[13] and unsurprisingly, clinicians are susceptible to such biases.[14] Just as transplant centers need to ensure that implicit bias does not influence decisions because of race, ethnicity, or sex, clinicians need to be aware of the existence of implicit bias toward individuals with disabilities and thoughtfully examine this bias in listing decisions for organ transplant.[15]

There is the misconception that transplant recipients with disabilities are unable to comply with posttransplant medical regimens, lack adequate support systems to ensure such compliance, have decreased life expectancy, and have a lower likelihood of transplant success.[12] There is the biased presumption that people with disabilities have a lower quality of life than those without disabilities and, therefore, do not receive as much benefit from the transplant as a person without disabilities or that they cannot be expected to derive any benefit by having their life extended by a transplant. For children with IDDs, a social value criterion focuses on their limitations and discounts the contributions that these children make to their families and society.[12] The variance in the defining of IDD and the inconsistent use of IDD as a medical criterion result in the unjustified exclusion of children with IDDs from access to solid organ transplant.

Correspondence in October 2016 from the US Congress to Jocelyn Samuels, the director of the Office for Civil Rights in the HHS, urged the agency to address what congress called "persistent" organ transplant discrimination. The letter called for guidance from the HHS clarifying that denying an organ transplant on the basis of a person's disability would violate the ADA.[16]

The most appropriate outcomes to consider when determining if a patient should be evaluated or listed for transplant are organ and patient survival with the same minimum thresholds for all patients with or without developmental disability.[17] In the determination of a qualifying pool of potential recipients, the literature suggests that there is no substantial difference in patient or organ survival between children with and without IDDs.[17,18] Studies have shown that patients with developmental or intellectual disabilities and appropriate posttransplant support have outcomes comparable to those of children without disabilities.[18]

Benedetti et al[19] described an institutional experience from 1968 to 1996 in renal transplant in adult recipients with ID. A psychologist and a social worker assessed the ability and commitment of the primary support person (the individual from the family or from the institution caring for the patient in charge of the daily medications and clinical follow-up). Only patients with expected long-term survival with a "cooperative" personality or a qualified primary support person were accepted as candidates. The average IQ was 56, chronological age range was 17 to 45 years, and average developmental age was 7.7 years (range: 3–14 years). The 1- and 5-year patient and graft survival was 100%. They found that kidney transplant in properly selected patients with ID provided excellent patient and graft survival rates and that patient quality of life and health, as judged by the primary support people, was highly improved after kidney transplant in comparison with dialysis or advanced chronic renal failure. The authors concluded that the presence of ID should not be considered a contraindication to kidney transplant.[19]

For children with intellectual and developmental disabilities, a social value criterion focuses on their limitations and discounts the contributions that these children make to their families and society.

Ohta et al[20] reported data from 8 Japanese institutions from 1988 to 2004; 522 pediatric kidney transplants were performed, including 25 (4.8%) in recipients ID. Follow-up data revealed all 25 grafts were functioning during a mean observation period of 41.1 months. All people providing primary support for these children were satisfied with the transplant and believed that quality of life was improved for both the transplant recipients and themselves.[20]

Galante et al[21] reported results of renal transplant in recipients with ID; graft survival and long-term renal function was equivalent to recipients without ID. They also concluded that renal transplant may offer significant advantages when compared to the need for dialysis in patients with ID.[21]

TRANSPLANT ETHICS

In transplant ethics, the ethical principles directly applicable to the allocation of organs for transplant are respect for persons, utility, and justice.[22] Respect for persons embraces respect for autonomy; this necessitates transparency of processes and allocation rules to enable stakeholders to make informed decisions. Utility describes the effort to maximize the greatest benefit for the greatest number of patients.[23] Utility applied to the allocation of organs should maximize the net overall good, balancing benefits and harms, thereby incorporating beneficence and nonmaleficence. For example, commonly accepted medical contraindications to transplant incorporate utility by excluding individuals whose diseases can be expected to recur after transplant, diseases that may be worsened by posttransplant immunosuppression, or diseases that make surgery unsafe for the patient.[24] In public policies related to allocation of organs, there is consensus that the social worth or value of individuals should not be considered. IDD as a social value criterion results in implicit and explicit bias that may reflect the values of the decision-makers and affect rationing decisions. For children with IDDs, a social value criterion focuses on their limitations and discounts the contributions that these children make to their families and society.[12] Justice refers to fairness in the pattern of distribution of the benefits and burdens of an organ procurement and allocation program. Equitable access to the transplant waiting list is the basis of equitable organ allocation. Justice requires that criteria for candidacy are applied in an equal manner. Equitable allocation incorporates efficiency and equity, as specified in the Final Rule implemented in 2000, "distributing organs over as broad a geographic area as feasible…and in order of decreasing medical urgency."[24]

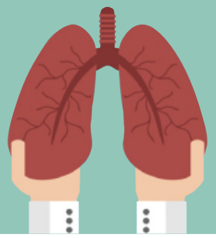
Excluding children with disabilities from the qualifying pool of potential recipients violates these ethical principles. Children with disabilities can be deceased organ donors and contribute to the supply of solid organs, so it would be unfair to categorically exclude them as recipients of organ transplants.

Beneficence and nonmaleficence apply not only to the pediatric patient being referred, accepted, or listed for transplant but also to the family construct. The family, in addition to the patient, is a stakeholder and must be educated in the benefits, risks, and harms of transplant and collaborate with the transplant team in the decision-making process. Evaluation for transplant includes determining if there are significant medical comorbidities that unduly limit transplant survival; transplant is not offered to any patient who will be harmed by the procedure.

One pediatric transplant center stated that developmental disability alone should not preclude transplant; however, "biological survival is not a sufficient goal for transplantation. Survival for the purpose of having continued conscious experience is a minimum goal of transplantation."[25] The center's neurodevelopmental task force, drawing on federal and expert consensus guidelines, defined terms including minimally conscious state and persistent vegetative state. As such, the center's policy is to not offer transplants to patients in persistent vegetative states. The task force concluded that a scarce resource should not be used to prolong the survival of people who very likely have no conscious experience. The task force sought assistance from a community ethics committee that used an absolute lack of benefit argument, claiming that it is ethically justifiable to exclude patients in persistent vegetative state from receiving transplants.[25]

In balancing beneficence and nonmaleficence, the benefits, risks, and harms of transplant to pediatric patients with developmental disabilities, it is necessary to acknowledge that the transplant can add to or reduce the burden of treatment. The pediatric patient with disabilities may have the burden of other organ system disease in addition to the failed organ. Many children are already dependent on technology for survival, such as a feeding tube or tracheostomy. For these children with medical complexity, certain inherent aspects of the disability, such as recurrent tracheitis or pneumonia, may pose a more significant risk after transplant because of the required immunosuppression.[26]

Many individuals with disabilities rate their own quality of life similarly to individuals without disabilities and higher than their families do when using proxy measurements.



Transplant teams have the responsibility of educating families about the benefits, risks, and possible harms of organ transplant and collaboratively making the best decision possible. Although many parents will naturally subordinate their own interests and the interests of siblings when dealing with the interests of their child with organ failure being evaluated for transplant, it is helpful to remind parents that it is acceptable to directly consider their own interests and the interests of other children when making decisions for and about their sick child. It is beneficial to have parents openly acknowledge the sacrifices associated with various treatment options and the effect on their own lives and the lives of their other children.[27] It is ethically permissible for some families to decide that because of the degree of IDD, their children may not attain enough benefit to warrant the immediate and lifelong burdens of transplant.

QUALITY OF LIFE

A core issue in the discussion of organ transplant for children has to do with the concept of quality of life. The World Health Organization defines quality of life as an "individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns."[28] By its very nature, quality of life is individualistic, and although many attempts have been made to measure and monitor quality of life for groups of people, one must not lose sight of the individual's understanding of his or her own quality of life.

As commonly defined, quality of life goes well beyond health-related matters and includes physiologic, psychological, and social factors.[29] Likewise, disability is commonly understood to cross multiple domains, including body functions, body structures, activity and participation, and environmental factors,[30] all of which affect an individual's assessment of his or her quality of life. This complicated interplay of medical and nonmedical factors is challenging to families and physicians who must decide whether to proceed with transplant for a child with a disability.

It is well known that many individuals with disabilities rate their own quality of life similarly to individuals without disabilities[31–33] and higher than their families or physicians do when using proxy measurements.[31,34,35] This has been called the "disability paradox"[34]; individuals with disabilities tend to base their assessment of quality of life on factors beyond their physical and mental functioning, whereas proxy reporters tend to focus on the disability.[29] Clinicians' bias as a result of their own perception of the disability may undervalue the actual quality of life of the patient. As stated by Graham and Robinson,[36] "while quality of life considerations should be considered when assessing the benefits and burdens of medical care, there is the concern that many clinicians may unconsciously use the phrase 'quality of life' to mask a set of more complicated, unspoken assumptions about the lives of the disabled." Many clinicians working in an inpatient setting may not recognize that their assessments of quality of life are based on an incomplete clinical picture and are, therefore, limited. The child's condition and function during a hospitalization provides limited insight into a patient's overall quality of life and the family's experiences, which may contribute to bias on the part of clinicians. Professional attitudes then conflict with parental assertions about the appropriateness of an intervention, not because of ethical or moral differences, but because of different perceptions about the baseline quality of life of the child.[36]

EVALUATION FOR TRANSPLANT

The evaluation for solid organ transplant is a multidisciplinary assessment that includes a psychosocial evaluation, the goal of which is to identify patient and family strengths and risk factors that may affect posttransplant outcomes. Transplant evaluations for all individuals also include an assessment of the psychosocial milieu in which the individual exists.[1] The degree of psychosocial support available to the individual is part of this determination. In transplant evaluations for all young children and for older children with disabilities, the presence of caring, able, and committed caregivers is of paramount importance. These caregivers must be committed to the immediate and long-term care of the individual and his or her medical and psychosocial needs. The American Academy of Pediatrics policy statement emphasized the goal of keeping the family unit intact during and after the transplant process.[1] For patients with disabilities, caregivers often include a number of people outside the immediate family and may include the extended family, home nurses, therapists, clergy, and educators. Developmental specialists may be of particular importance for making the individual "come alive" for the transplant committee, demonstrating how the individual functions within his or her psychosocial setting.[37] The commitment of this extended caregiving team should be taken into account when considering an individual for transplant.

The OPTN encourages individual transplant centers to develop their own criteria for these "nonmedical" evaluations, although some guidance is given.[38] For instance, they suggest addressing problems with adherence, such as for an organ failure caused by behaviors such as smoking and alcohol use, but do not give strict criteria for exclusion from transplant consideration.

The likelihood of nonadherence to posttransplant regimens and medical care is commonly cited as a disqualifying barrier for patients with disabilities. However, nonadherence is highly prevalent in other populations, particularly adolescents.[39] Patients with disabilities often require assistance with their medication regimen and, thus, have a high degree of oversight, which may improve the likelihood of adherence.[40]

The presence of behavioral and emotional problems seems to be a more important predictor of low quality of life among children with disabilities than the extent of the physical disability.[41] In typically developing children, behavioral and emotional problems would be an important determinant of eligibility for organ transplant[42] because such problems can affect the ability to adhere to complex posttransplant medical recommendations and should likewise be considered a factor for individuals with disability. Many children with chronic illnesses, particularly those with IDDs, have distress with medical visits or phlebotomy, often because of past painful interactions with the medical system.[43] Patients with these issues often respond to child life and other therapies to allow for medical tasks to take place.[44] However, if children cannot be accustomed to simple medical procedures such as phlebotomy, they would be poor transplant candidates because of the chronic and continuing need for blood tests. For such patients, posttransplant care is not likely to be practical, regardless of the presence or absence of a developmental disability.

Although patients with disabilities commonly report good quality of life, their caregivers often report poorer quality of life, which may be related to the intensity of the care that is necessary.[45,46] The caregiving burden is often more closely related to the extent of behavioral and emotional problems than the severity of the motor or cognitive impairment.[47] The psychosocial evaluation in these circumstances should include the functioning of the broadly defined family unit rather than only the individual to receive the transplant. The family of a child with disabilities might experience an increase or decrease in the caregiving burden, and this should be explored individually.

The lack of standardized mechanisms for transplant centers to assess cognitive development and adaptive functioning was noted by Wightman et al.[48] In a large (N = 2076) retrospective cohort analysis of children receiving a first kidney-alone transplant in the UNOS data set from 2008 to 2011, they reported 16% of the recipients were children identified as having definite or probable ID. For the purpose of the study, the authors created a definition of ID on the basis of information in the UNOS data set because of the lack of standardized mechanisms for transplant centers to assess cognitive development, academic level, or academic activity. Short-term (3-year) graft and patient survival were similar between children with definite or probable ID and without ID. The authors acknowledged that their study did not assess children listed for transplant who remain on the list, patients with end-stage kidney disease not referred to a transplant center, or those refused listing by a transplant center, thereby underestimating the number of children with disabilities eligible for consideration for kidney transplant.[48] The standardization of the definition of disability including both intellectual functioning and adaptive behavior may be helpful in predicting the outcome after transplant.

When transplant is likely to provide significant health benefits, denying transplant to people with disabilities on the basis of their supposed lower quality of life may constitute illegal and unjustified discrimination.

SUMMARY

When transplant is likely to provide significant health benefits, denying transplant to people with disabilities on the basis of their supposed lower quality of life may constitute illegal and unjustified discrimination.[8] The decision to initiate transplant must include consideration of both the individual patient's current quality of life with the diseased organ and the potentially improved quality of life with the transplanted organ, albeit with the burdens of surgery, immunosuppression, and other posttransplant therapies.[49,50]

The notion that children with disabilities have a lower quality of life than children with typical development is both incorrect and ethically problematic in decisions regarding organ transplant. Care must be taken to ensure that medical and psychosocial factors that may affect the transplant outcome are not confused with judgments of an individual's social worth. Children without disabilities have no more claims to scarce resources, such as organ transplants, than do children with disabilities.

To address concerns regarding the fairness of transplant evaluations for patients with IDDs, a framework for transplant centers is necessary to ensure procedural consistency and transparency. The definition and assessment of ID, including the evaluation of cognitive development and adaptive functioning, and the criteria for recipient candidacy and selection require standardization and transparency, making transplant centers accountable for their decisions. One pediatric transplant center used a multidisciplinary approach to develop a center-wide transplant policy. To increase transparency and accountability with respect to candidacy decisions for patients with developmental disabilities, the task force recommended the formation of a transplant listing advisory committee. The purpose of such a committee is to ensure that institutional transplant selection criteria are fair and nondiscriminatory and that patients declined for evaluation or listing were granted a fair and unbiased review, particularly with respect to characteristics that identify vulnerable or protected classes of people, such as those with disabilities, who may be protected under the ADA.[25]

In adhering to the ethical principles of respect for persons, utility, and justice, children with IDDs should not be excluded from the potential pool of recipients and should be referred for evaluation as recipients of organ transplants. IDD alone should not be a contraindication to the referral, acceptance, or listing for solid organ transplant. The presence of an IDD is relevant but should not be the determinative factor.

RECOMMENDATIONS

1. Patients should not be excluded from consideration for solid organ transplant solely on the basis of an intellectual or developmental disability. When transplant is likely to provide significant health benefits, denying transplant to people with disabilities on the basis of their supposed lower quality of life may constitute illegal and unjustified discrimination.

2. Transplant programs should standardize the definition and assessment of ID so that transplant decisions can be individualized, equitable, and transparent. The transplant team should consider both the cognitive and adaptive skills of the individual. Consistency in defining IDD allows the use of IDD as a medical criterion to prevent unjustified exclusion of children from access to solid organ transplant. There should be concordance among the respective solid organ transplant programs within an institution in defining IDD to avoid individual programmatic biases. The transplant team should consider both the cognitive and adaptive skills of the individual. Cognitive testing alone is inadequate to characterize a person's level of disability. The individual's level of adaptive functioning must be taken into account; specifically, the skills with which an individual lives within his or her environment (eg, the social, conceptual, and practical skills needed for self-care, self-direction, communication, home living, use of community resources, and functional academic skills) must be considered. Failure to consider adaptive functioning as part of the transplant evaluation results in an inaccurate assessment of ID.

3. The transplant evaluation is a collaborative process that should occur in person rather than by medical record review and should include caregivers such as therapists and developmental specialists who can illustrate the patient's degree of function. Evaluations for transplant to an individual with ID should include professionals with expertise in the evaluation and management of individuals with ID.[51]

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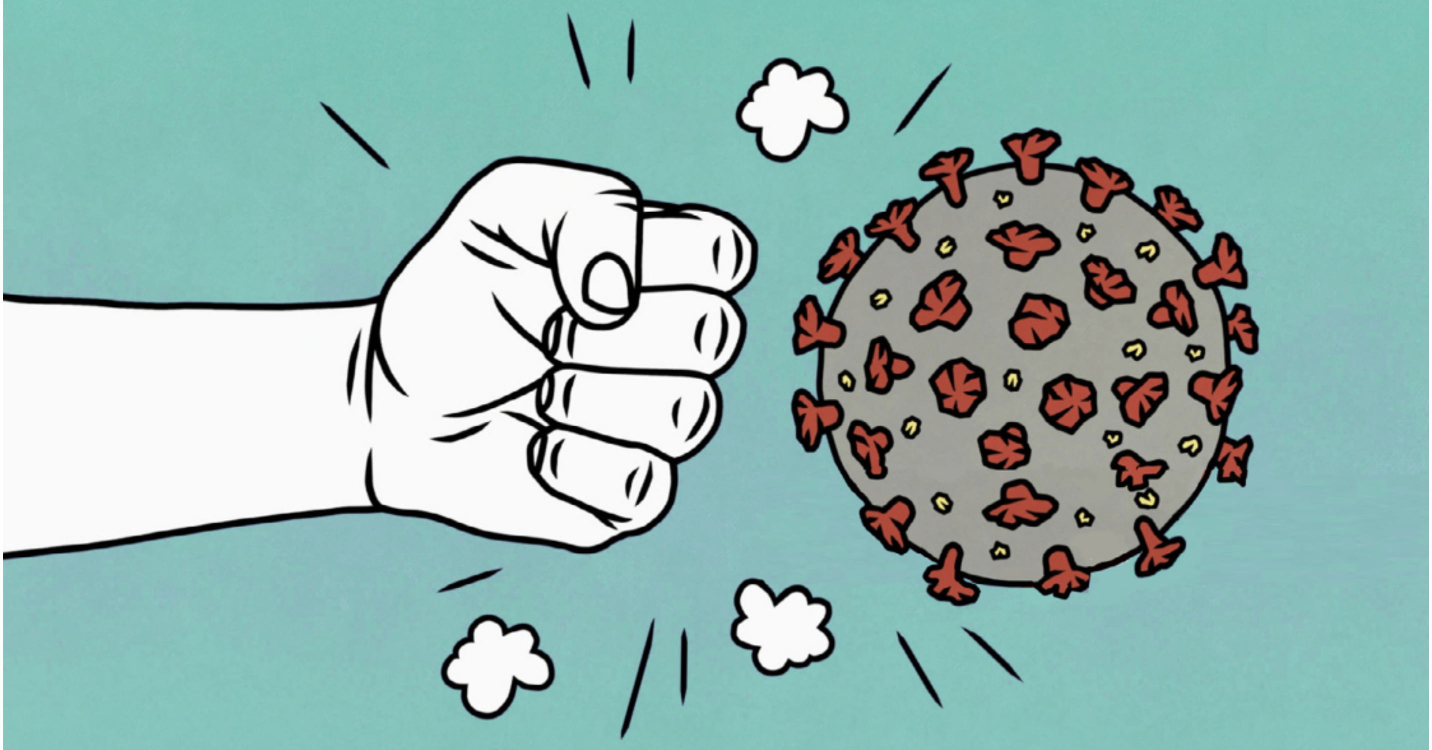
WELCOME TO MY NORM. NOW DO YOUR PART.



BY JOANNE DE SIMONE

When March began, my work calendar was loaded with special education conferences. As worries of the Coronavirus intensified, each organization cancelled their large gatherings and my calendar cleared. No work means no pay. I know many people in this situation. It's stressful but as I deleted each event, money wasn't the first thing on my mind.

This isn't the first time I've lost jobs, money, or my freedom to illness. Every time Benjamin gets sick, my life goes on hold and I'm reminded that everything I thought was important isn't. Benjamin's health and life are more important than work or debt.

I am worried, but worry is not a new state of being for me. Any respiratory infection could kill Benjamin.

Although the heightened media presence of the Coronavirus has me more concerned and has placed me in a higher state of preparation, there is one thing I cannot listen to anymore.

I will echo what others have been saying, but so many still haven't taken to heart: CORONAVIRUS IS NOT THE FLU

This is a new, not yet understood, virus. This is a fast-moving virus and it is clear from what the medical community is telling us that we are horribly unprepared. Our hospitals cannot manage flu patients plus outbreak patients and oh the unfortunate person who has a heart attack.

THIS IS NOT JUST ABOUT THE CORONAVIRUS. EVERY SINGLE PERSON WHO NEEDS ANY KIND OF MEDICAL CARE COULD BE ADVERSELY AFFECTED.

My personal concern centers around the fact that our hospitals do not have enough life-saving equipment. I can tell you with 100% certainty that if Benjamin catches the Coronavirus and the hospital is in the position to ration ventilators, Benjamin will die. His life will be deemed less valuable than a father of two or a mother of one or ABSOLUTELY ANY OTHER HUMAN BEING WITHOUT A DISABILITY.

I know this because that is also nothing new to me. Our society is in the bad habit of placing a hierarchy on life. If you have the luxury of believing the Coronavirus is just like the flu, consider yourself lucky. But don't tell me that because Benjamin is disabled that it is solely up to my family and those like us to self-quarantine.

That is an old, obnoxious and yes ABELIST song.

It signifies everything that is still wrong in this country regarding the disabled. It justifies blanket segregation. It justifies the idea that the person with a disability needs to make all the accommodations instead of understanding that environmental and behavioral changes by everyone could make all the difference.

DREAMS DELAYED: With coronavirus fears overwhelming us, suddenly graduation is the least of our worries.

My son is not disposable. My 90-year-old mother is not disposable. Stop implying that they are.

I can guarantee that my quarantined son and mother aren't out and about spreading this virus.

You know who's spreading it? All the "healthy" members of society walking around not taking this seriously.

Just stop.

Stop placing a hierarchy on life.

Stop saying it only kills the old and already compromised.

You're wrong.

Do your part to minimize the spread of the Coronavirus •

Reprinted with Permission from: Special-Education Mom (Special Education is my life)

ABOUT THE AUTHOR:

My name is Joanne De Simone. I am a graduate of Hunter College in New York with degrees in Dance and Special Education. I left dance to teach children with disabilities. Then I had two boys. My older son has a rare brain malformation called Lissencephaly. He has spastic quad cerebral palsy, doesn't walk, talk, or use his hands. He has a seizure disorder, and sports a feeding tube for supplemental nutrition. My younger son is on the autistic spectrum. Special Education is my life. Currently I work as the Outreach Coordinator for The Alliance of Private Special Education Schools of North Jersey.

PLAN WELL FOR YOUR EXCEPTIONAL CHILD...

AND THEN ENJOY EVERY MOMENT OF YOUR TIME WITH THEM

BY ROB WRUBEL, CFP

Sassy, friendly, confident. These are just several words people use to describe my daughter Sarah. She has many positive characteristics, even if as a junior in high school she'd rather be left alone with her friends. Every so often she expresses that she would like to drive, even though I know deep inside she loves having a chauffeur.

There is one small problem. Her feet do not reach the pedals. She is just way too short. As a father of three I have learned that raising Sarah, who has Down syndrome, is both similar and dissimilar to raising my other children. My son, excited to get his license, took his permit test the first day possible. My youngest looks forward to that day as well. Sarah might learn to drive, and if she does, the entire process will look different. It will take longer... and I will be more frightened to get in the "shotgun" seat as she pulls out of the driveway.

Thinking about and planning her future is a mixed bag, too. I want Sarah to live independently. I expect her to finish high school and participate in a higher education program before working, like her siblings. However, she will need additional support from benefit programs, aides, specialized programs and from me.

On some levels, special needs planning looks similar to typical financial planning. Typical families save for retirement, have term life insurance, get out of debt, and fund other desired life goals. So do our families. Unlike typical families we need to plan for benefit programs to provide income, health insurance, and supported living. We face higher hurdles to achieve success in schools, and for lifelong health outcomes, employment, and independence.

The following are key areas to consider in your plan:

Special needs trust. Typical planning includes having a will and other documents for when you die or become incapacitated. Families like ours want to include a special needs trust. Your family member with a disability can lose access to benefit programs by having her own funds. The trust is a way to continue to pay for a high quality of life without losing valuable health, income, and community benefits.

Two-generations. Adults planning for themselves hope to leave some money to family and charities, but it is often secondary to maintaining their current standard of living. Families like ours intend to create assets to care for a son or daughter with a disability. It requires saving additional funds to be passed along.

Circles of support. Try as we might we cannot live forever. My

LOOKING AHEAD: Typical families save for retirement, have term life insurance, get out of debt, and fund other desired life goals; so do special needs families. However, special needs families also need to plan for benefit programs to provide income, health insurance, and supported living.

goal is to outlive my daughter, but it is unlikely I will. We cannot leave the well-being of our family members to chance and we should be intentional about the people and nonprofits supporting us. Find organizations in your community serving families like ours and stay in touch with the ones you prefer so they can step in to help when you are ready.

Designated people. Your estate plan has people named to act in important roles – as trustee, guardian, attorney-in-fact. Review your documents every five to 10 years and always after a major life event occurs for one of them. Someone going through a divorce or moving to South America might not be the best choice for a trustee or guardian.

Trust funds. I expect my daughter to outlive me by five to 10 years. While she's alive, I pay for her to enjoy life. After I pass away, she will still need money to make her life fulfilling. Trusts can be funded with different assets – investment accounts, IRAs and retirement accounts, real estate, life insurance, and more. Your plan should include calculations about how much will go to the trust and which assets to use to fund it.

Special needs planning protects benefit programs that can be worth tens of thousands of dollars every year in income, health insurance, and community supports. Parents of people with special needs embrace their role; they know life is different than what was expected, and they also know it is full of new discoveries and great joys.

Find a good team to help you make future plans. Getting out of debt, saving enough to retire and pay for future special needs expenses, and having the trust in place will reduce stress and anxiety about what comes next. Knowing I have taken steps to fund future needs, lets me enjoy each day as it comes – even if one of those days is in the passenger seat next to a new driver.•

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.

I CAN HEAR YOU

BY CARL K. LANGE, M.D.

Two years ago, my 83-year-old mother visited my wife and me in Pittsburgh. We are both transplants from Washington D.C. and New York City respectively, migrating to the Steel City to avail ourselves of the premiere medical education offered in this city.

Driving to the airport to retrieve our feisty matriarch, my wife and I discussed the aggressive agenda we had planned for the woman who, just a year prior, assisted us in laying 18 yards of mulch in our yard, by the way, just shortly after losing her husband of 60 years.

As we approached the baggage claim area, we could see mom standing next to two airport employees. Allow me to tell you something about my mother. Time and osteoporosis have diminished

PHOTOS PROVIDED BY CARL K. LANGE, M.D.

her once five-foot three frame to just around four foot seven. Wispy white hair and a slight kyphosis combined with her shuffling gait highlight her senior citizen status.

As she clutched her carry-on while watching the baggage carousel circle, I could hear one of the workers shout over her head, “Hey, this old lady needs help!”

“What’s she want?” responded his colleague.

“I don’t know. She seems to be lost.” Worker number one.

“I don’t think she can find her bag. She probably can’t find the exit.” Worker number two.

Mom watched the interaction with amusement, finally responding, “You know, I can hear you!”

Allow me to tell you something else about mom. As a young woman back in New York City, she ran a multi-branch Savings Bank when glass ceilings were impenetrable. Her hobbies included piloting twin engine airplanes and playing trumpet in an all-male brass ensemble. She is still sharp as a tack and nobody’s fool. The airline employees, embarrassed by being schooled by an eighty-three-year-old grandmother then directed their attention to her, thereby validating her living, breathing, thinking, human-being status.

I am an emergency room physician at a major hospital in Pittsburgh. As such, I have the opportunity to see a wide range of pathology across a diverse population. Disease and tragedy know no bias. Among the patients that I often treat are the special needs residents from our local personal care facilities. They are almost always accompanied by relatives or caretakers, almost always toting a wheel-barrow full of charts, x-rays and medical records. An interesting common denominator reflected by everyone in the “supporting cast” which I noted early on in my career is an eerie air of calm and peace emanating from their persona, as if they knew something I didn’t. I couldn’t help bookmarking in the posterior aspect of my cerebrum that there was something very different about these caretakers. In the beginning, I felt intimidated by the thought that they potentially saw me as someone lacking in some way. Probably, it was my pride that ultimately extinguished this obviously inaccurate assessment they had synthesized of me. After all, I am the doctor. What could they possibly teach me?

LOUD AND CLEAR: The author with Max *(opposite page)* and Rufus *(above)*; “I had learned nothing from my mother’s experience at the airport. The fatal error I committed was assuming that because my young patient looked different on the outside, he must be different on the inside.”

Shortly after my mother had educated the airport baggage claim employees in the subtle art of human interaction, I was at work in the emergency department. I picked up my next chart and studied the chief complaint. “Twenty-seven-year-old male with abdominal pain.” After reviewing the past medical history, I ascertained that he also had reflux esophagitis and cerebral palsy. Upon entering the room, my astute observational skills drew my attention to a young man lying on the hospital bed contracted and writhing. His left arm flailed aimlessly in the air.

I began my history-taking, directing my attention to the two concerned parents sitting adjacent to the bed. Initiating my interview at a volume louder than a person should speak without the use of amplifiers, because that’s what we do when we think someone does not understand us, right? I asked my first question. “WHAT BRINGS YOU TO THE EMERGENCY ROOM?” The parents glanced at each other with the look with which I had become all too familiar.

“DOES YOUR STOMACH HURT?” Again, directed at the parents. I waited for a response. After a few moments of uncomfortable silence, I could hear a strained, dysarthric response. “I can hear you, you know.” Left arm flailing, my contracted, drooling patient was communicating with me. He again squeaked out the same words.

“I can hear you.” Speaking of stomach pain, I felt as if I had been punched in the gut. I was embarrassed. I was humbled. I think I gave a quiet apology and then quickly completed my physical exam.

I had learned nothing from my mother’s experience at the airport. The fatal error I committed was assuming that because my young patient looked different on the outside, he must be different on the inside. His parents patiently explained to me what I had already learned in medical school many years ago. Academically, I knew that his mental faculties and cognition could potentially be perfectly functional. I intentionally used the word “functional” rather than “normal” because after my humbling experience, I am now constantly reminded that different does not imply abnormal. Human beings are human beings, and how we choose to address a person should never be contingent on physical appearance.

Even if studies demonstrate that speaking directly to stroke patients, or even patients in catatonic states may lead to more favorable medical outcomes, I have learned that sometimes, medical literature is beside the point. We are all created equally and if this is to be believed, then every aspect of human communication and interaction should reflect it. A 27-year-old young man, whose physical presentation just happened to be different from what we have been conditioned to believe is the norm reminded me of this fact.

Several months ago, I again had the opportunity to take care of a young gentleman with cerebral palsy. Upon entering the room, I introduced myself, said a polite hello to the patient’s caretaker and immediately approached the patient’s bed to begin my interview. I asked him in a normal volume what brought him to the emergency room. Unfortunately, the severity of his condition was much greater than my previous patient. Contracted and consumed with spasticity he was emanating sounds that were untranslatable. He writhed on the bed again making sounds that I was unable to understand.

I was happy to be able to put my hand on his shoulder and answer him, saying, “I can hear you.”•

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.

A BROTHER'S PERSPECTIVE

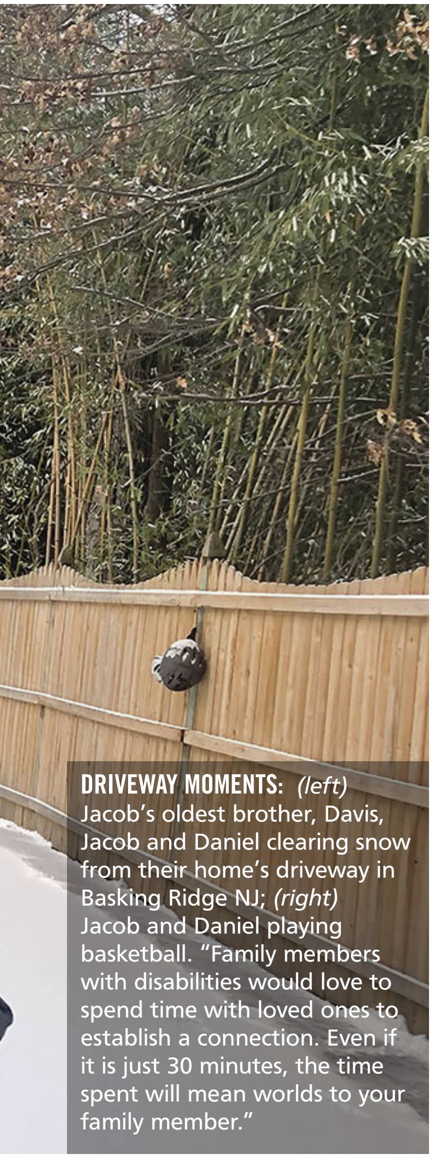
BY DANIEL GEORGE

Hi, my name is Daniel George and I am 15 years old. I am advocating as a sibling for family members to spend time with children with disabilities when the opportunity arrives. My brother, Jacob, sustained a severe traumatic brain injury ten years ago. As defined by the Centers for Disease Control and Prevention (CDC), Traumatic Brain Injury is a disruption in the normal function of the brain that can be caused by a bump, blow, or jolt to the head. Jacob was an average seven-year-old when the accident happened on a Halloween hayride. Because of the injury, Jacob is quadriplegic, cannot see, cannot speak, cannot eat, and he requires round-the-clock care. But that does not mean he cannot communicate. We know that Jacob loves it when our family spends time with him because he smiles. We assume he can hear us and comprehend the environment because he reacts to stimuli by laughing.

Even though there is so much uncertainty in an injury sustained over ten years ago, I know Jacob enjoys our company. So I watch T.V. with him, take naps with him, tell him jokes, and try to help my parents take care of him as much as I can. I was so young when it happened that the life we live right now is the norm. I do not really remember much about Jacob before the accident because I was only four. What I heard from my family is that he loved spending time with me when I was younger and he still does to this day.

I still find it hard to zoom out and understand the real depth of the impact of what happened to Jacob on me and my family. I want Jacob and many other people with disabilities to communicate because that is the best way to get to know and hang out with my brother. Laughter is great but, hopefully, that is only the tip of the iceberg for Jacob's ability to communicate with us. We tried to do many things to combat Jacob's locked-in syndrome, but not all of them have been successful. We tried to have him communicate with his eyebrows. I put aside 30 minutes a day to try to teach him to raise his eyebrows as "yes" and leave them where they are as "no". The results turned out to be inconsistent and we decided his tremor might make answering very random.Now we are trying to use a Brain-Computer Interface (BCI) to communicate with him.

PHOTOS PROVIDED BY DANIEL GEORGE



DRIVEWAY MOMENTS: *(left)* Jacob's oldest brother, Davis, Jacob and Daniel clearing snow from their home's driveway in Basking Ridge NJ; *(right)* Jacob and Daniel playing basketball. "Family members with disabilities would love to spend time with loved ones to establish a connection. Even if it is just 30 minutes, the time spent will mean worlds to your family member."

Researchers at the National Center for Adaptive Neurotechnologies, showed me how to set up the BCI on Jacob. If we can use the BCI regularly, hopefully, I can work with him on it a little bit a day and show the data we collect to a professional. Getting the opportunity to communicate will change Jacob's life dramatically. For example, he would be able to tell us when he is hungry or when he is uncomfortable.

I believe that research on BCI will have the potential to improve the quality of life for people with many disabilities that affect their communication. It might be some people's last hope and giving back that bit of life they lost would be wonderful.

As a sibling, my goal is to get to know Jacob more, make his life easier, and help the millions of people that are in the same situation as my family. Even with very limited means of communication, Jacob has a big personality and he is not afraid to show it. I have a feeling that that is the same way with many other kids with disabilities around the world. We don't hide our lifestyle even though it is so different from the norm.

"As a sibling, my goal is to get to know Jacob more, make his life easier, and help the millions of people that are in the same situation as my family. Even with very limited means of communication, Jacob has a big personality and he is not afraid to show it."

Completely immersing a sibling with a disability in our daily activities and lifestyle is difficult and unproductive for both parties. But family members with disabilities would love to spend time with loved ones to establish a connection. Even if it is just 30 minutes, the time spent will mean worlds to your family member. •

ABOUT THE AUTHOR:

Daniel George is a freshman at Ridge High School, Basking Ridge, New Jersey and is Jacob George's brother. Daniel has written other publications to tell Jacob's story. Daniel is keen on assessing the current challenges with his and family's situation and tries to identify solutions for aforementioned problems.

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ADDRESSING PHYSICIAN MEDICAL EDUCATION

A DEVELOPMENTAL MEDICINE FELLOWSHIP TRAINING PROGRAM

BY JORDAN KEMERE, MD

Sitting down in the exam room, I introduce myself to the new patient and her mom. They both appear anxious and not sure about transitioning from their pediatrician to the adult health care system. I carefully explain our clinic, "We are a patient-centered medical home for adults with intellectual and developmental disabilities (IDD)." I explain that I am an adult primary care doctor and in response, this mom asks me a question I have heard many times, "How do you become an expert in caring for adults with IDD?"

I detail to her how I have learned from my coworkers and extensively from patients and families. They have taught me so much about what their daily lives look like and their struggles finding appropriate health care for their family member with IDD. The patient and mom seem relieved that our relationship will be a team approach. Finally, the mom asks, "You mean there isn't any formal training to care for adults with special needs?" My response, "No, unfortunately at this time there is not."

According to the CDC, in the United States, there are approximately 61 million people living with disabilities, and about 6.5 million who have cognitive disabilities.[1] Just as the life expectancy of the neurotypical has increased over the last few decades, the life expectancy for individuals with intellectual disability is also increasing, thanks to advances in healthcare, greater resources in the community, and increasing advocacy.[2] The need for adult physicians who are competent and comfortable taking care of adults with IDD is greater than ever and yet, physicians are not receiving the training. There are no current requirements for medical students, residents, or practicing physicians to receive any education in caring for patients with IDD. Schools of medicine, hospitals, and continuing medical education efforts seldom address the IDD population's health care needs.

> “In response to this growing need and underprepared workforce, a new and necessary field of training is emerging with support of the AADMD and Special Olympics.”

When interviewed regarding care of individuals with IDD, primary care physicians have said they feel underprepared, lacked confidence, lacked knowledge about resources, felt anxiety about behavioral challenges, and felt overwhelmed delivering care for this population. When asked how they would like to learn about the health care needs of individuals with IDD, physicians expressed the desire to learn experientially about the general approach to these patients.[3] In response to this growing need and underprepared workforce, a new and necessary field of training is emerging with support of the American Academy of Developmental Medicine and Dentistry (AADMD) and Special Olympics. Change needs to take place at all levels, with added required curriculum and experiences for medical students, residents, and already practicing physicians. We need continued advocacy efforts at each of these levels of training.

QUESTIONS OR INTERESTED IN APPLYING?

Contact
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One solution is in-depth training for doctors who specialize in primary care and wish to devote their practice to delivering health care for individuals with IDD. With support from a grant from the Texas Council for Developmental Disabilities, the Baylor College of Medicine Section for Transition Medicine in Houston, Texas is offering a one-year Developmental Medicine Fellowship to formally train Med-Peds, Family, or Internal Medicine physicians as leaders in the care of individuals with IDD. The fellowship will begin July 1st, 2020.

Just as pediatricians have trained in Developmental-Behavioral Pediatrics and Neurodevelopmental Disabilities, our fellows will become experts on the healthcare needs for adults with many of the same childhood conditions that pediatricians currently treat. The yearlong fellowship will develop the individual into a national leader and advocate for adults with diagnoses of autism, cerebral palsy, Down syndrome, spina bifida, and other conditions associated with intellectual disabilities. Our fellows will have clinical training working in a multidisciplinary team within the Texas Children's Hospital-Baylor College of Medicine Transition Medicine Clinic, a clinic dedicated to providing health care for individuals with neurodevelopmental disabilities. Specialty clinical experiences will round out the fellow's experience. Additionally, fellows will gain valuable community exposure in mental health services, long-term care services, community living, employment training, day habilitation with expectation to engage in team building opportunity in the community through partnership with the local LEND (Leadership Education in Neurodevelopmental and Related Disabilities) program.

Improving healthcare for individuals with IDD will require curricular changes in the nation's medical schools, increasing exposure to the population in residency training and continuing education programing for physicians in the community. Ultimately, the goal for medical schools is to expose this type of training to their undergraduate and graduate medical education mission. If enough medical schools recognize the need and develop their own fellowships, the Accreditation Council for Graduate Medical Education (ACGME) hopefully will dedicate resources to this initiative as an area of importance in graduate medical education.

At the end of my visit with the new patient and her mom, we reviewed our discussion and developed a plan of care going forward. We discussed that the patient would have the right to stay in school until she was 22 years old and to start thinking about what types of volunteer and/or job opportunities she wanted to pursue. We reviewed medical insurance changes coming at age 21 and supportive decision making. The patient agreed to come back in three months to discuss adaptive exercising and healthy nutrition. The Developmental Medicine Fellow's training will insure that they too will be able to deliver comprehensive health care aimed at improving the quality of life for individuals with IDD. •

ABOUT THE AUTHOR:

Jordan Kemere, MD is an internal medicine physician at Baylor College of Medicine in Houston, Texas. She works as a primary care doctor at the Texas Children's Hospital-Baylor College of Medicine Transition Medicine Clinic, a clinic dedicated to providing health care for individuals with neurodevelopmental disabilities.

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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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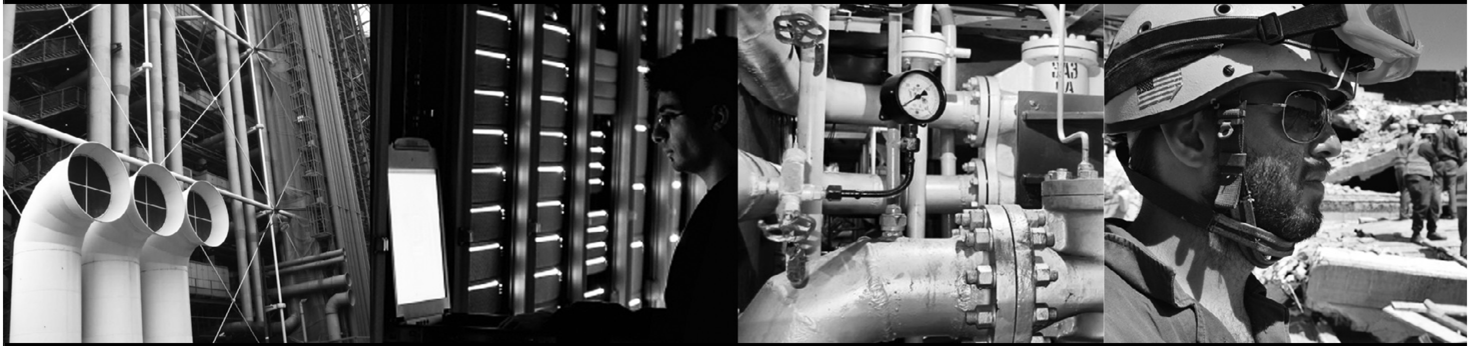

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THE DISABLING CONSEQUENCES OF A TRADITIONAL PRACTICE AND OUR REMEDIES

BY SAYYDAH GARRETT

> *"While we respect and appreciate cultural norms and variants, there are practices that we condemn for their cruelty and inhumanity. We base this on common human practices that provide respect, dignity, and self determination to everyone. This article describes "female mutilation" as practiced in many countries and features an advocate who is dedicated to eradicating the practice. We support Sayydah Garrett and her commitment to protecting the lives of innocent girls and women, many with disabilities and their right to refuse to participate in these indefensible rituals."*
>
> – Rick Rader, MD, Editor in Chief, *EP Magazine* (Exceptional Parent); Dr. Steve Perlman, *EP Magazine*, Editorial Advisory Board

When I went on a solo safari to Kenya in August of 2012 to see my favorite animal, the elephant, in its natural habitat, I certainly never thought that I would return to New Jersey with a promise to eradicate a harmful practice called "female genital mutilation" (FGM).

"Say what?" asked my husband. I told him about my visit to a tribal village in Samburu and how I was fascinated by the beauty of the tribe, colorful attire, amazing hand-beaded jewelry, diet, and how the people welcomed me with songs and dances. When I returned to the lodge in Samburu National Reserve, I summoned Samuel, the young assistant restaurant captain I had met the day before and excitedly showed him pictures of Namayiana Village. I had just visited his village! Who knew? He explained that he was educated, having

PHOTOS PROVIDED BY SAYYDAH GARRETT

studied hotel and restaurant hospitality at a Kenyan university. I asked him to tell me more about life in Samburu.

Most people in his community don't finish secondary school, let alone go to university. And so, here's where my life changed in my mid 50's. Samuel looked up to the sky and in a contemplative tone said, "Sayydah, I want to start a community based organization to eradicate FGM and forced early marriage before it's my youngest sister's turn to get cut."

"THE CUT"

Samuel revealed a tribal practice that tourists don't learn about during their visits to villages. When girls in his pastoralist (semi-nomadic people) community reach puberty, they experience a rite of passage to womanhood which requires them to undergo "the cut." FGM refers to all procedures involving partial or total removal of the external female genitalia, or other injury to the female genital organs for non-medical reasons. The removal of the clitoris and labia is performed by a female circumciser who uses a razor blade and no anesthesia. This non-medical procedure is a human rights violation, illegal, gender-based violence against girls and women, and causes dozens of harmful physical, psychological and emotional effects, even death.

Although practicing communities around the world perform FGM for various reasons, the primary goal is to suppress female sexual desire. Therefore, it is widely believed and accepted that the cut will ensure chastity and fidelity to husbands.

So, why would a Samburu (sister tribe of the Maasai) warrior have this wish? When Samuel's mother was diagnosed with throat cancer and approaching the end of her life, she lamented about not having gone to school and fulfilling her dreams of a better life. She, like 90% of girls in Samburu, underwent FGM and was forced to marry an older man. It was an abusive marriage that ended in divorce. Samuel's mother didn't want the same life outcome for her daughters. Samuel promised his mother that he would take care of his sisters and made a vow to protect them against what he calls "the vice" of FGM. Such a commitment is incredibly unusual for a man whose community is deeply rooted in this tradition.

When I realized how serious Samuel was, I offered to help. "I live 8,000 miles away in New Jersey but I'll help you. I have 10 years of nonprofit experience as a grant writer, fundraiser, and will help raise awareness."

He smiled, pointed at me and said, "Great! You will be our president!" I said, "Ok!" We co-founded Pastoralist Child Foundation (PCF) right then and there. We hadn't known each other 24 hours but I knew instinctively that this was the right thing to do. I believe God is the master planner and this was the real reason for my safari. Oh, and the elephants were amazing!

A BETTER FATE: *(Opposite page)* Makaki Lentoijioni, one of the Pastoralist Child Foundation's first sponsored students, just started studying commerce at the University of Nairobi on a full scholarship; *(Above, left to right)* Janet Sipayo Lenguris and Jenerik Lekapana have both attended a four-day "Alternative Rite of Passage" where "the cut" is replaced by education.

MEDICAL COMPLICATIONS

FGM is unnecessary and creates suffering to its survivors. It causes various medical complications for girls and women – particularly during childbirth. Babies are born with a higher risk of cerebral palsy due to the prolonged, obstructed labor and lack of oxygen during childbirth. The initial shock of being held down by your own mother and aunties in order to become a "woman" results in initial shock, excessive bleeding, PTSD, and a lifetime of

TAKING WING: Brandy Achoto, in grade 10, dreams of becoming a pilot. Quality girls' education empowers by giving them choices, alleviates poverty and yields great returns in socio-economics, health, population and politics.

trust issues; infant and maternal mortality rates increase; painful menstruation and intercourse increases; greater risk of depression, infertility, infections, cysts, and keloids, just to name a few. The vast majority of adults we teach are uneducated and illiterate. Therefore, they have no idea that the symptoms experienced are directly linked to FGM. According to WHO (World Health Organization), 200 Million girls and women around the world have undergone FGM. It doesn't just happen in Africa. Communities in the Middle East, Asia and diaspora communities in the UK, US, Europe, Canada, Australia and New Zealand are also affected. In fact, 500,000 women and girls in the United States are at risk of FGM. "Vacation cutting" is currently a great concern as girls in western countries are sent home to their native countries to get cut during school holidays. PCF has begun healing workshops in the US for victims of FGM.

In Samburu and Maasai Mara, Kenya many girls are forced into early marriage soon after undergoing the rite of passage. Girls drop out of school and never step into a classroom again. Their roles as wives, some in polygamous marriages, include bearing children, cooking, cleaning, fetching water, building huts, and washing clothes in crocodile infested rivers. This makes me very sad and angry. This isn't how teen girls should live. What can they look forward to?

THE SOLUTION IS EDUCATION

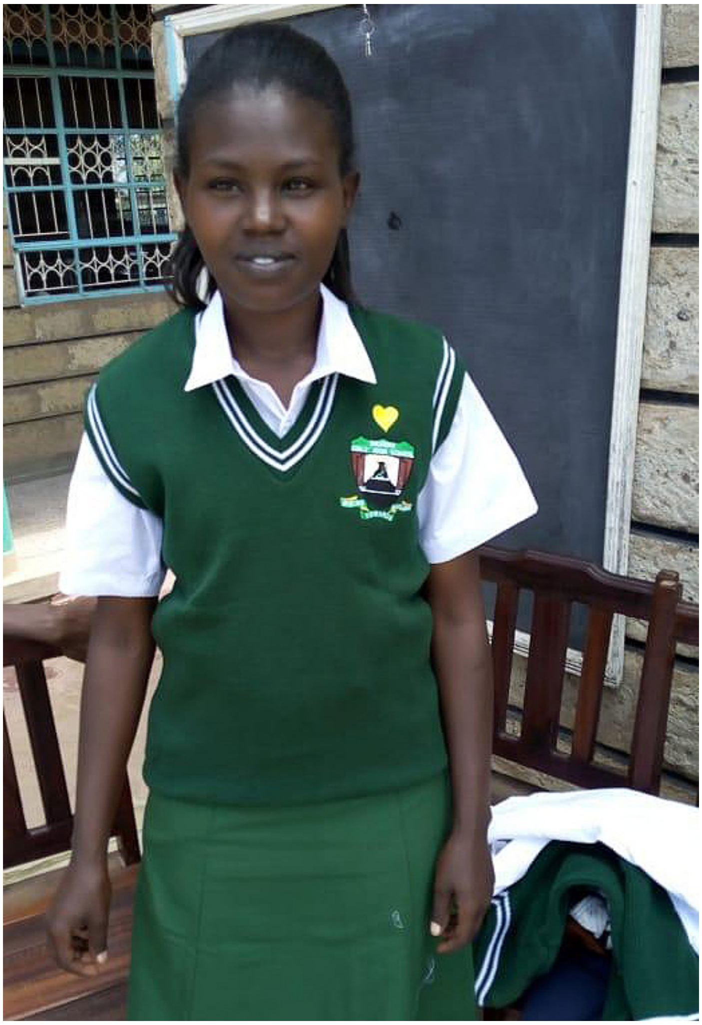
So far, I've presented a bleak picture of a horrific practice. The good news is that PCF has saved over 2,000 girls from undergoing FGM. The solution is education. PCF provides workshops, intergenerational dialogues, and scholarships for girls to attend secondary boarding schools and universities. Our workshop attendees are as young as eight years old up to village chiefs in their 90's. We incorporate the "Do No Harm" approach where every member of the workshop is heard, respected, and taught to work together to resolve conflicting views.

The girls' workshops are a four-day "Alternative Rite of Passage" for 60 participants where "the cut" is replaced by education. The curriculum consists of FGM, child marriage, teen pregnancy, sexual & reproductive health and rights, child rights, HIV/AIDS, self-confidence, self-awareness, and the importance of education. Parents are informed of the curriculum and are aware that PCF's mission is to end a harmful practice. PCF has gained the trust of the communities for its commitment to preserve the positive aspects of the Samburu and Maasai cultures. We only wish to abolish the negative aspects.

In our efforts to accelerate the abandonment of FGM, we collaborate with all stakeholders – teachers, healthcare workers, social workers, religious leaders, local government, village chiefs, former circumcisers, and many anti-FGM activists and organizations around the world who have pledged to end FGM by the year 2030. We're partners with UNICEF-Kenya, UNFPA, the Anti-FGM Board of Kenya, and committed to the United Nations Sustainable Development Goals (SDG's) 3: good health & well-being; 4: quality education; 5: gender equality.

PCF has a scholarship program for girls to attend secondary boarding schools and universities. We interview and select high-performing girls to receive full tuition and boarding at excellent schools. Educated girls are more likely to stay in or near their communities and become mothers who encourage their children to go to school. Quality girls' education empowers by giving them choices, alleviates poverty and yields great returns in socio-economics, health, population and politics. Education leads to increased income for girls themselves, but also for nations as a whole. We currently have 19 sponsored students – 15 in secondary school and 4 in university. The yearly sponsorship rate is $1,500.00 which pays for tuition, exam fees, computer fees, healthcare, transportation, uniforms, bedding, laundry detergent, personal care products, and a private lock box. The girls have realistic dreams about their futures. With hard work and focus on academics, they will become accountants, nurses, doctors, engineers, broadcasters, etc.

Brandy, in grade 10, wants to be a pilot. Imagine if one day I board a plane and see her as my pilot! Wow! And there's Makaki, one of our very first sponsored students and brightest scholar. She just started studying commerce at the University of Nairobi on a



A BRIGHTER FUTURE: Efforts of the Pastoralist Child Foundation have helped Dableya Sambakah, who has been spared FGM and benefited from educational programs.

full scholarship. This is why we do what we do. Education makes all the difference. PCF is keeping its promise to Samuel's mother.

Another method of educating teens is through our annual youth soccer and volleyball tournament. We invite 400 youths from across Samburu County to compete for three days for the coveted PCF trophies. Girls compete in volleyball and boys compete in soccer. All athletes must attend workshops during their stay. The curriculum covers FGM, child marriage, teen pregnancy, HIV/AIDS, and alcohol & substance abuse. Unfortunately, teens don't have constructive after school or weekend activities that prevent them from engaging in risky behaviors. PCF would love to build a youth center where they can learn music, art, theater, sports training, poetry, chess, and other games to pass the time in a positive way.

SUCCESS STORIES

Let's return to Namayiana Village. While in Samburu in 2015, I was requested to meet with the women there. We have become great friends and I love each and every one of them. They always express their gratitude for PCF's dedication to helping them live happier and healthier lives. Many tourists come and go, but very few keep the promise to "stay in touch."

They were excited to give me some news. I wondered, "What could it be? Is someone going to have a baby? Is someone getting married?" Well, it was neither. The women registered their self-help group to generate income so they could send more girls to school. And, the entire village unanimously agreed to never perform FGM on anymore girls! This was the best news ever! They now understood the importance of education. Soon after this announcement, PCF secured a grant for the women to construct a jewelry and artifacts store near Samburu National Reserve. The women sell their beautiful items to tourists and the local community.

Another success story is the formation of two registered women's self-help groups following our youth and adult workshops in Maasai Mara. Each group has 30 women, with a chair lady, secretary, and treasurer. Members pay a nominal monthly membership fee and they decide together how to invest the money. In August, 2019 we facilitated a table banking seminar for the women. We also secured a grant for them to purchase 17 bulls and 40 lambs. The animals will be fattened and sold for a profit. Proceeds will pay for children's school uniforms and school supplies. The women are keen on learning how to sew the uniforms themselves and plan on eventually purchasing sewing machines.

MORE TO DO

I have been to Kenya eight times since 2012. It's a long journey from New Jersey, yet I still get excited about going. My calling arrived almost eight years ago, and although our nonprofit has achieved successful milestones, there's still more to do. The population of Samburu is 260,000 people and in Maasai Mara it's about 1.2 million. I envision the day when FGM is eradicated. It must be eradicated. It causes too much harm and no longer has a place in society. Its time has come, at least by the year 2030. We at Pastoralist Child Foundation are so thankful for each and every person who believes in and supports our work that some call "noble." I am humbled. I am grateful for this opportunity to serve my fellow man and woman, no matter where they may reside. I tell my friends, "You know me. I'm a global citizen. I could have been anywhere in the world at that time of my life. I didn't choose Kenya. It chose me."

So, in August I'll pack three big suitcases with donated soccer cleats, school supplies, clothes, backpacks and candy to distribute to happy, screaming, excited children… okay, adults too.

If you'd like to learn more about PCF (a 501C3 registered nonprofit), make a donation, sponsor a student, collaborate, volunteer, or become a corporate sponsor, please visit our website at **www.pastoralistchildfoundation.org** You may also email me directly at **sayydah@pastoralistchildfoundation.org** or call (973) 980-7860. •

ABOUT THE AUTHOR:

Sayydah Garrett was born in Montreal, Quebec, Canada. Since childhood she has seen her parents set the good example of helping less fortunate people in their community. This instilled the lifelong passion Sayydah has for helping others. Her personal mission statement is, "Tell me what you want and I'll help you get it." Sayydah is a certified ESL (English as a Second Language) and Adult Basic Education (ABE) instructor. She holds a Bachelor of Arts, Honours in Russian Language & Literature from Carleton University in Ottawa, Ontario, Canada. Sayydah lives in New Jersey with her husband, award-winning jazz saxophonist and composer, Kenny Garrett.

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

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MORALE, WELFARE AND RECREATION DIGITAL LIBRARY

Military OneSource provides free, online resources to service members and their families via the Morale, Welfare and Recreation Digital Library. You'll find eBooks and audiobooks on virtually every topic, as well as databases and reference books that can help you learn a new skill, keep kids engaged and serve as a homework source, or prepare you to land your next job.

The Morale, Welfare and Recreation Digital Library (**www.militaryonesourceconnect.org/achievesolutions**) is an incredible free resource for service members and their families. Just log into your Military OneSource account or create a username and password to get started and enjoy browsing. Note that the list provided here includes just some of the resources available. The categories are guidelines only. Many of the resources can be useful or entertaining across age groups.

FOR KIDS

The digital library offers online resources to help children learn to read or keep their grades up, research topics for writing assignments or just find a great story for a long afternoon:

- **BOOKFLIX** pairs classic video storybooks with related nonfiction titles to reinforce early reading skills and develop real-world knowledge.
- **EXPLORA PRIMARY** features a database of colorful and fun resources that help children in grades K – 5 learn about animals, music, health, history, people and places, science, math and sports.
- **GALE IN CONTEXT: MIDDLE SCHOOL** provides reference content to help students complete assignments in literature, science, social studies and history. Offerings include videos, newspapers, magazines, primary sources and much more.
- **NOVELIST K-8 PLUS** offers recommendations specifically for younger readers, helping kids find books that are appropriate for their reading level and interests. Parents, teachers, and librarians can also find tools to teach with books and engage young readers.
- **TUTOR.COM** for military children gives kids access to online tutoring and homework help from live, expert tutors in more than 16 subjects. Tutors can help with tonight's homework or catch your child up on missed concepts and lessons, all for free.

NOTE: Department of Defense Military Community and Family Policy has temporarily expanded program eligibility to Tutor.com beyond Department of Defense Education Activity students and active-duty children to ease academic disruptions due to COVID-19. Through June 30, 2020, online tutoring is available 24/7 through Tutor.com to any adult or child member of DOD civilian, National Guard, Reserve or wounded warrior military families. Students, kindergarten through college, can receive live, on-demand tutoring, homework help and test preparation from expert tutors in more than 100 subjects.

FOR TEENS

Teenagers can take advantage of the library's resources too, including:

- **EBSCO LEARNING EXPRESS** provides eLearning tutorials, practice tests, e-books, flashcards and articles that help users build their skills in a wide array of core subjects for success in the classroom, on the job, and in life, including preparation for CLEP, DSST, ACT, SAT, GRE and more.
- **INTERACTIVE: SCIENCE** provides a comprehensive view of the most-studied science subjects, including biology, chemistry and earth and space science. Reference and periodical content provide additional context for further understanding.
- **FREEDOMFLIX** brings history to life by capturing the dramatic and defining moments in American history through dynamic ebooks with embedded popup features such as maps, timelines, virtual tour clips, primary source videos and audio clips.
- **SCIENCEFLIX** offers more than 50 complete units of study with over 6,500 science-related assets in a variety of media, providing

students with a better understanding of science concepts and ideas through hands-on projects, videos, multiple text types, interactive features and more. This is also a great resource for young children.

- **TRUEFLIX** offers dozens of units to supplement social studies and science core curricula learning, helping students improve literacy skills, build content-area knowledge and cultivate the critical skills necessary for academic success and college and career readiness. This is also a great resource for young children.

FOR ADULTS

For adults looking to advance their education or career, there are even more resources available at the Digital Library.

- **ACADEMIC ONEFILE** provides millions of articles from scholarly journals and other authoritative sources with extensive coverage in key subject areas, such as biology, chemistry, criminal justice, economics, environmental science, history, marketing, political science and psychology.
- **ANCESTRY® LIBRARY** allows you to unlock the story of your family with billions of U.S. and international records.
- **BRAINHQ** can help improve your brain health with clinically proven personalized brain training exercises.
- **BRITANNICA ACADEMIC** allows fast and easy access to thousands of articles, biographies, videos, images and websites. The inclusion of ImageQuest offers more than three million images, all rights-cleared for educational, non-commercial use.
- **BRITANNICA ANNALS OF AMERICAN HISTORY** offers a rich and varied history of the United States, providing a year-by-year documentary of American thought and action. Read the original words of more than 1,500 authors who made and analyzed American history through their speeches, writings, memoirs, poems and interviews.
- **BRITANNICA LIBRARY** provides three sites in one—Children, Young Adults and the Reference Center—where you can conduct research, complete school assignments, work on special projects, or explore your unique interests. You can even store your research in your personal My Britannica account.
- **BUSINESS PLAN BUILDER** provides help for aspiring entrepreneurs, and individuals interested in planning an optimizing their small businesses or nonprofits. It provides a step-by-step process supported by a rich variety of recognized tools that enable users to produce complete business plans and other documents essential for gaining access to capital and growing their enterprise.
- **CAREER TRANSITIONS** will help you map your military experience to civilian jobs, write a resume and cover letter, participate in an interview simulation, find job announcements and more.
- **CHILTON AUTOMOTIVE MAINTENANCE LIBRARY** gives you the information you need to tackle vehicle maintenance and repairs with confidence. The library covers thousands of year, make and model combinations, including the most popular vehicles of the past 30 years.
- **CONSUMER REPORTS** help you find the best deals, ratings, and reviews on thousands of popular consumer items from one of the most respected sources.
- **EBSCO AUDIOBOOK COLLECTION** offer more than 2,000 audiobooks in different subjects and categories available for download. Log in with your EBSCOhost account (software download required).
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- **EBSCO LEARNING EXPRESS** provides eLearning tutorials, practice tests, e-books, flashcards and articles that help users build their skills in a wide array of core subjects for success in the classroom, on the job, and in life, including preparation for CLEP, DSST, ASVAB, GRE and more.
- **ENTREPRENEURSHIP** can help you learn how to plan, fund start or manage your small business. Resources include sample business plans, how-to guides, articles and websites.
- **FOLD3 LIBRARY EDITION** is a premier collection of historical U.S. military records and unique military content, bringing to life the details of America's military veterans with stories, photos and personal documents, from the Revolutionary War through today.
- **FUNK & WAGNALLS NEW WORLD ENCYCLOPEDIA** offers a vast reference library with full articles about thousands of topics.
- **GALE EBOOKS** is a database of encyclopedias and specialized reference sources for multidisciplinary research, which can be accessed remotely 24/7.
- **GALE HEALTH & WELLNESS** offers 24/7 access to full-text medical journals, magazines, reference works, multimedia and much more, covering a full range of health-related issues, from current disease and disorder information to in-depth coverage of alternative medical practices.
- **GALE IN CONTEXT: SCIENCE** is an engaging online experience for those seeking contextual information on hundreds of today's most significant science topics. Content includes full-text magazines, academic journals, news articles, experiments, images, videos and more.
- **GALE ONLINE RESOURCES** features 160 million full-text articles from leading books, journals, magazines, newspapers and primary sources, multimedia assets including videos, podcasts, tutorials and images and daily updates of new content. Additional resources are available through Gale include Opposing Viewpoints in Context, National Geographic Virtual Library and much more.

WORK YOUR WAY UP: Dozens of resources are available at the Digital Library for adults looking to advance their career, including Business Plan Builder and Career Transitions.

U.S. MILITARY ★

- **GREENFILE** contains well-researched information covering all aspects of human impact on the environment. It is provided by EBSCOhost.
- **IMAGEQUEST** brings lesson plans, assignments and projects to life with over three million rights-cleared images from 62 leading collections.
- **KANOPY** provides access to more than 30,000 award-winning films and documentaries anywhere, anytime with any device.

STAY INFORMED: The world's best newspapers and magazines can be found on sites such as Pressreader Digital Newspapers and RBDigital Magazines.

- **LEGAL FORMS** offers a wide selection of state and multi-state-specific legal forms. Users can draft specialized documents in many legal subject areas including: pre-marital agreements, bankruptcy, divorce, landlord/tenant and many others. A comprehensive attorney state directory and dictionary of legal definitions are also included.
- **LIBRARY, INFORMATION, SCIENCE & TECHNOLOGY ABSTRACTS** contains references on librarianship, bibliometrics, online information retrieval, information management and more.
- **MANGO LANGUAGES** is a digital language learning program for learners of all levels, with courses in more than 70 different foreign languages, 21 English language courses and 44 specialty courses. Mango's language-learning methodology is designed to simulate the way people learn a foreign language when actually immersed in everyday conversation.
- **MILITARY AND INTELLIGENCE** provides military personnel with access to scholarly journals, magazines and reports covering all aspects of the past and present military affairs. Updated annually, this library resource contains hand-selected content supporting key subject areas such as, governmental policies, the socioeconomic effects of war, the structure of the armed forces and more.
- **MORNINGSTAR INVESTMENT RESEARCH CENTER** gives you information on stocks and mutual funds. You can visit the Investment Classroom to hone your investing skills, explore dozens of articles and videos about the stock market.
- **NATIONAL GEOGRAPHIC VIRTUAL LIBRARY** includes every article of National Geographic magazine from 1888 through 1994. Users can search vivid photographs and historic articles.
- **NOVELIST PLUS** is a trusted source of expert reading recommendations for both fiction and nonfiction, and for all ages.
- **PRESSREADER DIGITAL NEWSPAPERS** provides interactive, digital access to nearly 7,000 of the world's best newspapers and magazines. Just like reading a print edition, viewers can browse articles and other key elements, including pictures, advertisements, classifieds and notices in full-color.
- **RBDIGITAL EBOOKS AND AUDIOBOOKS** provides a library of digital content that you can download or your home computer or mobile device.
- **RBDIGITAL MAGAZINES** allows you to read or download a large assortment of popular news and special interest digital magazines on your PC, smartphone or laptop. Use the access key MOSDOD to create your account.
- **O'REILLY ONLINE LEARNING** (previously Safari Books Online) provides access to more than 57,000 eBooks, videos, live learning and interactive coding sandboxes and tutorials.
- **SMALL ENGINE REPAIR REFERENCE CENTER** offers hundreds of reference books with original photos and illustrations of engines for motorcycles, all-terrain vehicles, snowmobiles, boats, outdoor power equipment, tractors, generators and other small engines.
- **STINGRAY QELLO CONCERTS** offer the world's largest collection of full-length concerts and music documentaries streamed on-demand to just about any digital device. From the 1920s to today's hottest artists, Qello Concerts spans more than 30 genres, from classical to rock, reggae to country. Enjoy more than 1,700 live moments in music history.
- **TEACHABLES** provides access to more than 15,000 teacher-created, vetted printables to support instruction. Download activities for any pre-K to 6th 8th grade subject: math, science, reading comprehension, STEM, writing and beyond. Download printable lesson plans, reading passages, games and puzzles, clip art, bulletin board ideas, teacher supports, and skills sheets.
- **TEACHER REFERENCE CENTER** has indexing and abstracts for more than 270 of the most popular teacher and administrator journals and magazines.
- **UNIVERSAL CLASS** offers lifelong learning courses in over 30 subject areas, many of which offer continuing education units (CEUs). More than 500 courses are available, and all are designed and led by professional instructors to build deeper understanding and mastery of subject matter. Universal Class includes videos, assignments, quizzes, tests and options for social media interaction with other learners. Patrons may take multiple classes and learn at their own pace.
- **U.S. MAJOR DAILIES** provides full-text, same day publication access to five major U.S. newspapers: The New York Times, The Wall Street Journal, Chicago Tribune, Los Angeles Times and The Washington Post. New content available by 8 a.m. U.S. Eastern time each day.
- **WEISS FINANCIAL RATINGS** offers access to financial literacy tools on retirement planning, home and mortgage, insurance strategies, and saving for your child's education.

The Morale, Welfare and Recreation Digital Library is an incredible free resource for service members and their families. Just log into your Military OneSource account or create a username and password to get started and enjoy browsing. Access the library at **www.militaryonesourceconnect.org/achievesolutions**

– Military One Source

Coronavirus.org

Artwork by Shepard Fairey | Amplifier.org

ad COUNCIL

MILITARY DISCOUNTS ON RECREATION AND ENTERTAINMENT

If you're looking for discounted travel, entertainment and recreation opportunities, consider taking advantage of your military discounts. Your military ID is your ticket to military resorts, discount flights, vacation packages, and more opportunities for fun and relaxation.

> *“Military resorts are located in popular vacation destinations such as Disney World and Hawaii. Military families are eligible to use military lodging around the world, ranging from cottages on the beach to world-class resorts”*

ACCESS FUN WITH INFORMATION, TICKETS AND TRAVEL

Your installation’s Information, Tickets and Travel office, (**https://installations.militaryonesource.mil**) sometimes referred to as Morale, Welfare and Recreation, is where you’ll find discounted recreation for you and your family.

To take advantage of recreation and leisure travel, you’ll need to provide proof of Department of Defense affiliation—a military ID or a leave and earning statements. Once you’ve provided proof, you and your family can begin to receive military discounts on the following:

- *Local attraction tickets*
- *Destination attraction tickets*
- *Concerts and sporting events*
- *Day trips and tours*
- *Cruises*
- *Rental cars*
- *Flights*
- *Lodging*
- *Leisure travel services*

You can also take advantage of exclusive offers available only to service members and avoid extra fees like tax or facility fees. Your installation’s website may also feature a price list that allows you to browse available attractions, events and destinations and compare prices.

FIND MILITARY LODGING AND RESORTS AROUND THE WORLD

Military families are eligible to use military lodging around the world, ranging from cottages on the beach to world-class resorts. These facilities provide a selection of affordable, safe and fun places to vacation, but keep in mind your status will usually determine when and how your reservation can be made. The type of facilities available are:

- *Installation lodging: Located mostly on military installations, these facilities are generally designed for service members traveling on official business or families with permanent change of station orders.*
- *Recreation facilities: For families interested in short or long getaways, these facilities offer lodging, rental equipment, tours and other activities at an economical rate.*
- *Resorts: Military resorts are located in popular vacation destinations such as Disney World® and Hawaii, and in areas with a large military presence, such as Japan, Korea and Germany.*

  You can usually make reservations, but you should plan ahead for travel during peak periods.

  Rates will be based on rank and duty status, but are generally lower than comparable civilian lodging.
- *Nongovernment-owned hotels: Managed by private nonprofit organizations, hotels such as Marines’ Memorial Club in San Francisco or Soldiers', Sailors', Marines', Coast Guard and Airmen's Club (**www.ssmaclub.org**) in New York serve active-duty and former service members.*

PLANNING YOUR GETAWAY

You should research military lodging in the area you want to visit, as well as the amenities and reservation policies. Here are a few things to keep in mind:

- *Find the best time to go: If you plan on visiting a resort during peak vacation period, such as summer time, be sure to make your reservations as soon as possible. Keep in mind that some lodging facilities prioritize reservations by branch of service, duty station or status.*
- *Use military lodging and service branch websites:*

  Army MWR **www.armymwr.com**

  Marine Corps Community Services **www.usmc-mccs.org/services/activities/tickets-travel/**

  Navy Lodges **www.navy-lodge.com**

  Air Force Inns **af.dodlodging.net**
- *Take advantage of leisure services: Many facilities offer services such as restaurants, boat rentals, ski equipment rental, area tours and discount tickets to area attractions. Before making your reservations, be sure to inquire about available services and if they require advance reservations.*

If you need travel inspiration or help finding military discounts, you can call Military OneSource and speak with one of our consultants at 800-342-9647.

– Military One Source

PUZZLES & CAMO SHELLY HUHTANEN

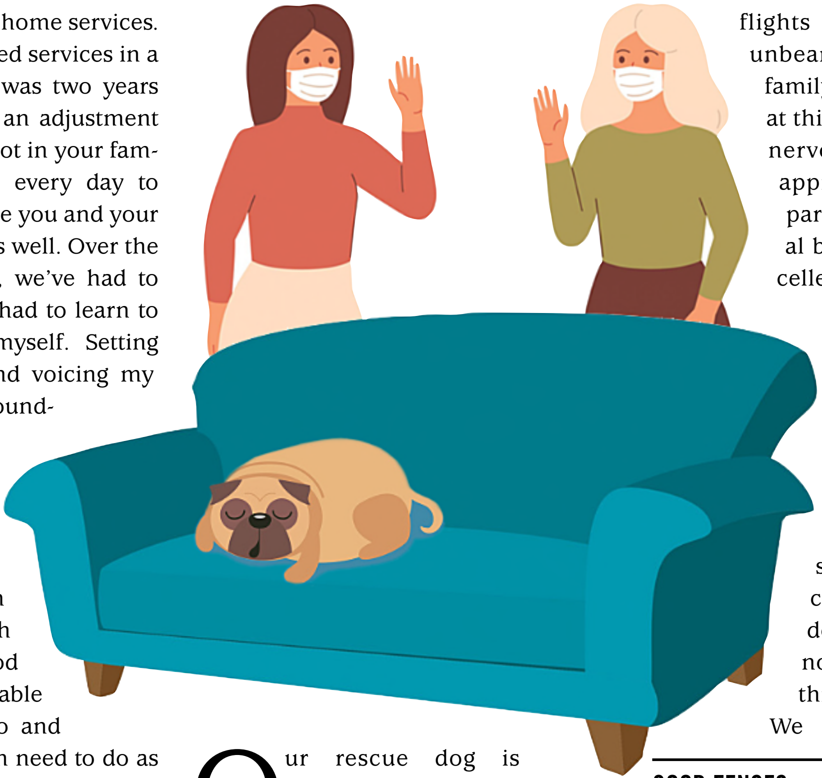
This Too Shall Pass

As I sit on my couch next to my snoring rescue dog, and as my son's ABA therapist gathers her things for the day, I'm reminded that I need to be grateful for good friends, supportive family, and flexible ABA services for my son.

With no end in sight to the pandemic, I admit I've almost forgotten what my life was like before it all happened. All I know is that we've made it to May and April in a discombobulated blob of denial, frustration and adjustment. I would be lying if I said that I haven't spent time in my master bathroom quietly crying because I don't know what normal looks like anymore. Is this our new normal? If it is, I realized I needed to come to terms with it and focus on moving forward.

My son is still receiving in-home ABA services since the clinic has temporarily closed due to COVID-19. This is the first time we have ever had in-home services. Broden has always received services in a clinical setting since he was two years old. It is definitely quite an adjustment having someone who is not in your family come to your home every day to work with one child, while you and your other child are at home as well. Over the course of the six weeks, we've had to learn to coexist and I've had to learn to be more honest with myself. Setting boundaries is healthy and voicing my need for more defined boundaries in my home while my son receives therapy does not make me a bad mom. I'm a mom who is a realist and understands that if I'm going to make it through this home therapy period in one piece, I need to be able to do what I need to do and support what my children need to do as well. This is a lesson I've had to learn through this quarantine mess.

The college course I'm teaching online is coming to an end and I've already started to understand that I will need to find other things to fill my day that will be my own. Between helping my oldest with school work and reminding him to spend more time outside to get fresh air, and keeping abreast of my youngest son's in-home ABA program, I still had enough time to have the craziest idea of adopting a rescue dog. I know. Adopting a rescue dog during this insane time is like sitting in an idling car on the edge of a cliff and slamming my foot on the gas. What was I thinking?



Our rescue dog is named Jack and I have never seen a dog destroy a decorative pillow as fast has he can. He has the worst gas out of all of us combined and he snores louder than my husband. I never knew I could find any living thing that could accomplish that feat. The one thing he has going for him is that he is the cutest thing and there is an overpowering need to save him because he's had such a hard life. I remind myself of that fact as I scrub his urine out of my light cream rug.

One thing is certain – taking care of needy animals helps distract me from the idea that I have not seen my family in Texas for quite a while. Being away from them for so long has been difficult, and not being allowed to see them due to flights cancelled is almost unbearable. Every year, my family goes to the beach and, at this time, I'm getting more nervous as the date approaches. I'm not prepared to say that our annual beach trip could be cancelled, but as time creeps on, I'm wondering if this will soon be another event down the COVID-19 drain. I still remain hopeful as I stock up on sunscreen.

Even though daily schedules have changed, and fancy designer face masks are now in style, there is one thing that remains true. We are not alone, even

GOOD FENCES: Over the course of the six weeks, we've had to learn to coexist and I've had to learn to be more honest with myself. Setting boundaries is healthy and voicing my need for more defined boundaries in my home while my son receives therapy does not make me a bad mom.

though we may feel it at times. Earlier today, one of my neighbors texted me, "Can you come outside? We are social distancing with face masks out front in our cul de sac." Hayden scurried downstairs to watch Jack so he wouldn't eat our couch, and I grabbed my flip flops to run out the door. I hadn't seen one neighbor of mine in almost a month. For about 30 minutes, we were able to see each other and share stories of how we were making it through. They reminded me how much I miss seeing them, but social-distancing rendezvous may be the only way I can see them for a while.

> "I need to be grateful for good friends, supportive family, and flexible ABA services for my son. By staying true to myself and ensuring I have boundaries, hopefully I'll be able to appreciate the good stuff during this quarantine craziness and spend time with the people I care about and love."

As I sit on my couch next to my snoring rescue dog, and as my son's ABA therapist gathers her things for the day, I'm reminded that I need to be grateful for good friends, supportive family, and flexible ABA services for my son. By staying true to myself and ensuring I have boundaries, hopefully I'll be able to appreciate the good stuff during this quarantine craziness and spend time with the people I care about and love.

I want to look back and know that when there were challenges, I was able to look within and find the positive, as opposed to drowning in the negative. This pandemic has created a new normal for all of us and we'll need to dig deep and find a way through it. In the words of someone trying to pass a kidney stone, this too shall pass.•

PUZZLES & CAMO

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

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