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AND:

GENETIC TESTING *in* PSYCHIATRY

ALSO IN THIS ISSUE:

POST-SECONDARY EDUCATION *for* YOUTH WITH DISABILITIES

PLUS • AADMD:

LGBTQ PEOPLE *with* DISABILITIES

CONTENTS

MARCH 2021 VOLUME 51 ISSUE 3

SCHOOLS, CAMPS AND RESIDENCES


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SCHOOL, CAMPS, & RESIDENCES

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COVER STORY
Philadelphia's Disability Arts Festival
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United States Military Section

Operation Giveback

Transfer During a Transition Phase in Your Child's Care

FEATURES

ON OUR COVER

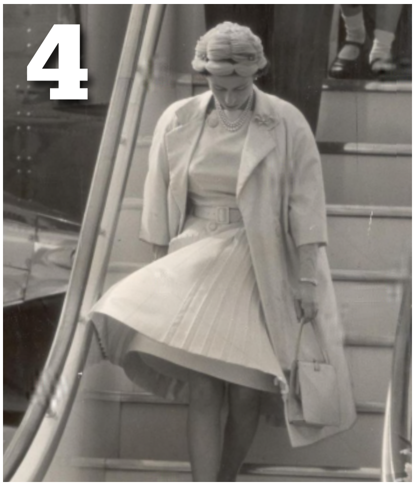
Superchefs Founder Greg Chang with camper Sahib Bhatti and counselors Cassandra Verseveldt and Malia Koslowsky; photo by Chiara Casellato. *Story on page 18.*

CONTENTS

MARCH 2021 VOLUME 51 ISSUE 3

DEPARTMENTS

MILITARY SECTION



56 BUILDING RESILIENCY THROUGH A COLLABORATIVE IEP PROCESS IN SUPPORT OF MILITARY FAMILIES
By Angela Shaw

MILITARY LIFE
59 STAYING CONNECTED WITH YOUR CHILD'S TEACHERS DURING A DEPLOYMENT

60 GET YOUR CHILD THE RIGHT START WITH SURE START

61 HEALTHY, ACTIVE CHILDREN AND ACADEMIC ACHIEVEMENT

PUZZLES AND CAMO
62 CAREGIVER STRENGTH
By Shelly Huhtanen

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

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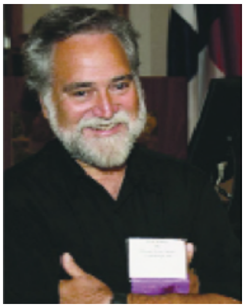
On Gravity and the Queen's Dress

You can be sure that parents of children with disabilities don't think of hiding, preventing or concealing the "incongruities" that are part of human nature, part of the human condition. In fact, they welcome them. They are signs of life without limits.

It's three o'clock in the morning and obviously I'm not asleep.

It's not due to a sleep disorder or anything burning a hole in my soul; in fact, I had a great eight hours. I was exhausted from a string of late nights and fell asleep at 7 o'clock. So it's three o'clock in the morning and I'm wide awake. I opted to go channel surfing and found a channel with a marathon featuring the Three Stooges. I knew this is where I wanted to spend some time before I figured out a way to reconfigure my sleep-awake cycle. I am no stranger to the Three Stooges. It was one of my favorite TV shows growing up. I loved the antics of Moe, Larry and Curly. They were an American vaudeville and comedy team active from 1922 until 1970. They were best known for their 190 short subject films which have been airing regularly on television since 1958.



Michael Fleming in *The Three Stooges: From Amalgamated Morons to American Icons* wrote: "Their hallmark styles were physical farce and slapstick." What ten-year- old could resist the humor of seeing grown men slap each other across the face, hit each other over the head with a mallet, poke each other in the eye, or twist their noses? Any episode of the Three Stooges defined slapstick. They were the doyens of this brand of humor. Slapstick "is a form of humor that employs exaggerated physical activity that goes beyond the boundaries of normal physical comedy." The violence comes in two flavors; either it is intentional or it occurs by mishap. A classic is one person carrying a mop over their shoulder who turns around and smacks an innocent bystander in the face. Where one might consider that traumatic and begin to feel empathy for the victim, there is a reason why that can also appear to be hilarious.

DRESSED FOR SUCCESS: Queen Elizabeth returning to England from a 1959 royal tour; Weights sewn into the bottom hem prevented her dresses from flying above her knees. Assistants used circular lead curtain weights at a price of two dollars for a packet of four.

PHOTO BY F. APTHORP/DAILY MAIL

The term arises from a device used in 16th century Italian stage production consisting of two wooden sticks or slats. When stuck together, the impact produces a loud smacking noise. It was used to convey to the audience that someone was forcefully slapped. It wasn't just the Italians who saw the humor in smacking each other around. Shakespeare was fond of the effect and used it in many of his comedies, including his play, The Comedy of Errors. Slapstick relies on the "visual gag," or "sight gag." They convey humor visually, often without words. They often rely on a physical impossibility or an unexpected occurrence.

Humor leads to laughter, and the research is abundant that laughter is a both a health mediator and health process initiator. There are three main theories of humor and each serves to explain what humor is and why we might think something is funny. There is the relief theory, the superiority theory, and the incongruity theory. While, no joke, each proponent of the three theories all think their theory covers the essence of humor the best, humor most probably has elements of all three.

The Three Stooges thrive in the third theory, "The Incongruous Juxtaposition Theory". And before you so cleverly think, "You're kidding me, right?"... think about it. M.P. Mulder offers in *Humor Research: State of the Art* that "the incongruity theory states that humor is perceived at the moment of realization of incongruity between a concept involved in a certain situation and the real objects thought to be in some relation to the concept." I translate that into "laughter is a response to seeing something that is not supposed to be happening." A prime example is seeing a sophisticated gentleman in a tuxedo wearing a top hat, and watching him get hit with a snowball. That's not what is supposed to happen to sophisticated gentlemen. In 2015, former President Obama nearly tripped walking down the staircase from Air Force One. He caught himself and laughed it off. When it was immediately certain that he was not hurt, the "sight gag" was repeated on every newscast. The President became the poster boy of "incongruity." Presidents aren't supposed to slip, slide or fall. Former President Trump had an intense fear of falling, not based on personal injury, but in the visual of "that ain't supposed to happen." Trump was seen holding on to arms around the world while negotiating stairs.

Even an innocent ketchup stain on a clean, pressed white shirt elicits a smirk. Jim Henson, the creator of the Muppets, promoted the incongruity of humor with, "Beauty is in the eye of the beholder and it may be necessary from time to time to give a stupid or misinformed beholder a black eye." The black eye, a well-defined, circular sign around an eye has given many viewers a good laugh. The context is different if you're an emergency room doctor and it suggests potential ophthalmic, skull and brain injury.

The British royals know a thing about incongruity and go to lengths to prevent it from happening to its members.

Who could forget the scene from the 1954 movie, *The Seven Year Itch,* where Marilyn Monroe stood on a subway grate in New York City wearing a little white dress, and fought an upward breeze? The scene went on to become one of the most iconic moments in movie history. Despite its incongruity, no one thought it was a laughing matter, and most male viewers viewed it as a gift.

> "There are other things on the 'to-do list,' like being invited, being included, being respected, and being there."

The thought of that scenario happening to Queen Elizabeth had kept the royal wardrobe custodians up at night for decades. Their biggest fear was having her Majesty exit the plane on a state visit and having a windy updraft lift her dress as she descended the jet staircase.

Angela Kelly, the assistant responsible for the Queen's dresses, has revealed that weights sewn into the bottom hem of her dresses prevent the dress from flying above her knees. They use circular lead curtain weights at a price of two dollars for a packet of four. It is unclear if that appears as a line item on the Queen's reimbursement documents. Even picturing the 95-year-old monarch in a pose reminsescent of Marilyn's subway grate scene will guarantee a stay in the Tower of London for the offender.

Rising dresses aren't the only concern of the royals. Great lengths go towards ensuring that the Royals will never display ordinary human "incongruities." The Queen has specially-designed pins that guarantee her hats will never leave her head. She relies on hair nets. She also wears sticky pads in her shoes to insure they will never slip off and show that the stuff that happens to her subjects can also happen to her. The theory is, how can you have respect for a monarch who might lose a slipper? One wonders about the fate of the fairy tale Cinderella, if she insisted on wearing duct tape in her slippers. The Prince would have been out of luck since they didn't have closed circuit video surveillance cameras on royal staircases to track her down. Oh, the Queen also wears special leggings that prevent her from exhibiting any varicose veins (as if no 95-year-old woman has ever been prone to that indignation).

You can be sure that parents of children with disabilities don't think of hiding, preventing or concealing the "incongruities" that are part of human nature, part of the human condition. In fact, they welcome them. They are signs of life without limits. Children with complex disabilities have an abundance of protocols that prevent them from being injured, ignored or invisible. Providing "interventions" that prevent them from being viewed as who they genuinely are have never been endorsed by the disability community. It's okay if they lose a shoe, pass some gas, wear a helmet, or rock their heads. There are other things on the "to-do list." Other things like being invited, being included, being respected, and being there.

I stayed with the Three Stooges for about two hours before I got up, showered, got dressed and went to work. All the while thinking, how do you poke someone in the eye without actually hurting them?

It was enough for me that they knew how. •

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

WHAT'S HAPPENING

AN UPDATE ON AUTISM SPEAKS DIVERSITY, EQUITY, ACCESS AND INCLUSION (DEAI) EFFORTS

As an organization, Autism Speaks is working to achieve its vision of a world where all people with autism can reach their full potential, including those in minority communities who face greater disparities.

With this in mind, Autism Speaks recently shared an update on their diversity, equity, access and inclusion (DEAI) efforts. Recognizing that this important work will take time, Autism Speaks continues efforts already underway, while identifying new ways to sharpen their focus on the specific needs of people with autism in Black and other communities of color:

- **Advocating with and alongside the community:** Across the U.S, we advocate at the state level for expanded Medicaid coverage of services for children with autism which has provided access to care for individuals of all ethnicities and has had a meaningful impact on communities of color. We inform and engage Congress on inequities in autism healthcare for minority and other underserved groups and hosted a 2019 Congressional briefing (www.autismspeaks.org/advocacy-news/autism-disparities-addressing-needs-underserved-communities) on the topic. We advocated for the expansion of federal autism research investment in projects serving the needs of underserved groups in the Autism CARES Act of 2019. Advocacy efforts at the grassroots, state and federal levels will remain central to the organization now and well into the future.

REACHING HIGHER: In partnership with Autism Speaks, The Autism Intervention Research Network on Physical Health (AIR-P) aims to increase the evidence base for effective interventions and treatments, develop clinical guidelines and reduce inequalities in ASD care. It also seeks to accelerate the speed at which effective interventions and guidelines are adopted into clinical practice settings.

- **Engaging partners & peers:** Autism Speaks is committed to engaging, convening and supporting other organizations and families in the community in order to expand the impact of our mission, coordinate resources and advocate for priorities in the Black autism community. We also engage with the autism research community to shape research priorities, such as through our 2019 Thought Leadership Summit on Health Equity (www.autismspeaks.org/science-news/advocates-and-researchers-discuss-solutions-reduce-autism-health-care-disparities) featuring keynote remarks (www.facebook.com/watch/?v=569044620594281) by the co-chair and co-founder of the Congressional Caucus on Black Women and Girls, Rep. Bonnie Watson Coleman (D-NJ).This summit addressed barriers such as systemic racism and environmental justice. We are committed to continuing engagements like these to advocate with and for the Black autism community.
- **Ensuring access to early screening and supports:** Since 2007, we have worked with the Ad Council to lower the age of diagnosis, with a focus on underserved populations. We are starting to see the results of this work based upon the latest CDC findings (www.autismspeaks.org/press-release/cdc-estimate-autism-prevalence-increases-nearly-10-percent-1-54-children-us) , which show the gap in age of diagnosis between Black and white children has started to close, but we also recognize there is more work to be done to further improve timely access to supports and services once a child has been diagnosed. Through our work with the Ad Council and other partners, we remain focused on continuing to close this gap through public service campaigns, education and outreach.
- **Providing quality care through the Autism Treatment Network:** In partnership with the Autism Intervention

IMAGE PROVIDED BY AIR-P

WHAT'S HAPPENING

Research Network on Physical Health, we devote at least half of all activities in the Autism Speaks Autism Treatment Network to improving autism care for underserved groups. We recently released three new videos and five one-page tip sheets from some of the most used tool kits in our resources to help make these resources more widely available.

- **Activating local communities through outreach:** Being active in local communities is important to Autism Speaks. Our Outreach and community events bring together young adults and adults with autism, families, local groups and businesses and service providers from diverse backgrounds to share resources, examine needs, explore opportunities and connect with available resources and expertise. We also engage the community through online resources including: tool kits (www.autismspeaks.org/autism-speaks-tool-kits) and guides to help people with autism and their families with a variety of topics; Blue Blessings (www.autismspeaks.org/blueblessings), a guidebook for faith-based organizations to create more inclusive environments for people with autism; and webinars that cover a wide range of topics. Further, we provide a platform for autistic people to share their stories through our website, social channels and outreach efforts to highlight the diversity of experiences within the community. Anyone who would like to share their story is invited to reach out to us through social media or to send an email to connectwithus@autismspeaks.org.

> ***Recognizing that their DEAI efforts will take time, Autism Speaks continues to find and implement meaningful solutions to help people with autism and their families feel safe and supported in their communities.***

- **Action to engage and educate law enforcement:** Nationally, individuals with autism spectrum disorder (ASD) are seven times more likely to interact with law enforcement officers than their peers without disabilities. We have partnered with Dr. Lindsay Shea of Drexel University, who is leading the development of a policy brief devoted to the criminal justice system and the treatment of people with autism. Members of the Autism Speaks services and support team have served on this committee leading this effort for the past year, and the resulting policy brief will be shared publicly in the year ahead. We know that the brief will have significant impact for our community."

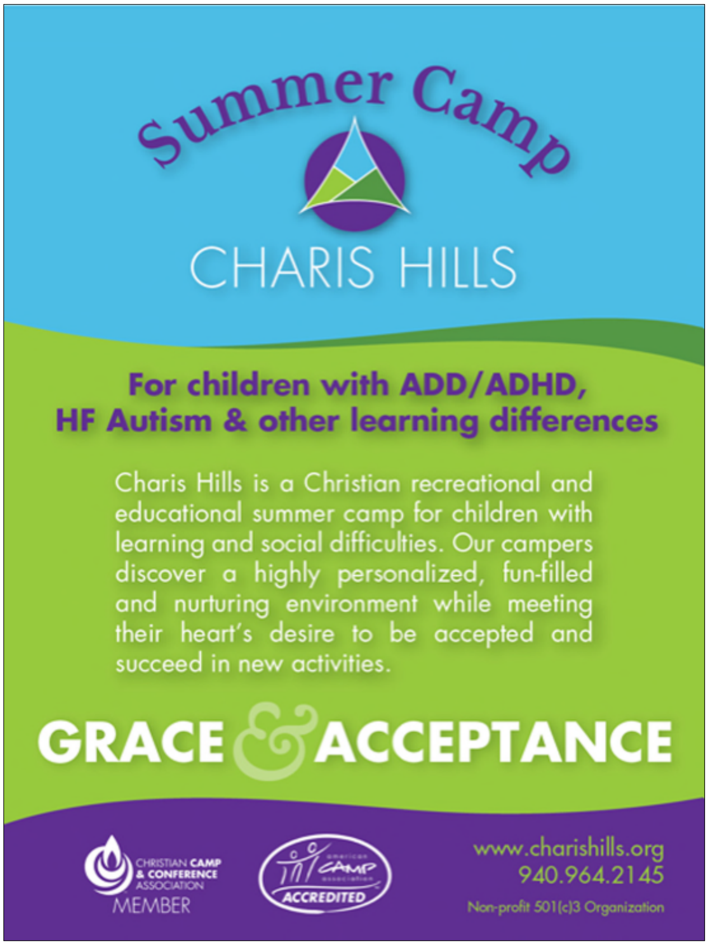
Finally, as part of Autism Speaks' ongoing DEAI efforts, their aim is to find and implement meaningful solutions to help people with autism and their families feel safe and supported in their communities. Autism Speaks is working with minority-owned diversity consultancy Nonprofit HR (https://www.nonprofithr.com/to help guide the next steps. By reviewing internal and external data about their work to date, they are looking to shape a targeted strategy to inform their work in the future.

Autism Speaks welcomes an ongoing dialogue. Please reach via ConnectWithUs@autismspeaks.org. *For information on how you can advocate for the diverse autism community, visit* autismspeaks.org/advocate.

ABOUT AUTISM SPEAKS

autism speaks

Autism Speaks is dedicated to promoting solutions, across the spectrum and throughout the life span, for the needs of individuals with autism and their families. Autism Speaks does this through advocacy and support; increasing understanding and acceptance of people with autism; and advancing research into causes and better interventions for autism spectrum disorder and related conditions. Through partnerships and collaboration, Autism Speaks is committed to increasing global understanding & acceptance of people with autism; being a catalyst for life-enhancing research breakthroughs; increasing early childhood screening & timely interventions; improving the transition to adulthood and ensuring access to reliable information & services throughout the life span Learn more at www.autismspeaks.org



WHAT'S HAPPENING

BRUSH UP ON YOUR DENTAL CARE ROUTINE

On average, four out of every ten athletes with intellectual disabilities on a Special Olympics team are experiencing untreated tooth decay, and one to two of them need urgent dental care. Significant challenges in accessing quality health care and a lack of accessible materials result in pronounced health disparities among people with intellectual disabilities.

ON YOUR MARK, GET SET, BRUSH!: Special Olympics athletes Novie Craven and Justin Hunsinger are joined by Dr. Ho and Dr. Navarro from The Smile Generation® to encourage good oral health and teach proper brushing, flossing, and oral hygiene techniques. When left untreated, oral disease can be painful and expensive to treat.

Special Olympics has been documenting these disparities for more than 20 years through its Healthy Athletes Special Smiles health screenings.

Special Olympics athletes Novie Craven and Justin Hunsinger partnered with a group of dentists from The Smile Generation® to create a set of educational materials for people with intellectual disabilities. These include a Caregiver's Guide to Good Oral Health and a fun "how to" video. Their focus was to make sure these materials are easy to understand, share, and put into practice by people of all abilities: www.specialolympics.org/oral-health

"As Special Olympics athletes, we want to make sure we do everything to keep our bodies healthy, including our smiles," shares Novie Craven, a Special Olympics athlete from Washington, DC.

Novie and Justin looked to Smile Generation-trusted dentists Dr. Isaac Navarro and Dr. Miran Ho for help with their questions about preparing for a dental visit, flossing, adapting toothbrushes, COVID-19 safety and more. Dr. Ho explains: "Having a healthy mouth allows you to eat, speak, sleep well, be alert and compete. Everything from your brain, to your heart, to your feet is impacted by oral health. Every time you breathe, whatever is in your mouth, goes into your body."

With World Oral Health Day (www.worldoralhealthday.org) celebrated on March 20, now is the perfect time to encourage everyone in your life to 'brush up' on their dental care routine. A healthy smile is an important part of your overall health. •

Visit www.specialolympics.org/oral-health *and* www.smilegeneration.com/education/mouth-body-connection *to access a range of interactive resources.*

PHOTO COURTESY SPECIAL OLYMPICS

LJS Fac/X

WE CAN HANDLE YOUR PROJECT

HOME ELEVATORS • STAIR ELEVATORS • AUTOMATED SYSTEMS

Bring together more than thirty professionals, each a craftsman in his or her former industry, in one organization and no industry, situation, or challenge will be new to us. Not to say that we've seen it all. Technology adds novel challenges daily, making a flexible organization – one willing to grow in those new disciplines – invaluable.

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

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

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LJS FAC/X

AMERICAN ACADEMY OF DEVELOPMENTAL MEDICINE & DENTISTRY

LGBTQ People with Disabilities

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

> *“More than one-third of LGBTQ adults identify as having a disability”* [1] (Note: LGBTQ is the abbreviation for lesbian, gay, bisexual, transgender and queer or questioning persons.[2]*)*

> *“Working with gay and lesbian consumers with disabilities has become an imperative of cultural diversity.”* [3]

> *“Both people who identify as LGBTQ and people who have invisible disabilities such as learning disabilities like dyslexia, mental health or ADHD have to decide whether or not to ‘come out of the closet.’”* [1]

Norm-breaking sexuality and gender identity are still relatively invisible in habilitation centers. People with ID are still predominately desexualized and perceptions regarding their sexuality are lagging behind the rest of society. [4]

The decision to go public is not an easy decision for most people because of the uncertainty of whether or not they will be accepted. LGBTQ youths who come out sometimes are rejected by their families and friends. Some are even kicked out of their homes and forced to live on the streets. According to a University of Chicago report, LGBTQ young adults had a 120 percent higher risk of reporting homelessness compared to youth who identified as heterosexual and cisgender (i.e., a person whose gender identity corresponds with the sex the person had or was identified as having at birth). [1,2]

There is substantial literature regarding **young gay people with intellectual disabilities** (ID) that emphasize the complexity and

AMERICAN ACADEMY OF DEVELOPMENTAL MEDICINE AND DENTISTRY

AADMD

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.

the invisibility of this group. The possibilities to demonstrate a variety of sexual expressions are dependent on the attitudes and behaviors toward them. "Therefore it is important to teach about different sexualities in the sex education at schools… without having the heterosexual norm as a starting point." [5]

SOME SPECIFICS

- Within an **ableist culture**, people with ID have been recognized as eternal children and asexual. (*__Ableism__ is the discrimination of and social prejudice against people with disabilities based on the belief that typical abilities are superior. At its heart, ableism is rooted in the assumption that people with disabilities require 'fixing' and defines people by their disability.*[6])
- Individuals with ID who pursue sexual relationships with members of the same sex or embraced a sexual orientation different to the norm were seen as unnatural and immoral. [7]
- Individuals on the autism spectrum may be more likely to identify as homosexual and experience more unpredictable gender identity. [8]
- In dire situations, gay men with ID have exercised self-harm, either intentionally ending one's life or attempted suicide, to alleviate emotional distress and combat the stigma associated with internalized homophobia.
- There are reports that lesbian women with ID are under-represented in society when compared to gay men with ID.

Conducting sexuality research among youngsters has been proven to be difficult due to the sensitive and confrontational

IT WILL GET BETTER : HEALTH AND SOCIAL SERVICES FOR LGBTQs WITH DISABILITIES

"Having to 'come out.' Being called 'abnormal.' Or described as 'queer.' All of these phrases are regularly used as descriptions of non-straight sexualities, yet they work equally well as definitions of disability." [9]

REACHOUT USA

www.reachoutusa.org

ReachOut USA focuses on the intersection between disability and LGBTQ concerns. ReachOut USA seeks to influence people with disabilities to be more responsive to LGBTQ individuals and at the same time influence LGBTQ individuals and organizations to be more accountable to people who have disabilities. ReachOut USA pursues these goals through advocacy, training, and technical assistance.

THE DEAF QUEER RESOURCE CENTER (DQRC)

www.deafqueer.org

The Deaf Queer Resource Center is a national nonprofit resource and information center for, by and about the Deaf Lesbian, Gay, Bisexual, Transgender, Transsexual, Intersex and Questioning communities (hereafter referred to as the "Deaf Queer community"). This is "the place" to find the most comprehensive and accurate information about this unique community.

BLIND LGBT PRIDE INTERNATIONAL

wwww.blindlgbtpride.org

Blind LGBT Pride International is the largest organization of its kind in the world serving vision-impaired people in Canada, England and Japan, as well as the United States.

AXIS DANCE COMPANY

www.axisdance.org

AXIS Invalid began in 1987 with vision to gather a group of dancers with and without disabilities to explore dance and create a performance piece. [9]

RAINBOW ALLIANCE OF THE DEAF

Resources for Deaf Lesbian, Gay, Bisexual, Transgender Individuals

www.deafrad.org

"The Rainbow Alliance of the Deaf (RAD) is a 501(c)(3) nonprofit organization established in 1977. The purpose of this Alliance is to establish and maintain a society of the Deaf LGBT to encourage and promote the educational, economical, and social welfare; to foster fellowship; to defend our rights; and advance our interests as Deaf LGBT citizens concerning social justice; to build up an organization in which all worthy members may participate in the discussion of practical problems and solutions related to their social welfare. RAD has over fifteen chapters in the United States and Canada." [9]

WHISPERS4U

Disabled Dating Service

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Having a disability can sometimes hinder your prospects of finding love. It's a fact that many so- called "Able" folk are just not as receptive when it comes to disabled people and matters of love. If you happen to also be Gay or Lesbian, then that narrows the field even further. Here at Whispers4u, we aim to bring together Gay & Lesbian Disabled Singles in one community without prejudice, to share thoughts, make new friends, and maybe even find love! (87% Users Are Women).

SINS INVALID

www.sinsinvalid.org

A performance project that incubates and celebrates artists with disabilities, centralizing artists of color and queer and gender-variant artists as communities who have been historically marginalized.

nature. Parents of children have a tendency to disapprove sexuality research among minors, as many are afraid of causing further harm to their child's wellbeing. Furthermore, children with various disabilities may not have developed sexual maturation or fully understand the concept of sexuality and may possibly convey inaccurate information or feel obliged to respond biasedly. [7]

OUTLOOK

Dysphoria is the state of unease or generalized dissatisfaction with life, which can result in adolescents with depression, mania, and anxiety disorders. Gender dysphoria has a very real impact on people's lives. It is important that we acknowledge and respond to the needs of those with an intellectual disability who experience gender dysphoria.

> *"Society makes judgements about gender based on what individuals wear (gender expression), what they do (gender role) or even who they are attracted to (sexual orientation), but we must caution against such assumptions as they can often be wrong. Gender is a uniquely individual experience, one that no can impose on another. Biological sex is generally considered to be binary but neither is this an accurate classification."* [10]

"Both people who identify as LGBTQ and people who have invisible disabilities such as learning disabilities like dyslexia, mental health or ADHD have to decide whether or not to 'come out of the closet." [1]•

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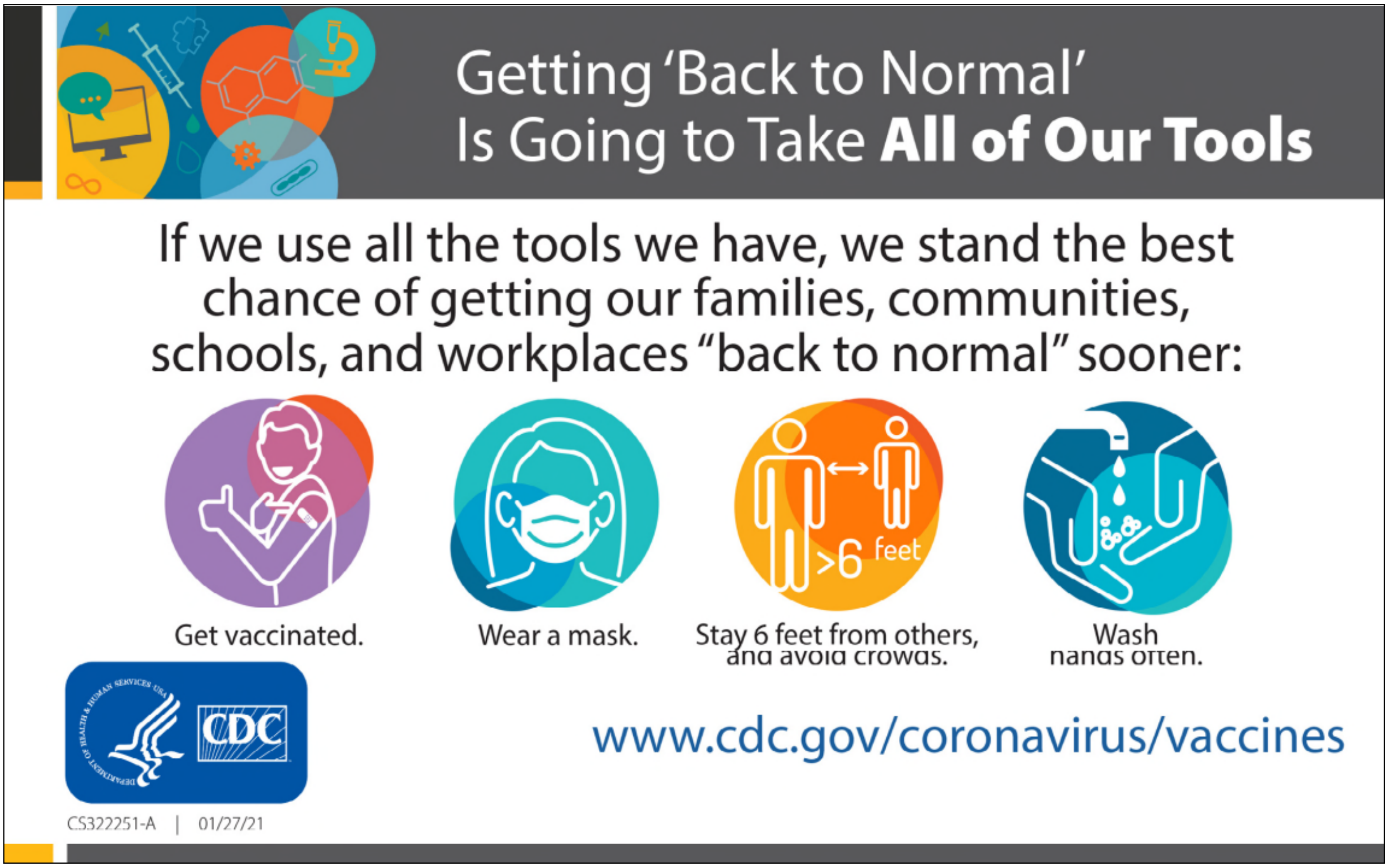

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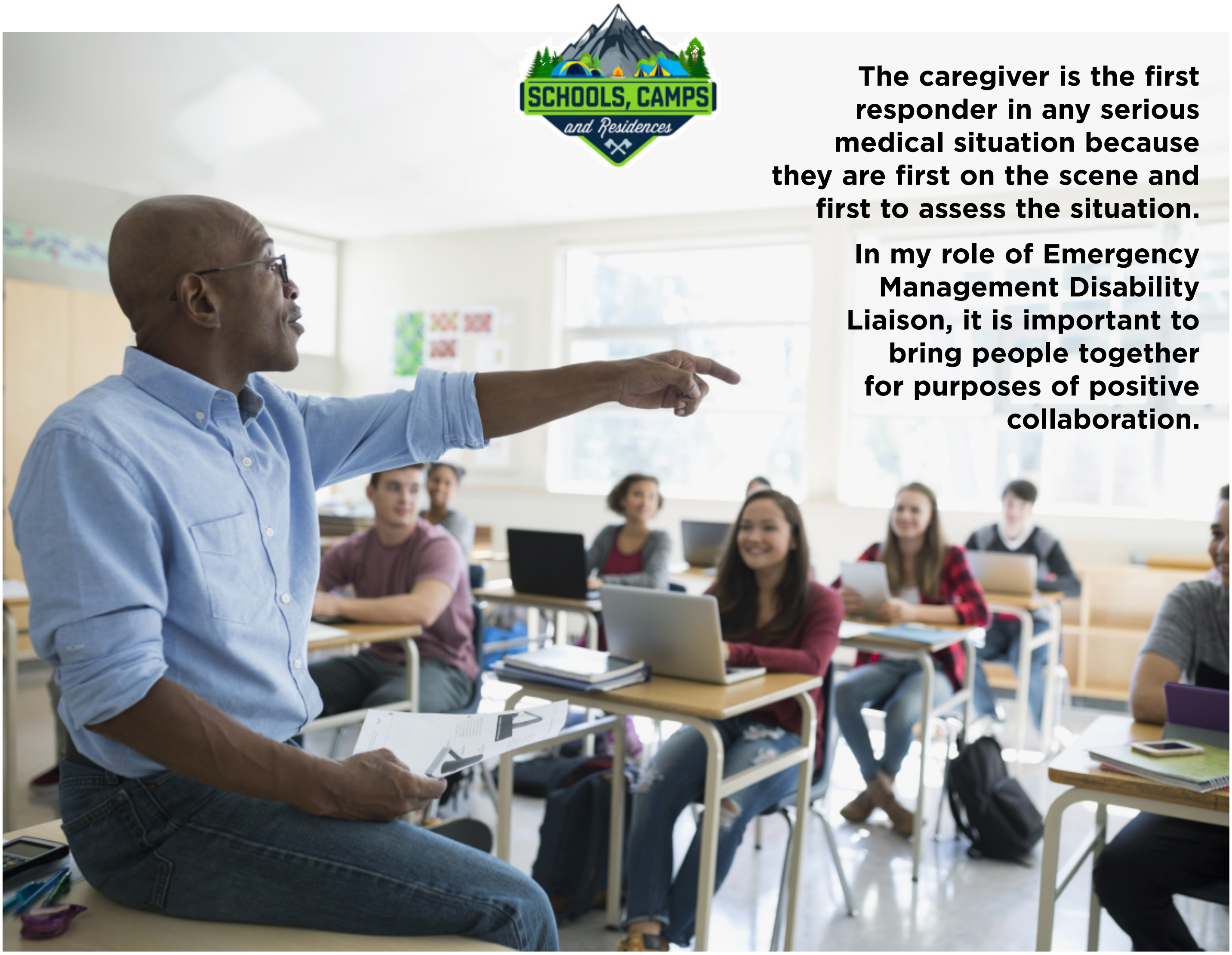

The caregiver is the first responder in any serious medical situation because they are first on the scene and first to assess the situation.

In my role of Emergency Management Disability Liaison, it is important to bring people together for purposes of positive collaboration.

AT SCHOOL

FIRST PERSON ON THE SCENE

BY LAURA GEORGE

Having a background as both a caregiver and as an Emergency Management Disability Liaison (EMDL) has provided me with a unique perspective about preparedness, sometimes in ways that are totally unexpected. Recently, we moved from one state to another. My child is in middle school and has both PANS (pediatric autoimmune neuropsychiatric syndrome) and colophony (allergy by way of fumes to pine tar or pine rosin, which is in just about anything you can touch, taste, see or feel). As the school has a policy of calling 911 when a child is having a reaction, it was very concerning. This is because most people have never heard of colophony, let alone would know what to do.

IMAGES PROVIDED BY LAURA GEORGE

It is my firm belief that in any serious medical situation, the caregiver is the first responder. This is because they are first on the scene and first to assess the situation. In my role of Emergency Management Disability Liaison, it is important to bring people together for purposes of positive collaboration. As a result, many one-of-a-kind projects have come about and are still in place to this day. Stepping outside the role of "mom," my mind began an intense debate on what the local responding fire department would need from the first person on scene. The school would also have no familiarity with colophony and yet, they would be the first people to arrive on the scene if my child had a reaction.

> **"THIS EXERCISE WAS NOT JUST ABOUT MY CHILD'S HEALTH. IT WAS AN OPPORTUNITY TO BRING A WIDE VARIETY OF PROFESSIONALS, WILLING TO WORK TOGETHER FOR MY CHILD'S EDUCATIONAL FUTURE AND SUCCESS, AS WELL AS FOR THE FUTURE OF OTHER EXCEPTIONAL CHILDREN."**

The first item completed was to contact the school board and locate the District Exceptional Student Education Specialist (ESE). Being concise, I shared the most important points about my child's health concerns, along with their educational needs. I further explained that it was important to contact the school quickly to preemptively train them on how to work with my exceptional child. Fortunately, the ESE Specialist understood that this was a unique situation and she immediately got to work in assigning my child to a school. She did this quickly, prior to the holiday break, as opposed to having to navigate the normal seven day process. This was to quickly facilitate communications between the school and myself. Within a week, yet prior to the holidays, I was connected to the school counselors.

GETTING TO KNOW YOU: *(Left)* The notification cube would sit on my child's desk name side up. When green was facing the teacher it meant that everything was fine. When rotated once, yellow would appear and the teacher would then know that a reaction might be coming on; Once more for red, and the teacher would know immediately to get assistance. *(Right)* A self-portrait cartoon of Charlotte; While the focus was for my child's benefit, I felt it would be an opportune moment to create a future stepping stone opportunity that would benefit any family with an exceptional child having high medical needs.

Once again, I explained my child's health concerns, educational needs and desire to have the school pre-educated on my daughter's health, so that when she physically attended, there would be no surprises. Instead, it was hoped that there would be calm order when my child's reactions occurred. They not only welcomed my discussion, but embraced it and together we decided that we would create a plan that would work for everyone who would be involved with working with my child.

The first step was to create a small document about my child, the diagnosis, the symptoms, how to respond and the role I felt each group (school administration, counselors, teachers, the clinic and myself) should play when my child had an allergic reaction. This was followed up by letting the reading audience know that in reading the document, they were automatically considered as part of my child's team, which also included medical professionals and the fire department. Additionally, I offered resources about the condition, suggestions for alternative supplies, my willingness to be there for each question they will have, and what they would see my child do during the reactions. Knowing the completed document would need tweaking and additional items addressed, each version was always sent with the accompanying statement, *"How else can I help?"*

After sending out the, "Things to Know About my Exceptional Child" document, the school suggested that my child and I come in to create the 504 (with the medical plan), meet the counselors, and other staff members. While there, we were able to tour the school and see what items (in terms of fumes) and challenges there might be. To my astonishment, this did not just occur once but three times. In hindsight, it was actually a great idea, as each walk-through presented something differently. The third walk-through even had the school principal accompanying us, and he started catching things that might be problematic.

Some of the challenges that were found were a few classroom floors, jugs of sanitizer, and formaldehyde used in the science class. To address those items working with the school, some of the classes were changed to navigate around the flooring, and a different science class was assigned. The COVID-19 sanitizer was a bit tricky. Due to the chemical composition of some routine household supplies as well as sanitizer, the bottles are designed with micro-perforations to accommodate the chemical fumes so it can breathe instead of becoming combustible. As my child was reacting very poorly to the sanitizer being used in the school, it was decided that each classroom bottle would have a loose covering garbage bag placed over it, with only a hole for the liquid to come out so students could still use it. Later it was learned that some of the teachers who previously met on the conducting the tours moved the sanitizer away from the entrance door so it would not be in the direct path of my child.

One other challenge that came up was addressing the manner in which my child would self-identify to the teacher that she was not feeling well. This needed to be accomplished easily, without the concern being advertised to the rest of class. Recalling an idea from my earlier employment years working as a secretary for an executive social worker, a communication cube was created. Green floral foam was purchased from the dollar store, along with red, yellow, and green fume safe paints for my child. On one side their name was placed (in case it was left behind), the second side was painted green, the third was yellow and the fourth was red. This cube would sit on the desk name side up with the green facing the teacher. Green would mean that everything is fine. When the cube was rotated once, yellow would appear and the teacher would then know that a reaction might be coming on. Once more for red, and the teacher would know immediately to get assistance. *(We later learned that the common retail/grocery store has four-sided emory boards which would also work in this situation.)*

For the next week or so, the school, their clinic, and I worked together to iron out the details while navigating the changing semester schedules and COVID-19. Then my child was assigned to online classes, as the next semester had started. She had already missed two weeks of school due to leaving the old one a week early, and the new one delaying the start in coordinating the additional details. Even though my child physically was not on campus, the document about my child (named, "How to Work With my Child"), was sent to all of the teachers with the counselors copied on it. A few responded right away and expressed their appreciation for the preparedness plan that was being put in place. With the plan in place, the backpack packed, two communication cubes packed, my child began physically attending the school the week after.

Of course, a few days later, my child was sent to the clinic with the symptoms of a mild reaction. The plan the school and I had created together worked. The teachers called the clinic and sent my child down even though the reaction was mild. They called me and, as we live around the corner, I was there within minutes. During that event, we discovered another item to overcome – which was that the neighboring building on the other side of the road, a high school, was letting their kids out early for the day, and it prevented me from getting to the school more quickly than if I was not there. But that was okay, because the plan is still in the early stages. There will be hiccups, and it provides an additional opportunity to collaboratively refine another item in my child's preparedness plan. This also lends to positive relationship building between the parent and the school.

THINGS TO KNOW ABOUT MY EXCEPTIONAL CHILD

- Name
- Parent's Name, Phone, Email Address (Include best time to call)
- Diagnosis
- Symptoms
- How to Respond/Role Play
- Alternative Supplies
- Authoritative resources supporting Child's Unique Needs

Aways reiterate your willingness to work with them. Remember to add, "How else can I help?"

PRODUCTIVE DIALOGUE: The school not only welcomed my discussion, but embraced it and together we decided that we would create a plan that would work for everyone who would be involved with working with my child.

Since then, my child has had additional subsequent reactions at the school. As a result, I felt it was important to bring the fire department into the plan with the school and myself. With the ESE Specialist's assistance, a connection was made to the county fire training department. They were not only receptive to the idea, but have brought up many worthwhile questions and ideas on how they can best respond to the unique situation my child brings to the community. Due to my background as an EMDL, I suggested that a meeting be held with the local fire department, the school, and my child so we could all collaborate and meet each other at the same time. While the focus was for my child's benefit, I felt it would be an opportune moment to create a future stepping stone opportunity that would benefit any family with an exceptional child having high medical needs.

In Dr. Seuss' book titled *The Lorax* there is a great quote. It says, "It is not about what it is, it is about what it can become." This exercise was not just about my child's health. It was an opportunity to bring a wide variety of professionals, willing to work together for my child's educational future and success, as well as for the future of other exceptional children. Today, my exceptionally one-of-a-kind child is successfully physically attending school, making friends, has a big smile on her face—and this first responder, caregiver, EMDL mom is very happy. •

Footnote: On the day this article was submitted to *EP Magazine,* my child and I gave a presentation and answered questions to representatives (including executive and training staff) from two of the county fire departments, a deputy sheriff, and a representative from the school clinic. Throughout this entire event, we were consistently thanked, with grateful appreciation, for educating everyone about my exceptional child, as well as their needs before they physically attended school. One person even called me a "Mighty Mike Tyson!"

A huge Thank You! goes to the St. Lucie Fire Department and Middle School, for working so hard to make this happen and benefit so many now, and in the years to come! A special Thank You to E.G, M.A, L.M., S.L. and O.L. for their volumes of time and sense of humor that made all the time invested to accomplish the above on my child's behalf, worthwhile.

ABOUT THE AUTHOR:

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


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SCHOOLS, CAMPS and Residences

CREATING A SPECIAL SPACE... IN THE KITCHEN!

BY MALIA KOSLOWSKY

When Dr. Greg Chang, the Founder of SuperChefs (www.superchefs.org) *was a child, he remembered how his mother taught cooking classes in their family home to neighbors wanting to learn Chinese cooking techniques. Seeing this excitement in the kitchen brought joy and instilled a passion to share this love of food with others, as well as be involved with health and fun development, as his father was a caring physician with an engaging sense of humor.*

PHOTOS PROVIDED BY MALIA KOSLOWSKY

TO-DOUGH LIST: Part of creating a safe environment for children with special needs is teaching through various learning styles, using clear and direct language, breaking down steps and skills for all activities, eliminating additional stimuli and loud noises, and preparing children for transitions. We make use of task analysis, an evidence-based approach for breaking down a complex task into manageable steps.

After graduating from dentistry, Dr. Greg began to see many overweight children in his practice with associated dental caries. It was clear that many of these parents and children lacked good nutrition knowledge and were confused about what to eat to maintain good oral health and overall wellness. This was especially true for children with developmental disabilities, whose families may face challenges to access needed programming and resources.

Using his dental training, the culinary knowledge learned from around the world, and community funding to hire university students with a passion for promoting healthy lifestyles for kids, a health program called SuperChefs was born. Guided by experts, including dentists, doctors, chefs, dieticians, educators and entertainment experts, SuperChefs has partnerships with Fortune 500 companies, governments, schools, universities and leading advocacy groups to stir up fun in the kitchen while raising healthier kids through local and global programming.

During the first camp in 2009, a child named Allen came to SuperChefs. He described himself as obese, regularly eating at McDonalds and doing little in the way of regular exercise. During the four-day camp he was taught how to cook, about nutrition guidelines, and was ushered into team sports. Allen lost 40 pounds in one year. SuperChefs changed his life, as it has for the many thousands of kids seen over the 12-plus years these free camps and events have been offered around the world. Additionally, SuperChefs' healthy Kids Eat Well menus adorn the offerings in over 200 Westin Hotel restaurants globally.

One of the SuperChefs team members had a passion for working with kids with disabilities and expressed a deep desire to offer these opportunities in the kitchen to children with intellectual and physical disabilities. Since the camps did not have the capacity to include children of all abilities, I helped to create an adapted program to achieve similar results of the world-famous and award-winning, Dr. Greg's SuperChefs Cookery for Kids program. Thus, the Special SuperChefs program was born, rooted in the belief that "A Good Chef is Never Without Friends", and testament to Jacques Pepin's definition that cooking is about adjustment.

By encompassing SuperChefs Cookery for Kids' core values and mission, Special SuperChefs provides an inclusive opportunity for children requiring additional support. We believe every child has the right to be empowered to join in the fight against childhood obesity and malnutrition. We teach the essentials of balanced nutrition, food preparation, and inspiring lifelong habits of physical and social well-being. Special SuperChefs was adapted from the original SuperChefs program to promote inclusivity within our programming. We see inclusivity as an attitude and approach that seeks to ensure that every child, regardless of ability or background, can meaningfully participate in our events.

> **"Cooking is the art of adjustment."**
> **~ Chef Jacques Pepin**

Unlike any program, Special SuperChefs offers free summer camps in Surrey BC, partnering with the largest school district in British Columbia and providing a unique 1:1 support model by trained staff for each child participant. Recognizing the power of creative therapy, we take advantage of the natural developmental opportunities our cooking provides. All activities were designed to be accessible for all participants. Each activity has multiple modification ideas to shift the focus to the child's strengths rather than their limitations. The intentional structure of each day at Special SuperChefs camp allows every child to fully experience the contents of the program.

We prioritize creating an environment that is optimal for our campers to learn and explore. Daily routines and consistent activities help the kids settle into their new environment, which can often be a challenge. Many children are triggered by the new environment for the first two days, but excited on the third day to see the daily routine written on the board with their 1:1 leader waiting next to their chair. This relationship allows them to learn at their own pace. Having a strong support system creates a positive inclusive environment. Part of creating a safe environment for children with special needs is teaching through various learning styles, using clear and direct language, breaking down steps and skills for all activities, eliminating additional stimuli and loud noises, and preparing children for transitions. To support these intents, we create customized tools for our program. Some of our favorite tools include token boards, flip schedules, visual choice boards, and visual "first-then" boards.

Each day, we learn to cook different recipes encompassing various important kitchen skills. The cooking lesson is broken up throughout the day to maintain engagement. The group comes together to observe a demonstration, which clearly illustrates the next steps and coordinates with our visual recipe book. We make use of task analysis, an evidence-based approach for breaking down a complex task into manageable steps. Our campers and leaders work together to complete each task, through guided verbal, visual, or physical prompts. The nutrition sections include basic oral and digestive health content curated alongside interactive activities and games to create excitement around topics that can seem dull to children. The "Mystery Box" is a well-loved game. One child is selected to stand behind a box that is open to the rest of the group. A leader places a food item in the box, correlating with the recipe of the day. The child puts their hands through the box's side armholes to feel the item. We laugh lots as the camper tries to identify the food item, and their friends help by giving clues!

ABOUT SPECIAL SUPERCHEFS

Special SuperChefs is an adapted SuperChefs Cookery program created to enable children of all abilities to participate despite physical or cognitive limitations. Children of a variety of types of disabilities are welcomed into the kitchen, including many participants diagnosed with autism spectrum disorder. Every child should be empowered to join the battle against childhood obesity by learning the essentials of balanced nutrition and food preparation. By encompassing SuperChefs' core values and mission, the Special SuperChefs program is able to provide an exclusive opportunity for children requiring additional support.

We work closely with Occupational Therapists from the Centre for Childhood Development in Surrey, B.C., who provide feedback and consultation for our program. These specialists help our staff foresee potential obstacles and barriers and work with us to create possible solutions and adaptation ideas. Our adaptive equipment toolbox has grown over Special SuperChefs' three years and includes assistive devices for limited motor functions, sensory calming toys, easy-grip cooking utensils, and other tools that make cooking challenges accessible for all kids!

RECIPE FOR SUCCESS: Many children are triggered by the new environment for the first two days, but excited on the third day to see the daily routine written on the board with their 1:1 leader waiting next to their chair. Having a strong support system creates a positive inclusive environment.

Teaching children the importance of cooking nutritious meals and engaging in healthy habits build steps towards future independence. Cooking is a wonderful chance to work on sensory processing skills as kids are exposed to new smells, colors, textures and experiences. Our controlled environment where children feel safe facilitates these experiences.

Often, kids arrive at camp with texture aversions, picky food preferences, and lacking an appetite. With the gentle encouragement of leaders and fellow campers, many kids have stepped out of their comfort zones to try new things through small and manageable steps. We use fun challenges to encourage campers to choose at least one piece of vegetable to put on their homemade pizza, or move in gradual stages towards trying new textures. One of our first campers said he hated all vegetables. After being convinced to put one tiny piece of red pepper on his pizza, he thought that red peppers taste, "much more delicious on pizza than they do on their own." Throughout camp he would frequently exclaim, "I love red peppers on pizza!" Another camper with texture sensitivities discovered her love for granola over three days, after playing with it first in her hands, then exploring with it gingerly with her tongue, and finally chewing and swallowing a piece on the third day. She is now a Granola Girl! Many kids are averse to the feeling of raw chicken or sticky pasta dough, and we always find alternate ways for them to work with ingredients by using utensils found in the kitchen.

Including kids in the preparation of a meal or snack opens them up to explore beyond their dietary preferences. Giving kids choices empowers them to make decisions they feel confident about while putting them on course for positive experiences with new foods.

The Special SuperChef kitchen is a place where our campers can come as they are and grow. One of our first campers has attended three years of our summer program, and he and his family have eagerly participated in events throughout the years. When our program was covered by a local television station, he displayed the skills and speech confidence he developed through learning to cook and making friends at camps. His parents have graciously communicated how much they appreciate the program by offering video endorsements, and sharing that, “although we don’t know what the future holds for our child, SuperChefs has provided opportunities for our son that we could never have imagined. It has enriched his development in so many ways, and he enjoys his time in the kitchen with you all, and now has the confidence to do this at home as well. We can’t thank you enough!”

APPETITE FOR LEARNING : For campers like Sahib and Connor *(left)* and Brooklyn *(right)*, new skill development leads to confidence that opens the opportunity for social engagement by cooking and sharing meals together.

> **“Teaching children the importance of cooking nutritious meals builds steps towards future independence. Cooking is a wonderful chance to work on sensory processing skills as kids are exposed to new smells, colors, textures and experiences.”**

We’ve seen many lasting connections built between campers, as working in the kitchen brings them together and creates a common interest. Including kids in the kitchen is an amazing way to incorporate therapy aspects with a fun, common interest in the home. Many parents have shared that their kids are teaching them how to make pizza from scratch and are even excited about washing dishes and shopping for ingredients after just four days in the kitchen. What family doesn’t need an extra dishwasher or pair of hands doing groceries? This excitement is cultivated by giving kids the freedom to explore various cooking skills, interacting with different ingredients, and doing it alongside others. Making dinner may be a chore for you, but has the potential to be an exciting activity! It can feel daunting to invite them in, but great success can be achieved by breaking down the steps and being quick to offer adaptations. Almost all of our participants leave camp wanting to be a chef when they grow up. We believe that everyone is a chef in their own kitchen! Parents of past campers are consistently sending photos of their kid’s new culinary creations, thankful for the kitchen exposure we provide.

New skill development leads to confidence that opens the opportunity for social engagement by cooking and sharing meals together. We have seen this in our camps, as parents have been delighted to see their children make friends with other campers, leading to new bonds through shared culinary adventures. This is possible for your child as well! Try starting with simple recipes and using basic methods.

Some tips for supporting your new chef through kitchen tasks include “hand-over-hand” assistance when stirring, cutting, or kneading dough to keep the child actively involved in the learning stages. It is also helpful to draw checkboxes next to each step on the recipe to help visually stay on task. Try to make every part of the cooking process fun by incorporating games, such as an equipment scavenger hunt and the “eye spy” ingredients game.

Special SuperChefs summer camps were turned upside down at the onset of the COVID-19 pandemic. We pivoted to provide virtual camps for families alongside prepared food and activity kits. Each family received detailed daily schedules with correlating videos and tangible activities and recipes. This content equipped families to guide their child through a “camp from home” experience. This virtual experience empowered families to include all their children in the frequent activity that cooking is. Parents expressed gratitude for how the program made a daily task fun and inclusive for the entire family. Regardless of whether the cooking experience is live or virtual, guided culinary instruction can be a fulfilling and vital attribute that leads to a lifetime of developing new skills, cultivating a sense of creativity, and shared fun memories in the kitchen. •

ABOUT THE AUTHOR:

Malia Koslowsky is a Community Support Worker for individuals with disabilities through Strive Living Society and Creator of Special SuperChefs. She and Dr. Greg Chang work collectively with the non-profit SuperChefs team to teach food literacy, nutrition and physical activity to kids in Surrey BC and beyond with global partners. Dr. Greg is a dentist/food educator/clown and the Founder of SuperChefs Cookery for Kids.

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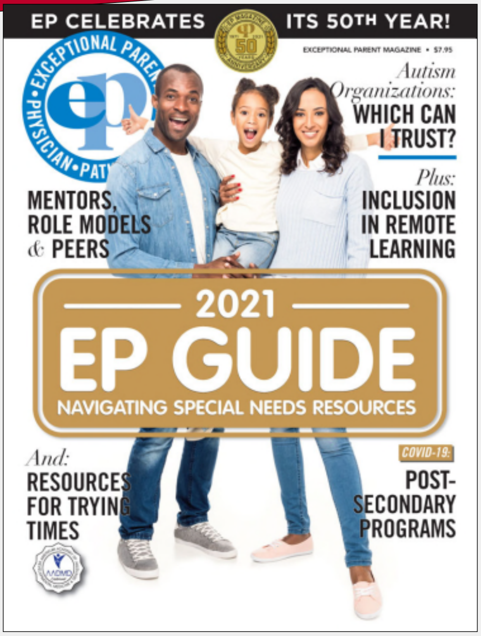

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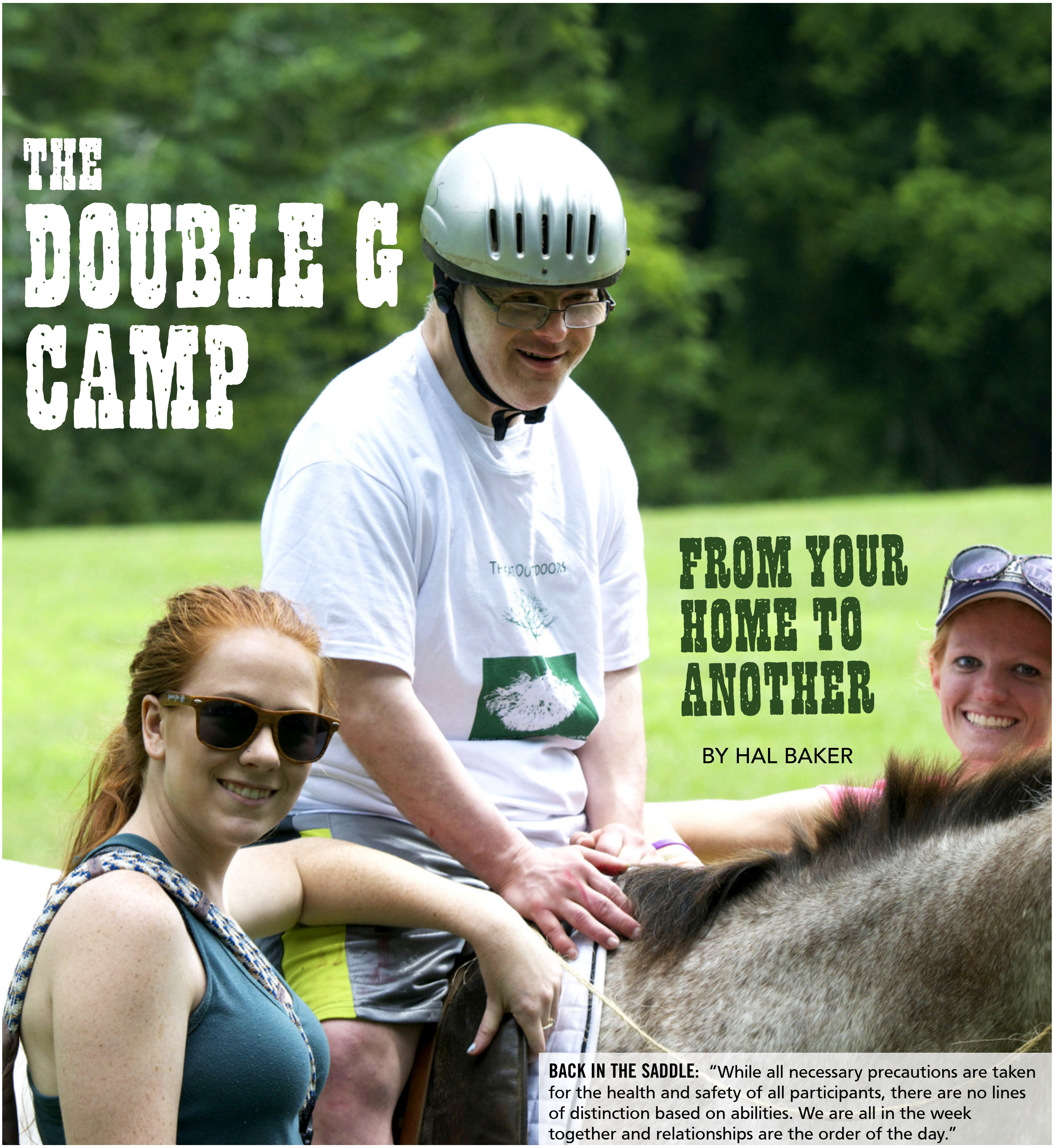
THE DOUBLE G CAMP

FROM YOUR HOME TO ANOTHER

BY HAL BAKER



BACK IN THE SADDLE: "While all necessary precautions are taken for the health and safety of all participants, there are no lines of distinction based on abilities. We are all in the week together and relationships are the order of the day."

"The Double G Camp was named after the family members who owned the camp grounds and generously provided it to the Orange Grove Center. So while the Double G did not stand for Growth and Gratitude, that is exactly what happened at the camp year after year. Both the campers and the counselors grew in so many ways and expressed gratitude to each other for the opportunity and experience."

– Rick Rader, MD, Editor in Chief, EP Magazine

PHOTOS COURTESY DENNIS WILKES PHOTO COLLECTION

The Orange Grove Center's (Double G Camp) residential camp began in the 1950's for children and youth and offered two sessions of two weeks each for 48 boys and 48 girls under the watchful eyes and friendships of half as many young counselors. During the decades, as the children became adults, needs changed, and the number of campers declined to 60 men and women for a one-week session, still under the watchful eyes and friendships of half as many counselors, some, the children and grandchildren of counselors from years past. At least one camper had attended all previous sessions, 62 years.

Double G has become a legacy camp in our community. The facilities have not changed much since the camp was developed in 1958 to give children with diabetes a summer experience with the support they needed. There is no running water or air conditioning in the cabins, and the bathrooms are up a hill. Yet, there is a fondness for the place shared equally by campers and counselors alike.

It goes without saying that there are all sort of fun activities during the week that are pretty standard fare in residential summer camps across the country. What occurs however between the activities, are the relationships that develop between campers and counselors. We can't pretend that an objective for the camp when it was started was to be an inclusive setting for individuals with/without IDD – but what has evolved over the years is a group of people with and without special needs cavorting together for a week in a camp setting, all day and every night. Everyone eats together, swims together, fishes together, and stays in cabins together.

The number of young counselors who have been a part of this experience over the years are in the thousands, and many have stayed connected, even currently serving on the volunteer Board of Directors. Throughout our community, there is an alumni of counselors who remember fondly their week or weeks as a member of the group, and still promote the camp whenever there is an opportunity, and are quick to point out the how the relationships developed there have affected their lives in a positive way. Many counselors are second and third generation participants, and the campers have returned year after year to develop new relationships with them.

The camp is tradition plus inclusion in the same manner of the unified sports of Special Olympics. While all necessary precautions are taken for the health and safety of all participants, there are no lines of distinction based on abilities. We are all in the week together and relationships are the order of the day. At the end of the week, there are heartfelt good byes and expectations of meeting again next year.

SO HAPPY TOGETHER: What has evolved over the years is a group of people with and without special needs eating, swimming, fishing, and staying in cabins together.

MAKING MEMORIES: Hal Baker *(top left)*, the former Director of the Double G Camp, spends some time lakeside with a camper. “What occurs between camp activities are the relationships that develop between campers and counselors.”

We have contacted counselors from each decade since the founding of Camp GG and asked how their experience affect them today. The Fifties and Sixties yielded the most transformative impressions; these were young people who for the most part weren’t sure what they were getting into. Some were looking for summer work while some were talked into it by friends or family. One counselor from 1959 clearly admitted he was worried as a 16-year-old, but when he met the first camper, he would spend two weeks with the camper. He was changed completely into a friend for life. Another counselor from the Sixties said, when the session was over, he felt that both he and the campers were lucky to be alive after the shared experience.

Over the last several years, we have asked the counselors to share their impressions of camp so we could keep our efforts on track to make the sessions relevant. The comments we received were all about the relationships developed; some said that the cabins could use some air conditioning. One counselor from the Nineties stated that the relationships he forged at the camp carry over to this day. Another from the Eighties is an elementary school principal who admitted that he considers the campers he spent time with good friends that he sees often.

> “Double G Camp sessions were conducted for two weeks, they provided thousands of memories for hundreds of campers and counselors which lasted for over 60 years.”

Raymond Duncan said, “A lot of parents pack up their troubles and send them off to summer camp.” The parents of the Orange Grove Center never thought of their children as “trouble,” they sent them to fish, swim, chase fireflies, dance and toast marshmallows and to form life-long friendships.

Here’s how the math added up. The camp sessions were conducted for two weeks, they provided thousands of memories for hundreds of campers and counselors which lasted for over 60 years.

We will attempt to conduct the 63rd session of Camp Double G in Soddy Daisy TN on the shores of Lake Chickamauga in June. This will be an attempt due to the outbreak of the COVID-19 virus which caused the cancellation of last year’s session after 62 years of continuous operation. Decisions can only be made with the understanding that utmost consideration must be given to the health and safety of everyone. •

ABOUT THE AUTHOR:

Hal Baker is the former Director of the Double G Camp, as well as the Deputy Director at the Orange Grove Center for several decades. He is presently an advocate at The Arc of Tennessee. He has been a dedicated professional in the field of developmental disabilities and is the former President of the Board at the Chattanooga Autism Center.

STAND IN THE PLACE WHERE YOU LIVE: "I love the word 'upstander.' For me, it means when you experience an injustice like someone being bullied, you take a stand to make it right. When you see someone sitting alone in the lunchroom, you choose to sit with them. When you see a child being picked on, you take that child out of the situation and ask if they would like to walk to class with you."

PHOTOSPROVIDED BY POSITIVE EXPOSURE

How I Found My Voice

BY DINA ZUCKERBERG

As I stood before a crowd of 100 middle school students presenting my talk, I felt a range of emotions: Elated. Vulnerable. Nervous. Apprehensive.

I openly shared my story of growing up with a craniofacial condition and all the struggles that came with it, especially at school. I talked about how I sat alone on the school bus and in the cafeteria. I revealed how I was teased and picked last for team sports in gym class. The kids said I had "cooties." I shared how I wished I had upstanders in my life, people who stood up for me.

As the Director of Family Programs at myFace, I had come to this school to talk to the students. At that point in my career, I had just begun to visit schools and share my experiences with students.

However, if anyone had told me then that I would be revealing my past to these particular students and loving it, I would have said, "no way, you're crazy." Especially since I had been a student at this very school from kindergarten through the ninth grade. And I was describing how I was treated at this very place.

I was born with a cleft lip, hearing loss, and no vision from my small left eye. From the time I was three, I wore a hearing aid. I also had six surgeries, years of orthodontics and speech therapy. Although I had challenges, through my unwavering determination and support of my parents, I continue to be unstoppable. I can drive a car, ski, ride a bicycle, play the piano, and more.

The pull to visit schools and present my story came after reading the young adult novel *Wonder,* by R.J. Palacio. The book centers around Auggie Pullman, a ten-year-old boy born with Treacher Collins syndrome who is homeschooled until the fifth grade. "I won't tell you what I look like, but whatever you are thinking it's probably worse," says Auggie. Throughout the book, Auggie grows to experience his own power as his life transforms.

I so deeply connect with Auggie when I think of my own middle school experience. The more my voice was silenced in school, the more powerless I felt. That caused me to discredit what I had to share and I withdrew.

Yet, sharing my stories with the students has helped me transform and find my voice. I feel so strongly that I never want any child to experience what I did growing up. I have grown to understand how I needed to use my voice to educate others. And the more comfortable I have become to divulge how my voice was silenced, the more I can make a difference.

When I visit schools, I share how I wish I had an upstander. I love the word "upstander." For me, it means when you experience an injustice like someone being bullied, you take a stand to make it right. When you see someone sitting alone in the lunchroom, you choose to sit with them. When you see a child being picked on, you take that child out of the situation and ask if they would like to walk to class with you. If you see someone standing alone, a simple smile and "hello" can make all the difference.

UPSTANDER: *(Clockwise, from top left)* Dina held by her older brother; Delivering her inspiring message to students during a myFace event; and with myFace patient Anibel, who was born with a condition called Nager's Syndrome, a very rare syndrome related to Treacher Collins Syndrome.

Since that school visit, I have shared my story in over 150 schools, reaching more than 35,000 students through myFace. A non-profit that supports children with craniofacial differences, for 70 years myFace has worked with patients and families to provide comprehensive critical team care. Every day, we work to deliver support, education and raise public awareness.

Many times, after presenting my speech, the students cheer and give me a standing ovation. And I think of Auggie's wise words, "Everyone in the world should get a standing ovation at least once in their life because we all overcometh the world."

Sometimes I still can't believe that I am sharing my deeply personal story and the message of choosing kind and what it means to be an upstander. AND I continue to love it. Yet here I am, wanting to visit more and more schools and connect with students because I love seeing the impact that I have on them. As much as I teach them, they teach me so much too.

In fact, myFace even designed a whole program, The Wonder Project, which we can make available to schools. It includes an anti-bullying virtual assembly, activities and lessons centered around compassion and empathy, along with inspiring stories from kids with craniofacial differences. Also, I look forward to the opportunity to virtually visit your school.

"Courage. Kindness. Friendship. Character," writes Palacio in *Wonder*. "These are the qualities that define us as human beings, and propel us, on occasion, to greatness." I think of the journey that I have taken so far and how it embodies so many of those qualities. In the process, I have learned so much about myself and grown in ways I could never imagine.

Looking back, I wish that kids didn't tease and exclude me when I was growing up. I wish that I didn't need to have surgeries. I wish that things weren't so hard. But if not for those experiences, I wouldn't be the person who I am today. And then I think, maybe I am exactly where I was meant to be. •

To learn more about the myFace Wonder Project, please visit **www.myface.org/wonder**

ABOUT THE AUTHOR:

As Director of Family Programs at myFace, Dina Zuckerberg brings her life experience growing up with a craniofacial difference to the programs she helps implement for the individuals and families they serve. Whether it's through their emotional support groups, online educational series, family networking events, or public awareness initiatives, her goal is to advocate for the craniofacial community and make sure their voices are heard. She wants everyone with a facial difference to know that they are not alone.

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www.bantec.store

INCREASINGLY, POST-SECONDARY EDUCATION IS A CHOICE FOR YOUTH WITH DISABILITIES

BY ALEXANDRA BAIG, MBA, CFP®

A friend of mine, who is close to my age and happens to have a diagnosis of Down syndrome is very proud of the fact that she attended and graduated from the Path to Academics, Community and Employment (PACE) program and National Louis University. She will tell you that she majored in clerical studies and that she later put her education to good use as an office assistant at L'Arche Chicago, the community of people with and without intellectual and developmental disabilities where she lives. Like all of her nine brothers and sisters, she too, launched her adult life from college.

When I work with a person with a disability and their family to create a future plan, we first have a conversation about what the person wants in life. It turns out that people with disabilities want the same things as the people without obvious disabilities: a home of their own, a job where they can contribute, a romantic partner, a community, friends, and things to do for fun. If you think back, many of us took our first significant steps towards obtaining those things when we went to college. So, it should not come as a surprise to anyone that people with disabilities often want to go to college. Nor should it come as a surprise that people with disabilities who complete post-secondary education have a higher success rate in the workplace, according to the Department of Education and several research projects. Link: https://search.proquest.com/openview/970b93f7d23bcd56905137c50f18a77a/1?pq-origsite=gscholar&cbl=18750&diss=y

The first post-secondary opportunities for youth with disabilities emerged in the 1970's. Since then, the number of opportunities has increased dramatically. Today, Think College (www.thinkcollege.net) has documented 300 post-secondary programs for youth with intellectual and developmental disabilities across the United States. Nearly every state has at least one program except Wyoming and West Virginia. New York State has the most, with 33. My home state of Illinois falls in the middle as host to 14. The programs range across public and private institutions, including four-year colleges, two-year junior or community colleges and technical/vocational schools.

The Think College initiative, which is national, but also has links to state-specific, focused resources, classifies post-secondary opportunities for students with disabilities into three categories.

- *In the "substantially separate" model, students with intellectual and developmental disabilities take classes only with other students with disabilities, although they usually have the opportunity to participate in general campus events and activities.*
- *In the "Inclusive Individual Support" model, students with intellectual and developmental disabilities take general education courses for credit or audit alongside students without disabilities. Tailored supports are provided by a collaboration of the school's disability support office, adult disability service provider agencies and generic community services.*
- *In the "Hybrid" model, students with intellectual and developmental disabilities may take classes with other students with disabilities and also with students in the general education population.*

Think College, as well as PACER's National Parent Center on Transition and Employment (https://www.pacer.org/transition), are good sources of information on the numerous post-secondary opportunities for youth with intellectual and developmental disabilities and can help students and their families think through which characteristics are most important in determining the program or programs that will best assist the student's successful move into adult life. Families may want to consider and screen for things like whether the program provides opportunities to live on campus, whether the program offers financial aid, whether students can audit or take for credit general education courses, whether the student will emerge with a certificate or degree and how much access the students have to campus life outside the program. Since a primary reason for students – with and without disabilities – to obtain post-secondary education is to make themselves more employable, students will also want to consider to what degree a program facilitates student internships or work experiences both on and off campus.

Regardless of the nature and structure of the program, the post-secondary environment is significantly different from that of high school. The Individuals with Disabilities Education Act (IDEA) does not go on to cover post-secondary education. Instead, education beyond high school is governed by the Americans with Disabilities Act (ADA) and section 504 of the Rehabilitation Act. As a result, the student's Individual Education Plan (IEP) will not follow them into the post-secondary environment. The ADA and section 504 are focused not on outcomes, but on access. Educational institutions are required to provide equal access to students with disabilities. This may include providing reasonable accommodations such as additional time to complete assignments or take tests, coaching, tutoring or note-taking services, course materials in alternate formats, accessible classroom locations and the flexibility to substitute some courses for the completion of degree or certificate requirements. However, the schools are not required to modify materials, requirements, practices or policies if this would alter the fundamental nature of their programs.

In addition, in the post-secondary setting, rather than the school taking the initiative to determine and recommend accommodations and services, the student and their family must approach and work proactively with the school's disability support office to put the necessary supports in place.

Students with disabilities who want to pursue post-secondary education may benefit from "dual" or "concurrent" enrollment; that is, from enrolling in post-secondary courses while they are still participating in their high school's transition program. There are two benefits to this approach. The first is that the student will be able to have in the post-secondary environment the level of support and type of services which has helped them to succeed in high school. The second is that the post-secondary courses can be paid for with IDEA Part B funds because they are determined to fall under the student's entitlement to a Free and Appropriate Public Education (FAPE). Link: **www.isbe.net/Documents/A-Transition-Guide-Education-Employment.pdf**

> ***"Think College has documented 300 post-secondary programs for youth with intellectual and developmental disabilities across the U.S.***
>
> ***The programs range across public and private institutions, including four-year colleges, two-year junior or community colleges and technical/vocational schools."***

As for any student, funding post-secondary education can be a challenge. Students with intellectual and developmental disabilities may be eligible for Federal Supplemental Educational Opportunities grants and Pell grants, as well as state-specific and institution-specific grants and institution-based work-study programs. In addition, students with disabilities, including intellectual and developmental disabilities, may be eligible for funding from their state's Divisions of Vocational Rehabilitation. A section of the Rehabilitation Act permits state vocational rehabilitation agencies to pay for postsecondary education tuition, so long as maximum efforts have been made to obtain grant assistance. Link: **www.federalregister.gov/documents/2020/02/28/2020-03208/state-vocational-rehabilitation-services-program**

Students with disabilities and their families can also fund post-secondary education using 529 College Savings Plans or 529(A) Achieving a Better Life Experience (ABLE) Plans. Wearing my financial planner hat, I encourage families to pay close attention to any tax documentation generated by withdrawals from College Savings Plans. Frequently, the student is the beneficiary of a 529 plan, but not the owner. Typically, tuition is paid directly from the plan to the educational institution. Under these circumstances, plan assets should not be countable resources and plan distributions should not be countable income and neither should affect the student's eligibility for Supplemental Security Income (SSI) or Medicaid, including Medicaid waiver-funded adult supports. However, because tax documents are often issued carrying the Social Security number of the student-beneficiary, the documents may trigger questions about the student's ongoing eligibility for those benefits and the family will need to set the record straight. This problem does not arise when using an ABLE account to fund education because the ABLE is never a countable resource nor are ABLE distributions countable income for SSI and Medicaid eligibility purposes.

As for any student, there are challenges to selecting and funding post-secondary education but once those hurdles are crossed, college can be a good fit for some students with disabilities. In addition to my work as a financial planner for people with disabilities and their families, I currently teach financial literacy at the Elmhurst Learning and Success Academy (ELSA) at Elmhurst University. My students are curious, hard-working and optimistic about their future and I believe their college experience plays a role in fueling all three characteristics and will contribute to their successful emergence into adult life.•

ABOUT THE AUTHOR:

Alexandra Baig maintains her own national financial planning practice, Companions on Your Journey, and also acts as the Benefits Specialist for Clancy & Associates, a Chicago-based law firm focusing on special needs planning. Alexandra has an MBA from the University of Michigan and her Certified Financial Planner™ designation and is a member of the Academy of Special Needs Planners. In particular, she is well-versed in the government benefits available to people with special needs and the rules governing them. Her goal is to help people with disabilities and their families make the most of public and private money to live the life they chose.

ANSWERING BACK-TO-SCHOOL & COVID-19 CONCERNS

BY LAUREN AGORATUS, M.A.

Some school districts are seeking to reopen, others are using a combination of in-person and remote learning for students, while others continue to provide remote instruction only. Families and professionals working with children with disabilities are concerned about deficiencies in remote learning, as well as how to reopen schools safely.

The US Department of Education has issued numerous guidance documents that help families and schools understand their rights, responsibilities, and obligations regarding special education during the COVID-19 pandemic, regardless of whether schools are operating remotely, in a hybrid model, or in-person.

HOT TOPICS IN SPECIAL EDUCATION DURING THE PANDEMIC

Evaluations: School districts may not waive a 60-day timeline for an evaluation. The initial evaluation has to be conducted within 60 days of receiving consent, or a different timeline if the state has established their own. Districts may not refuse conducting a virtual evaluation. If in-person evaluations are not pos-

sible, schools should make good faith efforts to conduct assessments virtually, or via other comparable methods. Schools can do this by investigating all appropriate instruments and tools to determine if some can be administered remotely. Districts can also work with the developers of their current assessment instruments, to determine if those instruments can be administered remotely (without significantly affecting the validity and reliability of the results.)

Developing the IEP: The U.S. Department of Education issued guidance stating that the requirements for IEP meetings are not changed during the pandemic. All children with disabilities must continue to receive a free, appropriate public education, and have the chance to meet challenging objectives. The parent and district may agree not to meet to make IEP changes and can develop a written document to amend or modify that current IEP, as long as both agree and it is consistent with state law, rules and regulations. IEP teams must continue to identify how the special education and related services included in a child's IEP will be provided.

FAPE and LRE: Districts must ensure that students have access to equipment and connectivity for remote virtual learning. This requires the district to consider what assistive technology and other special education and related services are needed to ensure that the student is provided with a free, appropriate public education (FAPE) in the least restrictive environment (LRE). IEP team considerations of strategies to address challenges with connectivity include the possibility of providing mobile hot spots to students with disabilities who don't have good connectivity in their home.

If a student is not benefiting from online instruction, the US Department of Education reminded states and districts that no matter what primary instructional delivery approach is chosen, they and the IEP teams remain responsible for ensuring that FAPE is provided to all children with disabilities, including to students with significant disabilities.Even students who haven't received extended school year services typically may be eligible for ESY now. Many students didn't need ESY when they had access to in-person education and related services but now might meet the criteria for receiving ESY services due to having received virtual services this and last school year.

Remote Learning: Districts may not require parents to sign a waiver of FAPE and IEP implementation if they "opt" for remote learning. This is because schools may not require parents of students with disabilities to waive any rights afforded to students under the Individuals with Disabilities Education Act (IDEA), or Section 504 of the Vocational Rehabilitation Act as a condition of receiving a free, appropriate public education. If a district's plan involves only remote learning, and a parent is concerned that their child cannot benefit from remote learning, it's the responsibility of the IEP team to come up with a plan that allows the child to benefit from remote instruction. Some districts are inappropriately requiring families to select one option at the beginning of the school year, and will not allow any changes, even if the selected option is not working for their child. Under IDEA, a parent may request an IEP meeting at any time to discuss needed changes to the IEP, to ensure that their child is receiving FAPE.

Home Instruction vs. Remote Learning vs. Homeschooling: Some families are confused about the differences between remote instruction, home instruction, and homeschooling. Remote instruction, or virtual learning at home, simply means that the student is home while being educated virtually, just like students without disabilities. Home instruction is a placement on the continuum of placements under IDEA. It is a placement option whether or not in-person schooling is typically available. A student may need home instruction because of his or her own individual health status, for example, not just during a COVID-19 pandemic.

STAYING DILIGENT : SPECIAL EDUCATION DURING THE COVID-19 PANDEMIC

US DEPARTMENT OF EDUCATION

COVID-related Guidance

www.parentcenterhub.org/cv19-feds

Webinar from the US Department of Education on Provision of EI and Special Education Services during COVID-19

www.parentcenterhub.org/webinar-questions-answers-service-provision-ide/

IDEA PARTNERSHIP: CREATING AGREEMENT

www.ideapartnership.org/using-tools/learning-together/collections/411-collection-tools/1579-1579-creating-agreement-collection-tools.html

CENTER FOR APPROPRIATE DISPUTE RESOLUTION IN SPECIAL EDUCATION (CADRE)

"Got Back to School Questions? We've Got Your Answers" webinar

www.cadreworks.org/events/got-back-school-questions-we%E2%80%99ve-got-your-answers

SPAN PARENT ADVOCACY NETWORK

Remote Learning vs. Home Instruction vs. Homeschooling

https://spanadvocacy.org/wp-content/uploads/2020/08/SFS-021-20-School-at-Home-Fact-Sheet.pdf

School at Home Video

www.youtube.com/watch?v=JCjni7sOLLg

COVID-19 Resources

(includes service tracking & sample letter for compensatory services)

https://spanadvocacy.org/covid-19-resource-page/

PARENT CENTER HUB

www.parentcenterhub.org/find-your-center/.pdf

Center for Parent Information and Resources

www.parentcenterhub.org/coronavirus-resources

NATIONAL TECHNICAL ASSISTANCE CENTER ON TRANSITION

https://transitionta.org/effectivepractices

Homeschooling is when parents take legal responsibility for educating their child, as opposed to having the school district assume that responsibility. In many states, this means that the family is also responsible for related services like physical, occupational, and speech therapy.

Safety and COVID: Some families are concerned about requiring their child to wear a mask to participate in in-person learning. Schools should make reasonable modifications in their policies, practices or procedures, including any that address the use of face coverings, when those modifications can be made consistent with the health, safety, and well-being of students and staff, and are necessary to avoid discrimination based on disability.

Other parents are concerned that their child may be disciplined if they do not comply with COVID-19 safety requirements like wearing a mask or maintaining physical distancing. Again, school personnel may consider any unique circumstances on a case-by-case basis when determining whether change in placement, such as suspension, is appropriate for a child with a disability who violates a code of student conduct. This is true whether the behavior occurs in school, or during virtual instruction at home. Students with disabilities should not be punished for behavior that is caused by their disability, or caused by the fact that they did not receive the services in their IEP.

> “IDEA has not changed. All students with disabilities must continue to receive a free, appropriate public education.”

Compensatory Services: Some families wonder if students with disabilities who missed services due to the pandemic are eligible for compensatory services. If a child doesn’t receive services after an extended period of time, the school must make an individualized determination whether, and to what extent compensatory services may be needed, including to make up for any skills that may have been lost. The IEP team, which includes parents, should consider when discussing the IEP, the possible need for compensatory services. IEP teams should consider the effect of the closure on the child. Did the child regress during the closure from previously-attained skill levels targeted in his or her goals? Did the child lose critical skills, and will it take a long time to regain? Did the child fail to progress enough to realize meaningful progress toward annual goals by the conclusion of the year for which the current IEP was written?

Waivers: Nothing in IDEA has changed and families may not be required to sign a waiver of their child’s right to a free, appropriate, public education in the least restrictive requirement as a condition of receiving services. If parents are asked to sign waivers, they can contact their Parent Center *(see Resources)*. If that is unsuccessful, families can use the formal dispute resolution mechanisms in IDEA, such as mediation, requests for complaint investigation, or requests for due process hearing.

Transition: Districts are struggling with how students can access transition to adult life services during the pandemic. Usually, in developing the transition plan, there is discussion of community placement at work sites, internship sites, etc. It is an individualized and team process that includes the parents and the youth with the disability, as opposed to a unilateral process based on a blanket policy under the pandemic. The National Technical Assistance Center on Transition *(see Resources)* has useful resources, including transition-focused instructional services, online instruction resources and tips, transition assessment and planning resources, employment preparation-focused instructional resources, and transition resources focused on students with complex needs that can all be provided virtually.

Some students may need transition services beyond the planned academic year or initial date of exit from special education. The IEP team can convene and change their decision about the age of graduation. In terms of extended education beyond the age of eligibility, the discussion is more likely to be focused on the issue of the need for compensatory education services.

Dispute Resolution: Some dispute resolution procedures and mechanisms can be waived during COVID-19. For example, a state education agency is permitted to extend the 60-day time limit for resolving a state complaint due to circumstances related to the pandemic, but only on a *case-by-case basis*. The regulations specify two reasons for extending this 60-day time limit: if exceptional circumstances exist with respect to a particular complaint, or if the parent or individual organization, if mediation or other alternative means of dispute resolution are available to the individual organization under the state procedures, and the public agency involved agree to extend the time to engage in mediation or other alternative means of dispute resolution.

Families and districts can use the Creating Agreement tool *(see Resources)* to work together towards solutions. However, some parents may have to use the formal dispute resolution mechanisms in IDEA, discussed above. This would also be used, if needed, to obtain compensatory services. It is important for families to be aware that some states like AK, CT, DC, DE, GA, MN, NJ, NY, and WV have put the burden of proof on the district in due process hearings and court cases, but for most states, it is on the family.

Concerns regarding the provision of special education services during COVID-19 include evaluations, IEPs, FAPE, remote learning, compensatory services, transition, and procedural safeguards. Districts and families need to be aware that the requirements under IDEA remain, and that students with disabilities still must receive a free, appropriate, public education even during the pandemic.•

[Adapted from CADRE webinar “Got Back to School Questions? We’ve Got Your Answers” presented by Diana Autin.]

ABOUT THE AUTHOR:

Lauren Agoratus, M.A. is the parent of a young adult with autism and medical complexity. She serves as the State Coordinator for Family Voices-NJ and as the central 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


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MAKING VIRTUAL LEARNING ACCESSIBLE FOR THE VISUALLY IMPAIRED

BY SCOTT READY

Online learning presents an array of challenges to any student. Screen fatigue, technical glitches, and the many distractions that come with learning from home are all too familiar to parents, pupils, and instructors. But for students with disabilities, the difficulties associated with remote instruction are often even more acute, compounded by barriers to accessibility.

Online learning presents an array of challenges to any student. Screen fatigue, technical glitches, and the many distractions that come with learning from home are all too familiar to parents, pupils, and instructors. But for students with disabilities, the difficulties associated with remote instruction are often even more acute, compounded by barriers to accessibility.

One poignant example is students with visual impairments. Adapting virtual learning to meet these students' needs starts with recognizing that - as is the case with in-classroom learning - one size does not fit all in remote settings.

FINDING A FIT: Adapting virtual learning to meet the needs of students with visual impairments starts with recognizing that one size does not fit all in remote settings.

REMOTE ACCESS : THREE WAYS TO IMPROVE THE DISTANCE LEARNING EXPERIENCE

Here are three key paths to accessibility to consider when it comes to students with visual impairments and online learning:

ACCESSIBLE DOCUMENTS

In order to guarantee that lessons are user-friendly for students of every stripe, instructors should ensure that all documents they are sharing on online platforms are accessible.

That starts with paying attention to documents' format. For example, many assignments are uploaded as PDFs. But if a PDF document is not saved properly, it is saved as an image, rather than as a text-based document. The downside to this is that a document saved as an image cannot be read by a screen reader, which is a vital accessibility tool for the blind and visually impaired.

Taking the time to verify that each document is screen reader-compatible can mean the difference between an accessible learning experience and a deeply frustrating, inequitable one.

INTUITIVE WEBSITE NAVIGATION

Just as most of the sighted population can read a PDF image as easily as they can a Word document, navigating websites with a variety of interfaces is generally a straightforward experience.

Whether it's knowing where to click to move on to the next page or identifying where to enter a search query, website navigation is generally intuitive for those with full visual faculties. But for the visually impaired – particularly students with loss of central vision or peripheral vision loss ("tunnel vision") – it's another story.

This was driven home for me in a profound way while helping my grandson with his distance learning assignments at the outset of the coronavirus pandemic. One of his teachers had placed the class's homework assignments on no fewer than four different locations on the class webpage. I immediately thought of how difficult it would be for a visually impaired student to navigate the site – and how the same phenomenon could hinder academic progress for countless students with visual challenges.

How can teachers make web pages user-friendly for students of all visual abilities? Student-centered design can go a long way. During my years as a university professor, when building online courses, I would ask students of varying abilities to review all online materials and to identify any potential barriers to accessibility. Before finalizing the course materials, I would do my best to eliminate those barriers.

What's more, designing virtual course materials with the visually impaired in mind can help all students navigate better and succeed academically – and it can be a great exercise for spurring teachers to think more deeply about how else they can calibrate the learning experience to optimally serve diverse groups of students.

EXTENDED AUDIO DESCRIPTIONS FOR VISUAL MEDIA

Whether online or in person, whenever teachers incorporate visual media into their lesson plans, it should be accompanied by extended audio descriptions for visually impaired students to better understand, appreciate, and absorb the material.

It's important to distinguish between standard and extended audio. Whereas the former involves things like voiceovers that describe what is taking place in a particular scene, extended audio goes much deeper.

Take for example a teacher showing his/her students a video about proper conduct on the playground. The video shows a child pushing a classmate and then running away. An extended audio description would help clarify why this video is being used and what the learning objectives are. Students do not need to know what color shirt the children are wearing or what the playground looks like – the kinds of information we would expect from standard audio descriptions. Instead, what they need to know is, "Johnny pushed Becky and then ran away." With extended audio, the video is stopped, and the audio description is inserted with the proper amount of time to convey the behavioral message in a clear way, uninhibited or diluted by superfluous information.

A UNIQUE OPPORTUNITY

With many school districts moving toward a *hyflex* (hybrid and flexible) model for the foreseeable future, accessibility for students of all backgrounds and abilities must be at the forefront of how learning materials are designed for all modes of instruction.

While moving between in-person, remote, and hybrid learning has come with no shortage of challenges, there's another way to look at COVID-19's impact on education: a rare opportunity to think critically about new ways schools can foster a supportive and inclusive environment where all students have the tools needed to thrive. •

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EP LOOKS BACK: MARCH 2008

Finding a Preschool Where ALL Children Are Welcome

Tips for Evaluating the Inclusive Practices of Private Preschool Programs

By Amy Nicholas, Ph.D.

What is a "typical" preschooler's natural environment? More likely than not, one would say either at home. a daycare program. or community private preschool. On the contrary. three- and four-year-old children with disabilities receiving public special education services are often enrolled in programs where they attend their neighborhood elementary schools for part of the day or only a couple of days a week. In addition. these programs are frequently in segregated classrooms away from their peers without disabilities. So. for households with working parents. what about the rest of the week7 And what about opportunities for the children to interact with other children without disabilities? For parents with these concerns, the search for a private preschool becomes eminent.

It may be news to some parents that private preschool programs are nor required to adhere to the federally mandated legislation for public schools. known as the Individuals with Disabilities Education Act (IDEA). which states that all children are entitled to access to an education that meets their individualized needs regardless of the nature or intensity of their disability. While the Americans with Disabilities Act (ADA) requires private programs to make reasonable efforts to enroll children with disabilities. meaning they can not simply deny admission based on the child's disability alone. it does allow programs to turn away a child if the needed modifications or accommodations will cause undue financial strain on the program or will involve a.n altering of the program's fundamental structure. So. while many private programs advertise open-door policies related to enrolling children with special needs. there is no actual guarantee that all children will be accepted and that, if given a chance. all children will be able to remain in the program if their needs cannot be met. In many cases. parents of young children with disabilities scramble to find programs in which their children are welcome and can fully participate. The concept of full. side-by-side participation in all program activities by children with and without disabilities is known as "inclusion."

The benefits of inclusion have long been revered by educational researchers. Benefits for children with disabilities include enhanced self-esteem and self-respect stemming from being a part of their community, stimulation of social and language skills through peer models, and facilitation of friendships. Similarly, studies have found numerous benefits for children with typical development as well. such as increased awareness and acceptance of diversity and enhanced feelings of empowerment from helping others succeed. With benefits evident for children with and without disabilities alike. it becomes apparent why it is important for all parents to be able to identify programs that demonstrate effective inclusive practices. But, what does an effective inclusive program look like?

What questions should parents ask when shopping around for programs for their children? The chart to the right provides suggested questions to ask of program administrators, a brief description of the core inclusive practices addressed in each question, and specific examples of possible obstacles and practical suggestions for overcoming them. Discussing the suggested questions with program staff can provide immediate insight as to how they feel about inclusion and what supports they put in place to help ensure that all children are successful.

While there are specific things parents need to find out about a program, they too need to be sure to be open and forthright about the child's needs. Parents should be sure to tell program staff about any special medical or dietary instructions; their expectations for discipline and home communication; the child's strengths, abilities, and favorite activities; and things that are difficult for the child. Keeping lines of communication open and honest from the very start is essential to establishing a trustworthy, collaborative relationship with the program's staff. In general. it is important to remember that the teachers and administrators who work in these programs are there because they love children (they are certainly not there to become rich). So, more likely than not, if they truly feel they can do what is in the child's best interest, they will.

Now, where to begin? Locating preschool programs that are accredited by the National Association for the Education of Young Children (www.naeyc.org) is a good starting place on your journey to finding the best fit for your child. Checking with local child care and referral agencies is also a good first step. To find offices by city and state, visit the federal Child Care Awareness Bureau website www.childcareaware.org).

References that accompany this article may be requested by writing to jhollingsworth@eparent.com.•

How does the program:	Core Inclusive Practice	If your child:	The program can:
Modify the physical environment to promote participation and engagement for ALL children?	Physical changes to the classroom or building necessary to insure the child's safety or ability to function as independently as possible.	Has trouble keeping his hands to himself or on his own materials when working on activities.	Use trays, box lids or placemats to designate a personal workspace for the child, while not being excluded from the group (i.e. at a separate table or desk).
Modify the social environment to promote participation and engagement for ALL children?	Changes to socially-oriented routines or activities that enable the child to participate as a member of a group	Has trouble finding playmates.	Have staff join in on free play activities with the children, modeling how to approach a group and ask to play.
Modify materials so that ALL children can participate in activities?	Changes to the materials used during an activity that allow the child to participate independently or with minimal assistance.	Has difficulty grasping pencils, crayon, and paintbrushes.	Build up the handles by wrapping and taping pieces of foam around them to make them easier to grip and hold.
Modify procedures so that ALL children can participate in activities?	Changes to schedules, routines or agendas that facilitate the child's ability to successfully participate in an activity. Flexibility is the key!	Is often quick to finish an activity, but then has difficulty waiting for the next activity	Set up a quiet area (book corner, music area with headphones) so that the child can leave an activity when finished but not disturb others who are still working.
Identify and incorporate children's preferences into activities?	Taking into consideration the unique likes and dislikes of the child when developing activities in an effort to motivate and encourage participation.	Often refuses to join large-group activities.	Start group activities with the child's favorite song or action, such as blowing bubbles.
Use special or adaptive equipment to increase children's level of participation	Adaptations to existing devices or special devices that enable the child to perform activities and interact with the environment.	Uses wheelchair or other adaptive device.	Use a bean bag chair during floor activities to provide necessary physical support while positioning the child at a natural eye level with his classmates
Use adults to support children's participation and learning?	Using adults as active participants in children's learning, providing support in a least to most inclusive manner.	Tends to get overly excited when preparing to go outside for playtime.	Position an adult next to the child to hold his hand and help get the excitement under control prior to announcing that the class is going outside.
Using peers as natural, socially-motivating models and sources of support?	Use peers to support children's participation and learning?	Gets confused and does not know when and where to go when given a choice of activities.	Pair the child with a classmate who knows the routine well, and ask the child to find his partner and go to the activity together.

Amy Nicholas, Ph.D., is an assistant professor of special education at Towson University in Maryland. Amy has worked on a variety of training initiatives aimed at increasing access to community programs for young children with disabilities. Her areas of research interest include high-risk infants, early childhood assessment, and family-professional collaboration. She can be reached at alnicholas@towson.edu.

5 SPECIAL NEEDS PLANNING ITEMS TO REVIEW DURING THE COVID-19 HEALTH EMERGENCY

BY JAMES TRAYLOR
AND NICOLE VANGORDER

HEALTH INSURANCE

If your child has private insurance AND Medicaid, remember to provide the insurance information to all medical providers (including pharmacies). If your child has both Medicare and Medicaid, consider enrolling in a Medicare Managed Care Plan for individuals that are "dual eligible." Many of these plans carry no cost and can provide additional benefits beyond Medicaid/Medicare alone. In certain States, if you have a co-pay insurance plan that covers your child, you may be eligible for premium reimbursement from the local Department of Social Services. Furthermore, some larger employer-based health plans may have provisions that allow an adult child with a permanent disability to remain on the group insurance plan beyond age 26. While every plan is different, check with your HR professional or review the insurance plan documents to verify if this is an option. If your child meets the Federal Social Security definition of disability, some plans will accept this as proof that the disability is permanent in nature.

SPRING INTO ACTION: "We had multiple clients reach out to us frantically this spring as their child began receiving unemployment benefits that were quickly accumulating. An ABLE account would allow an individual for Representative Payee to transfer funds that could be saved for future use."

RESPITE

Do you have family, friends, or paid staff in the community that could act as a short/long term staff member for your child if you were sick? For States with self-hire respite programs, COVID-19 has created onboarding delays in adding a new employee onto the payroll. Do you have an emergency plan if you were to fall ill? Consider speaking with other families in the community to share staff or leverage your other children's relationships to find qualified caregivers. We have seen clients turn to their church or synagogue, higher education institutions, as well as local non-profit providers with furloughed staff looking for extra hours.

EMPLOYEE BENEFITS

Given the major disruption in employment and potentially changing employer-sponsored benefits, it is not uncommon that an employee names their adult child with disabilities as the beneficiary of their retirement plan or group life insurance policy. A properly drafted supplemental needs trust may be more appropriate than leaving assets directly to a child with disabilities that is eligible for various public benefits. During annual enrollment, or upon starting a new job, make sure these beneficiary designations are not overlooked or set to default.

LETTER OF INTENT

As parents, you know your child's behaviors, habits, goals, and quirks. Many of these nuances are not captured in the medical records, your will or trust. A properly drafted Letter of Intent can capture critical data that would assist a future caregiver, trustee, or personal care attendant with the impossible task of replacing you. If you already have this document completed, Congratulations! It may be time for a quick update if life has changed since the last time you put thoughts to paper. Many organizations provide templates to get started. A useful place to start is through The Arc: **https://thearc.org/free-planning-guide-sign-up/**

ABLE ACCOUNTS

During the spring, we had multiple clients reach out to us frantically as their child began receiving unemployment benefits that were quickly accumulating over $2,000. Having an Achieving a Better Life Experience (ABLE) account established would allow an individual for Representative Payee to quickly transfer funds that could be saved for future use. States have different rules about establishing an ABLE account if the individual with a disability is not their own guardian. A great resource to get started is the National ABLE Resource Center: **www.ablenrc.org**

HOT TOPICS DURING COVID-19 : SOME QUESTIONS WE RECEIVED FROM CLIENTS DURING THE CRISIS

Q: What happens if a family member dies and leaves money to my child and not their Supplemental Needs Trust?

A: You should immediately contact a qualified Medicaid or Estate Planning attorney. If you move quickly, you may be able to limit the loss of Medicaid and Supplemental Security Income benefits to one month. The individual will lose benefits temporarily in the month they receive the funds; however, depending on State rules, they may be able to transfer their inheritance into a properly drafted Self-Settled Supplemental Needs Trust. In the best situation, an attorney may petition the local Surrogates or Probate Court for permission to place the money into an existing Supplemental Needs Trust without needing to establish another trust. Your local BAR association may have a list of Elder Law or Special Needs Planning attorneys. Another list that attorneys subscribe to is the Special Needs Alliance:

www.specialneedsalliance.org/find-an-attorney

Q: My child was laid off from their job and is receiving Supplemental Security Income (SSI). Do they need to apply for Federal Unemployment, or can they just continue to get SSI?

A: Yes. The Social Security Administration requires all SSI beneficiaries to apply for other means tested government benefits that they may be eligible for before resuming their Federal SSI benefits.[1] In the case of unemployment insurance, as unearned income, the benefit will reduce their SSI benefits dollar for dollar. Once the unemployment is exhausted it is important to notify the Social Security Administration to reinstate the SSI benefit. If the individual was receiving benefits under unemployment while simultaneously receiving SSI benefits it is likely that the dual eligibility will result in an overpayment of SSI benefits and lead to the SSA reducing future benefit payouts.

Q: How will government benefits such as Medicaid and Social Security be impacted by COVID-19 and the Federal Deficit?

A: Unfortunately, we do not have a crystal ball. Current Federal fiscal year 2020 was running a 1-Trillion-dollar structural deficit *before* COVID-19. According to the Office of the Comptroller General, both tax increases and cuts to government spending will be required to bring the U.S. deficit down. It would be prudent to assume future cuts or modifications to programs like Medicaid are inevitable.[2]

Q: I am worried that I have not received my Medicaid recertification paperwork in the mail. Will my child lose Medicaid?

A: Under the Families First Coronavirus Response Act signed on March 18, 2020, no Medicaid recipient will lose their coverage after March 18, 2020 through the end of the Public Health Emergency. The Federal Secretary of Health and Human Services, Alex M. Azar II, extended the Public Health Emergency effective October 23, 2020. The extensions are for 3 months, so the Public Health Emergency is set to expire April 21, 2020 unless renewed again. After this point, consumers could expect to see Medicaid renewals and correspondence from their local Department of Social Services or State Medicaid Office. If an individual maintains SSI eligibility under Federal law, they will remain eligible for Medicaid. •

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[1] https://secure.ssa.gov/poms.nsf/lnx/0500510005

[2] https://www.gao.gov/americas_fiscal_future

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GENETIC TESTING IN PSYCHIATRY

BY BENJAMIN MARGOLIS, M.D.

As a psychiatrist, if I had an available tool that would provide a tailored genetic map of an individual I'm working with that would allow me to prescribe exactly the right medication, I'd want it available for every patient I treat. Such is the promise of genetic testing to guide prescribing of psychotropic medications.

This technology is already being applied robustly in cancer treatment, where antibody-based therapies can be precisely targeted to the genetic makeup of a particular tumor, or we can look for genetic markers that directly correspond to response to certain standard chemotherapeutic agents. In oncology, the era of pharmacogenomics has arrived. In both neurology and psychiatry, testing for HLA genes can help predict risk for a potentially serious side effect from mood-stabilizing antiepileptic medications.

In psychiatry, the promise of pharmacogenetics is great. We can simply run a test where a cotton swab is gently swiped inside each cheek, sampling a few cells from the mouth, and then mail that swab to a lab. In a few days, a comprehensive report returns with a list of psychiatric medications and their potential "gene/drug" interactions. We should then be able to use this report to minimize the chance for side effects and maximize the possibility of therapeutic response.

If only it were so simple!

When someone has depression or anxiety and requires treatment with a medication, in our field, we carefully consider the nature of the symptoms we're treating, the efficacy and tolerability of the medications we are suggesting, the other medications the person is taking, other medical problems they have, and integrate this into our decision-making tree before suggesting a medication. This is our standard, and considering gene/drug interactions is not yet part of the algorithm.

While genetic screening sounds like a wonderful tool to add to our armamentarium, in psychiatric clinical practice, the evidence for clinical benefit is still pending, and there are some potential pitfalls.

To start with a brief description of the tests: in our bodies, genes are sequences of molecular code made of DNA that are translated by cellular machinery to create proteins. We now have sophisticated tools to be able to read and interpret variations in the DNA within particular genes. In the case of psychiatry, the genes we test for mainly code for a set of proteins within the liver called cytochrome P450 proteins, which are enzymes (molecular machines that speed along chemical reactions in the body) involved in processing and clearing medications. Those cytochromes have names like 2D6, 3A4, etc. When we take an oral medication, the medication is absorbed through the GI tract, and then can be either cleared and processed by the liver and excreted in stool, or by the kidneys and out through the bladder. Within the liver, those CYP450 enzymes, again with names like 2D6 and 3A4, take that drug and process it, creating metabolites. With each step, those metabolites themselves may have pharmacologic effects on the body and are themselves either processed by more CYP450s or excreted. The above process is a brief and hopefully not-too-baffling summary of the process of pharmacokinetics, which is what your body does to a medication.

For the majority of psychiatric medications, we have a detailed understanding of the entire pharmacokinetic journey from ingestion to metabolite to excretion. We know which particular cytochromes make which metabolites, what those metabolites do, and on average, what range of time they stick around in the body and where. So where does the genetic testing come into play?

Pharmacogenetic testing identifies variations in someone's genetic code that translate to different versions of those CYP450 enzymes. Some of them may work faster or slower to clear a medication or metabolite. We should then potentially be able to predict how quickly or slowly your body processes a medication. We may be able to predict how much or how quickly you may process metabolites associated with side effects, and then predict which medications might get along best with you.

It sounds brilliant, and it is. The promise is undeniable. The problem is that pharmacokinetics is only part of the story when it comes to your body. In addition to pharmacokinetics, there are multiple other factors at play. There are interactions with the other medications an individual may be taking. There are considerations of age, other medical history, hydration status and weight. In addition to what your body does to clear a medication (pharmacokinetics), there are considerations of what the medication is doing to your body (called pharmacodynamics). The genetic screening companies are now offering tools for genetic profiles of some of the drug targets, profiling differences of receptors themselves, but these are not yet necessarily correlated to clinical response.

We can't yet say whether someone will respond to a medication based on these tests.

> In general practice, pharmacogenetic testing in psychiatry for treatment of anxiety or depression is not standard of care, and the APA does not yet support its widespread use. That leaves doctors working with the I/DD community still waiting for the tools to mature.

In my clinics and in the care of individuals with I/DD, I have to a limited extent been using these tests for the past four years from the two largest commercial labs.

I don't yet offer these screens as standard of care before deciding to start a medication. If an individual or caregiver is interested in pursuing them, we talk about the process and the potentially limited information that these tests can provide. When we get test results back, there are color-coded results in green, yellow or red correlating to the extent of a particular predicted gene/drug interaction. However, that doesn't necessarily mean we would absolutely avoid a particular medication that may still have therapeutic value. That information may be helpful in predicting that someone may need a higher or lower dose of a medication, or that they may be more likely to have side effects at higher doses, but in terms of clinical practice, this does not change how we would go about prescribing a medication.

In practice, regardless of genetic testing, we "start low and go slow," regardless of a genetic test result, monitoring for both clinical response and side effects carefully along the way. If someone wants to incorporate the results of their genetic testing as we decide what medication to utilize, I of course have no objection, and we will use that information together as part of a plan, but not necessarily as the main decision-making tool. There is the risk that a potentially helpful medication could be withheld and the benefit missed if too much weight is placed on these tests.

There is a financial consideration, as insurance does not necessarily cover these tests and they can run into hundreds of dollars. When it comes to limited resources available for some individuals with I/DD and their families, this can be a significant consideration.

The practice arena I have found these screens to be most helpful is not in starting new medications, but in assessing which to taper or reduce. As a field, we are committed to minimizing polypharmacy, minimizing psychiatric medications as much as possible. Individuals with I/DD in psychiatric care have in the past been treated with two or sometimes even three antipsychotics at a time, a deep and complex discussion on its own, but here we will only discuss the universal effort to consolidate to antipsychotic monotherapy whenever possible. When I am assuming the care of an individual coming out of institutional care settings, or for whom limited history is available, and who may have been treated with two or three antipsychotics for 30 years, which medication do we choose to reduce first? Pharmacogenetic testing can potentially provide us with a suggestion on what we would target and can potentially guide our medication optimization.

Even in this circumstance, this comes with a potential financial cost and along with the caviat that there are multiple other factors at play in our medication optimization scenario above. Side effects, age and other medical considerations are often clear and help guide our reduction strategy.

In general practice, pharmacogenetic testing in psychiatry for treatment of anxiety or depression is not standard of care, and the American Psychiatric Association does not yet support its widespread use.[1] The FDA has issued warnings against unproven claims from some manufacturers.[2]

So where does that leave us psychiatrists working with the I/DD community? It leaves us still waiting for the tools to mature. When prescribing medication, we make decisions in the context of the whole person, integrating all of the complex factors discussed earlier before proposing a plan and a trial of medication. Someday soon (but not quite yet), genetic testing will likely be an integral part of that process.•

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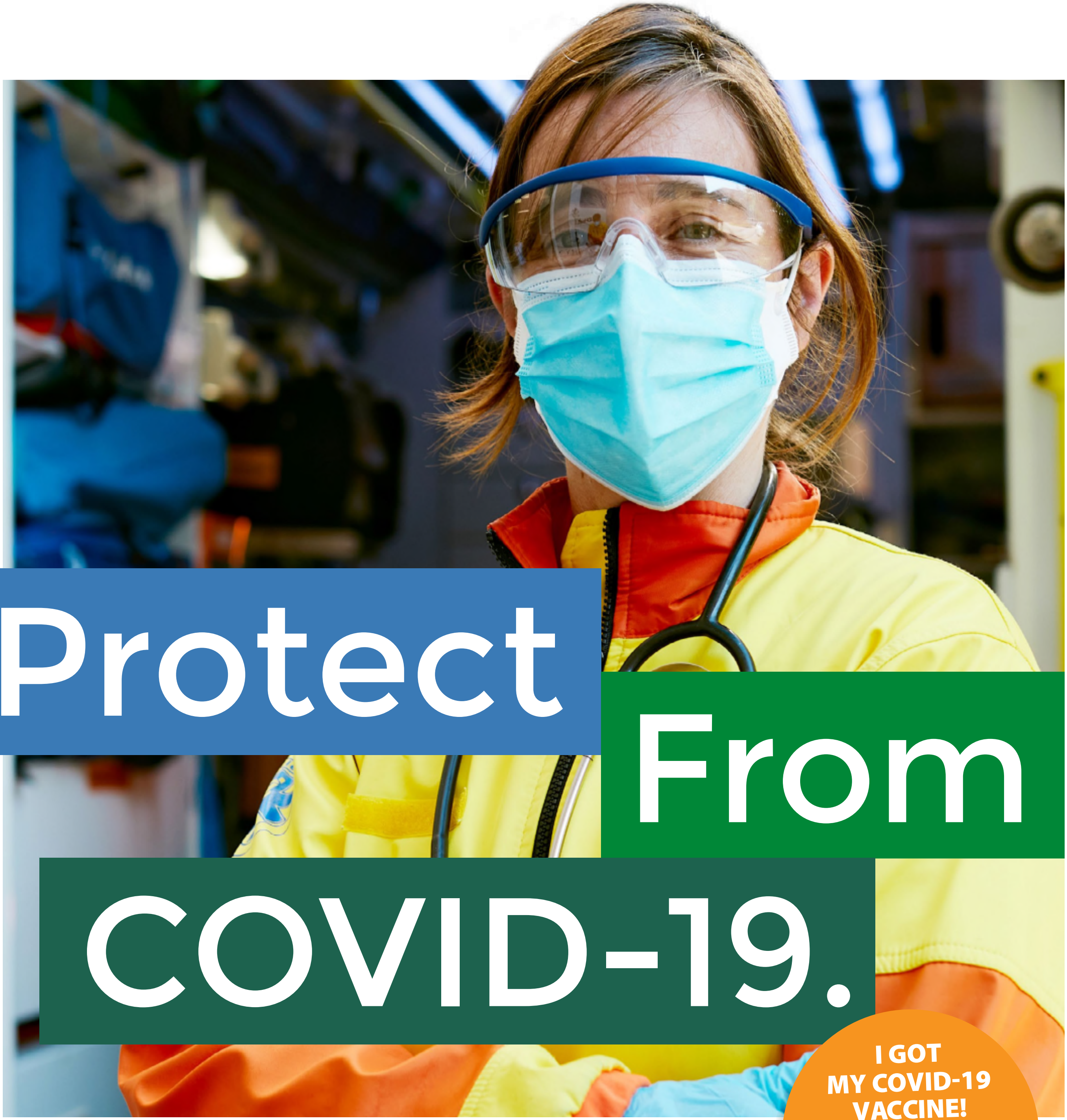

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EVALUATION AND MANAGEMENT OF OBESITY IN ADULTS WITH INTELLECTUAL DISABILITY

BY PHILIP MAY M.D.

Obesity, which is usually defined as Body Mass Index (BMI) of equal to or greater than 30 kg/m2, has become a serious health risk for many individuals and groups in the United States and worldwide. The US Surgeon General has declared that obesity has reached epidemic proportions and has called for immediate action designed to prevent and reduce the impact of this condition on the individual and society at large.

Obesity in the general population has been shown to be associated with high-risk for hypertension, diabetes, dyslipidemia, heart disease (both *atherosclerotic cardiovascular disease* and *diastolic heart failure*), osteoarthritis, sleep apnea, pneumonia, gallbladder disease, liver disease, 13 different cancers (e.g., endometrial, breast, colon, and others), and gynecological problems (abnormal menstrual periods, infertility). Obesity has also been shown to have adverse effects on brain anatomy and function, resulting in abnormalities of cognition, mood, and behavior.

Limited research has demonstrated that obesity is a major health threat for persons with Intellectual and Developmental Disabilities (IDD) as well as for the general population *(see Table 1, next page)*. Prevalence of obesity is 40-50% in various surveys for both men and women with IDD who live in the community. The cause of obesity in persons with IDD appears to be multifactorial and related to various genetic and environmental factors *(see Table 2)*. It has been shown that "mild" IDD, community residential status, and young age are all related to an increased risk for obesity in persons with IDD. Certain medications, especially second-generation antipsychotics, also appear to convey an increased risk for obesity. Obesity in persons with IDD can limit opportunities for community participation such as employment and leisure, require more effort on the part of caregivers in assisting individuals with IDD with various activities of daily living, and result in higher medical costs related to treatment of obesity-related health conditions, all of which can lead to a greater mortality rate and reduced life-expectancy for this medically underserved and vulnerable population of U.S. citizens. Currently, obesity has also been shown to be associated with increased morbidity and mortality from COVID-19 infection[1], and this effect may be even greater for individuals with ID.[2]

Table 1. ***Complications of Obesity in Adults with Intellectual Disability***

- **Associated with higher mortality rates and shorter life expectancy**
- **Increased rate of diabetes, dyslipidemia, hypertension, sleep apnea, arthritis.**
- **Increased Cardiovascular Disease (Heart attacks, Strokes, PVD)**
- **Increased Gallbladder Disease and Gallstones**
- **Increased incidence of Gout**
- **Increased Periodontal Disease**
- **Increased risk for Cancer**
- **Abnormalities of brain structure (atrophy) and function (worse Cognition, Mood and Behavior)**
- **Increased risk of morbidity and mortality from COVID-19 Infection**

Treatment of Obesity

In the general population, treatment of obesity is usually accomplished by behavioral/lifestyle approaches, medications, and/or surgery. Barriers to treatment of obesity encountered in *adults* with Intellectual Disabilities include sparse curriculum in Medical Schools and lack of research which addresses how best to evaluate and manage those health conditions (such as obesity) that frequently occur in adult men and women with IDD. Few physicians have experience regarding evaluation and management of health conditions, such as obesity, in adults with ID. This often results in “fragmentation” of care delivered by multiple specialists who do not communicate. For example, a psychiatrist may be prescribing an obesogenic psychotropic medication (e.g., olanzapine) for behavior with undocumented benefit, while an endocrinologist, without collaboration with the psychiatrist, might prescribe topiramate for obesity, which may also have a psychotropic benefit better than olanzapine. Both psychiatrist and endocrinologist need to communicate with each other, and with the primary care provider, who needs to ensure that this communication occurs.

Table 2. ***Causes of Obesity in Adults with ID***

1. **Socio-environmental: Food used as reinforcer for good behavior, boredom.**
2. **Genetic: e.g., Prader Willi Syndrome**
3. **Metabolic: e.g., Cushing’s Syndrome, Hypothyroidism**
4. **Medication Side Effects: e.g., Neuroleptic medication**
5. **Psychiatric: “Food Addiction”**
6. **Sedentary behavior**

Effective treatments of obesity in the general population exist. These include non-pharmacologic/non-surgical (“lifestyle”), pharmacologic, and surgical approaches. Non-pharmacologic/non-surgical approaches include various combinations of nutrition, exercise, and behavior modification programs. Reports of purely pharmacological and surgical treatments of obesity are not as common as the “lifestyle” approaches in treating obesity in adults with IDD. A recent *US Preventive Services Task Force*-commissioned literature review concludes that behavioral counseling interventions to promote combined lower calorie diet (500 Kcal/day reduction) and more exercise (150 minutes/week) produce a statistically significant reduction in cardiovascular risk factors (including obesity) at 12-24 months [3]. However, the relative contributions of diet vs. exercise, the importance of weight-loss, and the specific role of the primary care physician in this “behavioral” approach to reduction of cardiovascular risk factors (including obesity) have still not been clarified. It seems likely in most cases of behavioral treatment of overweight status, if significant weight-loss occurs, and is maintained, multiple cardiovascular risk factors (such as diabetes, high cholesterol, hypertension) will improve or even disappear completely without use of medications or surgery.

It has been noted by others that primary care physicians (for multiple reasons), while adequately *medically* addressing weight-related “complications” such as diabetes, dyslipidemia, hypertension, sleep apnea, etc., rarely provide CMS-recommended “behavioral” (non-drug or surgical) treatment of “obesity itself”.[3] In a recent JAMA interview,[4] Popkin commented that the specific issue of “obesity itself” has been relatively ignored by physicians and policymakers, when compared to attention given to the many “complications” of obesity (such as diabetes, hypertension, coronary heart disease, and even increased morbidity and mortality from COVID-19 infection). These same issues are also observed in treating obesity in patients with IDD.

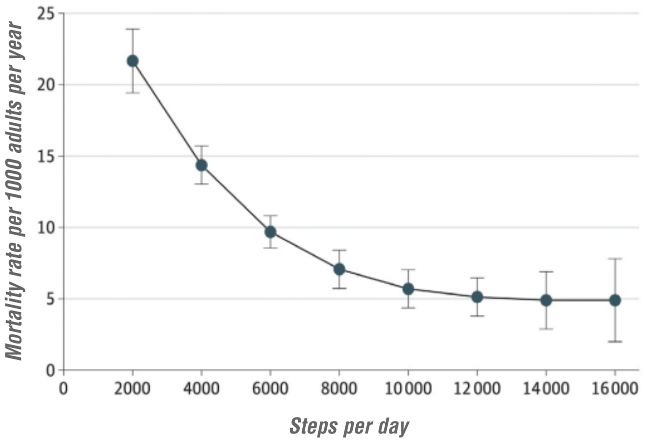
While a lower calorie diet alone has been shown to be effective for weight-loss short term (< 3 years), the preponderance of evidence suggests that very few people with obesity can *maintain* weight-loss by caloric restriction alone for more that 2-3 years. Long-term success (> 9 years) is more likely to occur in those obese individuals who exercise regularly.[6] This might be explained by the fact that people with obesity characteristically have reduction of volume of certain areas of the brain (“hippocampal hypovolemia”) which can cause both cognitive and mood disorders. Physical exercise has been shown to stimulate neurogenesis of hippocampal neurons by exercise-induced increased production of both brain and skeletal-muscle *Brain Derived Neurotrophic Factor* (BDNF), which then leads to improved mood and less emotion-driven compulsive eating.[7]

Table 3. ***Components of an Effective Quality Improvement “Fitness Program” for adults with IDD***

1. **“Meaningful” individualized *Daily* Physical Exercise Program (Establish the “Habit”).**
2. **Dietary: Reduced caloric intake & increased protein.**
3. **Supportive and Trained Staff and Caregivers.**
4. **Frequent Medical and Administrative Follow-up.**
5. **Documentation of Benefit to *provide feedback* to persons with IDD and their caregivers.**
    - **Body Composition Analysis of muscle and adipose tissue.**
    - **Routine metabolic tests (e.g., fasting blood glucose, A1C, lipids)**
    - **Baseline and Follow-up Psychometric Testing for cognition, mood, and behavior**
    - **Individualized Exercise Program prescribed and monitored by physician and monitored with an activity measuring device (Steps-per-Day).**
    - **Statistical Analysis to determine efficacy of interventions for feedback information for administration, staff, and participants of the QI Program.**

Thus, *maintenance* of weight loss and subsequent CVD risk factor reduction long-term may primarily be a problem of "the head not the scale" that needs to be addressed with the "habit" of daily exercise see Figure 1, before long-term weight loss and metabolic/CVD risk-reduction can occur.[8] Physicians could play a key role in this process if they required that "behavioral" treatments were in place before the "pills" were prescribed.

Figure 1. *Steps per Day and All-Cause Mortality in a Study of the Association of Daily Step Count and Step Intensity With Mortality Among US Adults*



Health agencies and governments could also be supportive by encouraging health provider organizations/clinics to establish **Quality Improvement Programs**[9] focused on obesity treatment. *(see Table 3)*. Quality Improvement "fitness programs" have been shown to reduce incidence of metabolic problems (diabetes, dyslipidemia), increase muscle mass and function (treatment of sarcopenia), correct hypertension and sleep apnea, reduce risk for cardiovascular disease and cancer, improve cognition, mood, and behavior and reduce polypharmacy.•

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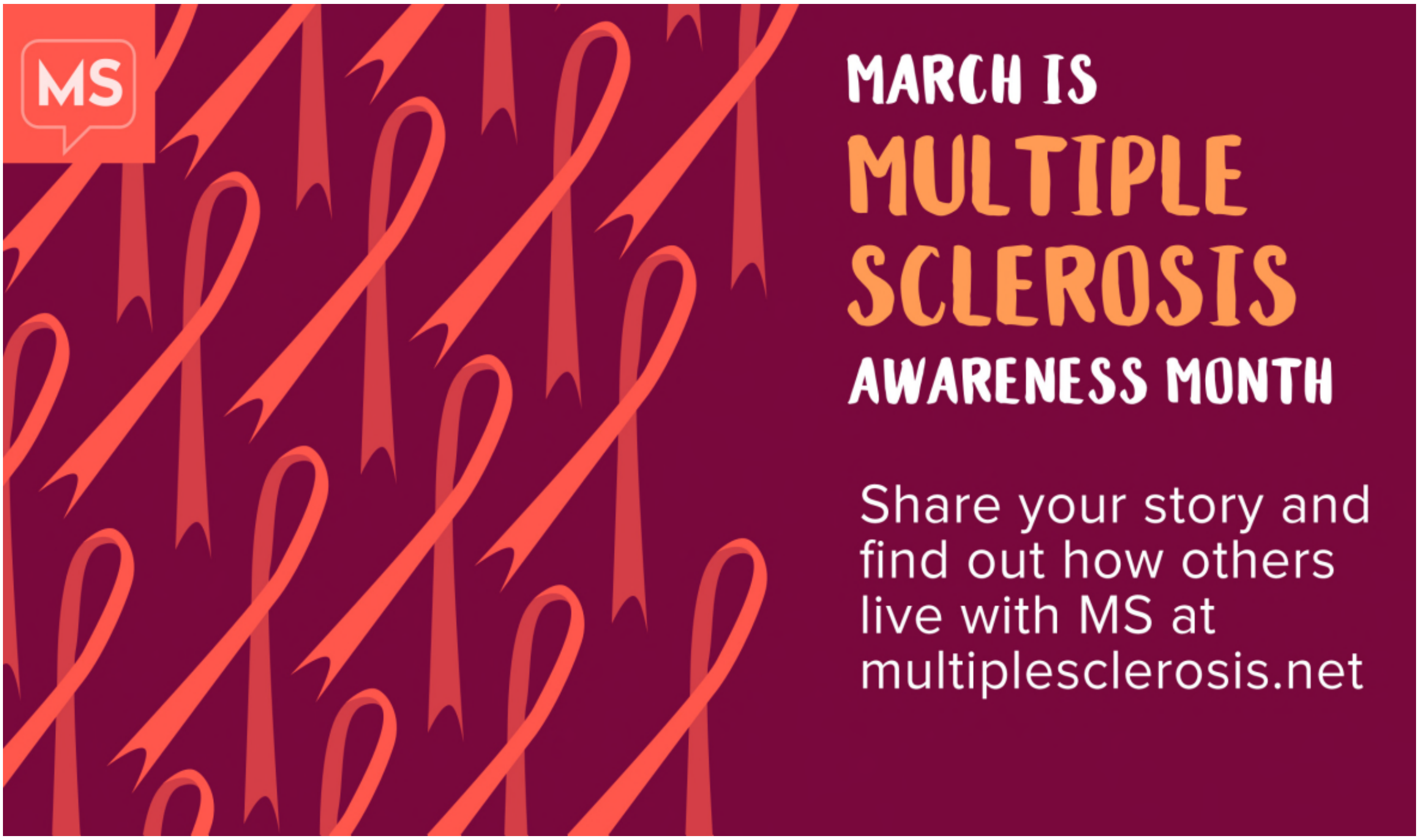

OUR FRIENDS

BY MARGY HOOD

> *“The aim of art is to represent not the outward appearance of things, but their inward significance.”*
>
> *– Aristotle*

Since 1998, my husband, Dr. Henry Hood, has spent his entire professional life caring for people with intellectual and developmental disabilities (IDD). For a time, I worked at the interdisciplinary clinic that he and Dr. Matt Holder created here in Louisville. I loved my job there, and I especially loved the patients we served.

In August of 2016, Dr. Hood and I were married, and one of the things we have really enjoyed doing together is attending various art shows and art fairs put on by people with IDD. Art seems to be a deeply satisfying way in which people with IDD can express what’s in their head and heart. There is a very active advocacy community for people with IDD in this area; these events happen frequently, and we always seem to be in attendance.

Over these last few years, we’ve created a wonderful collection of treasures. Each piece is singularly unique, and many of them have unbelievably touching stories behind their creation. An example is the set in Fig. 1 featuring three pieces that just seem to belong together. We call them the Bridge Club. Apparently, one of the ladies had to use pearls from her necklace to cover her gambling debts.

In Fig 2., the artist created a self-portrait. She made her right ear in the shape of her dog, Rosie, and even wrote the dog’s name on it. The left ear was fashioned after her cat, Gladys, whose name is

PHOTOS PROVIDED BY: HENRY HOOD, DMD

FIG. 1

FIG. 2

FIG. 3

FIG. 4

FIG. 5

also recorded. Her curly hair was created by pushing the pottery clay through wire screen. My husband's favorite are the two angels seen in Figs. 3 and 4. My favorite is the Teenage Mutant Ninja Turtle ink and watercolor seen in Fig. 5.

Without a doubt, all these pieces of art have transformed my sewing room into a mini-art gallery. The joy and comfort they bring means everything to us, as does the knowledge that they were created by people with big hearts and even bigger ideas. In the coming years, we will continue to bring new pieces into our home, and we will also give them as gifts to our friends and loved ones, knowing that everyone's day will be brightened by the work and talent of our very special friends. •

ABOUT THE AUTHOR:

Margy Hood is the wife of Henry Hood, DMD, who is Chief Clinical Officer at the Lee Specialty Clinic in Louisville, Kentucky; and Co-founder / Past President American Academy of Developmental Medicine and Dentistry.

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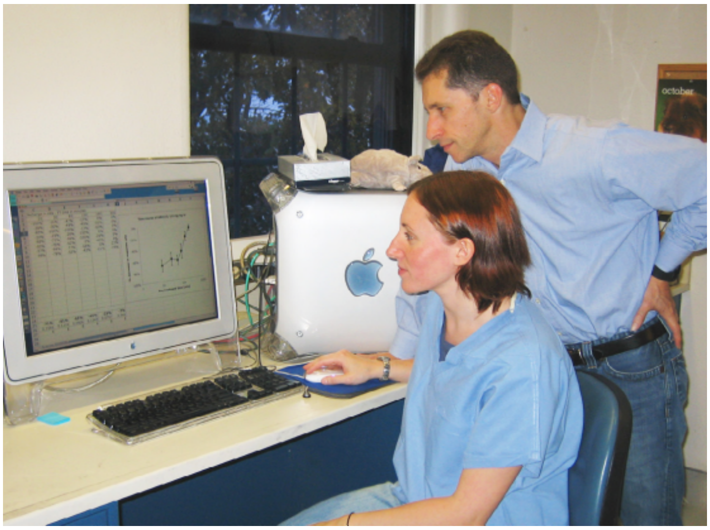

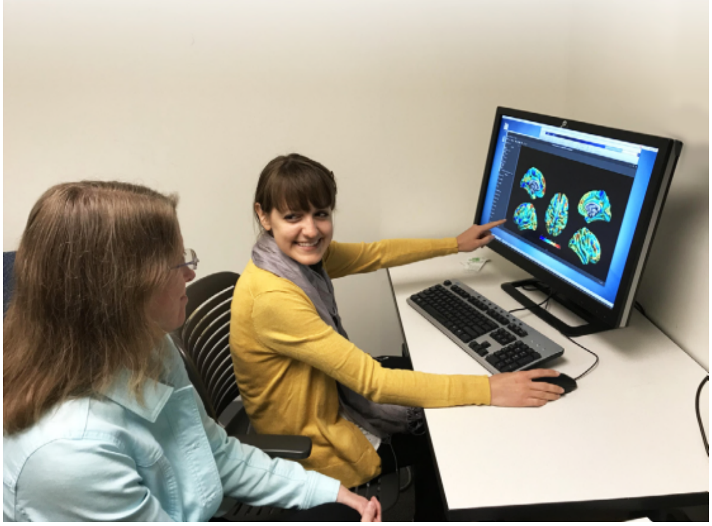

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THE 12TH EDITION of the AAIDD DIAGNOSTIC AND TERMINOLOGY MANUAL

BY ROBERT L. SCHALOCK, RUTH LUCKASSON AND MARC J. TASSE

The scientific definition of the term intellectual disability (ID) is relevant to the lives of people with ID and their families in very important ways – think personal identity and accessing needed services and supports such as early intervention, IEP, waiver services, Medicaid insurance, and Social Security Disability benefits. Think also about media and communication, and risk of stigma

This year, the premier professional organization in the field of ID published the updated definition of ID. This event occurs only about every 10 years (beginning in 1921), so it is worth paying attention to the 12th edition. In this article, we provide a summary of the updated definition of ID and other important aspects of the American Association on Intellectual and Developmental Disabilities (AAIDD) manual.

To begin, the purposes of a definition of intellectual disability are to explain precisely the term, establish the meaning and boundaries of the term, and separate who is included within the term from those who are outside the term. Significant consequences can result from the way a term is defined. A definition can make someone eligible or ineligible for supports and services, subjected to something or not subjected to it (e.g., involuntary commitment), exempted from something or not exempted (e.g., from the death penalty), included or not included (as to protections against discrimination and equal opportunity), and/or entitled or not entitled (e.g., certain Social Security benefits or other financial benefits).

The definition of intellectual disability found in the 12th edition of the AAIDD manual (Schalock, Luckasson, & Tassé, 2021) is that **intellectual disability is characterized by significant limitations both in intellectual functioning and in adaptive behavior as expressed in conceptual, social, and practical adaptive skills. This disability is manifest during the developmental period, which is defined operationally as before the individual attains age 22.**

Title: **Intellectual Disability: Definition, Diagnosis, Classification, and Systems of Supports (12th Ed.)**

Authors: **Robert L. Schalock, Ruth Luckasson** and **Marc J. Tasse**

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Assumptions are an essential part of the definition of intellectual disability because they clarify the context from which the definition arises and indicate how the definition should be applied. Thus, the definition cannot stand alone. The following assumptions are essential to the definition's implementation:

1. Limitations in present functioning must be considered within the context of community environments typical of the individual's age peers and culture.

2. Valid assessment considers cultural and linguistic diversity as well as differences in communication, sensory, motor, and behavioral factors.

3. Within an individual, limitations often coexist with strengths.

4. An important purpose of describing limitations is to help inform the development of a profile of needed supports.

5. With appropriate personalized supports over a sustained period, the life functioning of the person with intellectual disability generally will improve.

These five assumptions demonstrate, front and center on page 1 of the manual, important values about community living, authentic assessment, the presence of strengths and limitations shown by every person, the purpose for describing the individual's limitations, and the fact that improved life functioning will result if the individual is provided needed supports. The assumptions also reflect the distinction between the diagnosis of intellectual disability, which involves significant limitations both in intellectual functioning and adaptive behavior, and age of onset during the developmental period, and the expression of intellectual disability, which involves the reciprocal engagement among human

PROPER DEFINITION : PRACTICE GUIDELINES FOR DIAGNOSIS, CLASSIFICATION AND SYSTEMS OF SUPPORTS

Individuals with ID and their families, as core members of the teams that assess for eligibility, design for supported functioning, and monitor for quality of supports, may be especially interested in the practice guidelines listed below. Interactions with clinicians will be enhanced if all members of the team share an understanding of the guidelines for diagnosis, classification and planning supports. These practice guidelines are listed below:

PRACTICE GUIDELINES REGARDING THE DIAGNOSIS OF INTELLECTUAL DISABILITY:

1. A diagnosis of intellectual disability requires significant limitations in intellectual functioning and adaptive behavior, and origination during the developmental period, which is defined operationally as before the individual attains age 22.
2. Assessment instruments used to formulate a diagnosis of intellectual disability should use reliable, valid, individually administered, comprehensive, and standardized tests that yield (a) a full-scale IQ score (for the intellectual functioning criterion), and (b) a standardized adaptive behavior measure that assesses the following three adaptive behavior domains: conceptual, social, and practical.
3. Equal weight and joint consideration are given to intellectual functioning and adaptive behavior in making a diagnosis of intellectual disability.

PRACTICE GUIDELINES REGARDING CLASSIFICATION IN THE FIELD OF INTELLECTUAL DISABILITY:

1. Classification is an optional post diagnosis organizing scheme that uses an explicit framework and a systematic process to subdivide the group of individuals with intellectual disability into smaller groups.
2. The preferred subgroup classification scheme is based on the intensity of support needs. Other potential purposes of subgroup classification are to describe the extent of limitations in conceptual, social, and practical adaptive skills, or to describe the extent of limitations in intellectual functioning.
3. Any subgroup classification should serve an important purpose, have benefit to the person, be based on relevant information, and provide a better understanding of the person.
4. Best practices in subgroup classification reject stigmatizing subgroup classification terms. The selected terminology should demonstrate respect for the person, promote accuracy, and enhance understanding.

PRACTICE GUIDELINES REGARDING SYSTEMS OF SUPPORTS:

1. The assessment of the pattern and intensity of an individual's support needs should be based on a professional evaluation, including use of an individually administered standardized support needs scale.
2. Systems of support should be built on values and support relationships and should incorporate choice and personal autonomy, inclusive environments, generic supports, and specialized supports.
3. Systems of support should be person centered, comprehensive, coordinated, and outcome oriented.
4. The provision of supports should be coordinated through a personal support plan that (a) is developed, implemented, reviewed, and evaluated by a support team of which the person with intellectual disability is a member, and (b) aligns personal goals and support needs with specific support strategies with desired personal outcomes.

functioning dimensions, systems of supports, and human functioning outcomes.

An important feature of the 12th edition of the AAIDD manual is the inclusion of practice guidelines regarding the diagnosis, classification, and planning supports for people with intellectual disability. The basis of these practice guidelines is current research, expert opinion, and peer-reviewed publications The purposes of the practice guidelines are to: (a) facilitate best practices regarding the diagnosis, classification, and planning supports for people with intellectual disability: (b) provide an integrated approach to disability policy development, implementation, and evaluation; (c) suggest a holistic framework for ID-related research; (d) connect valued foundational concepts to valued policy; and (e) enhance the functioning and well-being of people with intellectual disability.

In providing this overview of the 12th edition of the AAIDD manual, we hope that the above information facilitates a better understanding of how important a scientific definition is and clarifying current best practices regarding defining, diagnosing, classifying, and planning and implementing individualized supports for people with ID. People with ID and their families are essential partners in understanding ID and the assumptions; collaborating in best practice procedures for its diagnosis, optional subgroup classification, and development and implementation of individualized systems of supports; and building strong relationships with clinicians. Facilitating this process is one of the major goals of the 12th edition of the AAIDD manual.•

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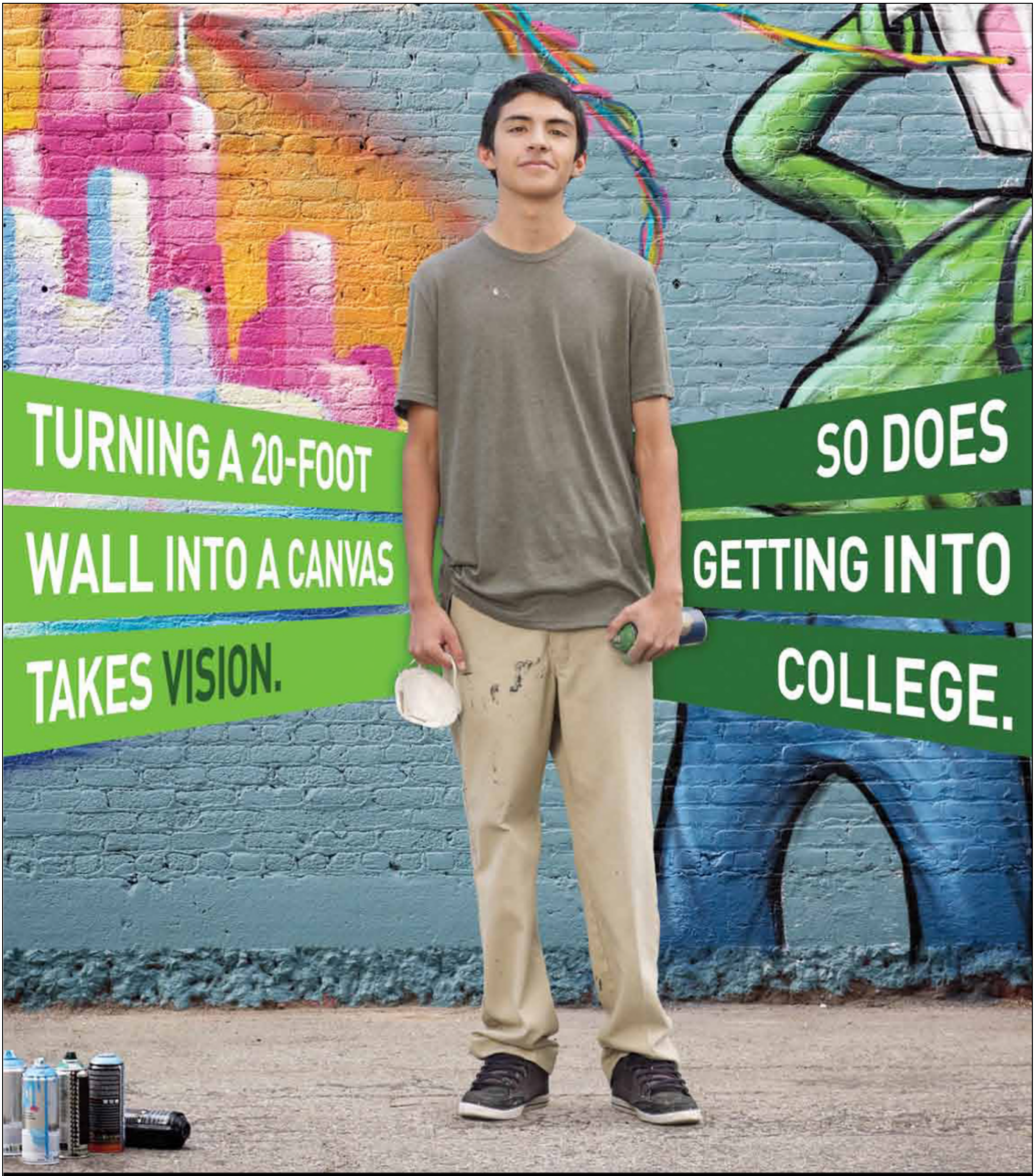
TURNING A 20-FOOT
WALL INTO A CANVAS
TAKES VISION.
SO DOES
GETTING INTO
COLLEGE.

I AM A VETERAN
AND THIS
IS MY VICTORY.

FROM OUR FAMILIES... TO YOUR FAMILIES

MILITARY
SECTION

SCHOOLS, CAMPS
and Residences

MILITARY LIFE

PUZZLES AND CAMO

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BUILDING RESILIENCY THROUGH A COLLABORATIVE IEP PROCESS IN SUPPORT OF MILITARY FAMILIES

BY ANGELA SHAW

One of the most precious and durable commodities that parents can nurture within their children is the quality of resiliency. Resilience – the bounce-back quality that supports an individual in adapting to and recovering from setbacks and overcoming snags in life – allows one to power through unexpected or long-term difficulties, while becoming better equipped to manage future hurdles.

In times of adversity or crisis, an individual's inner-strength and coping skills are often called upon to manage and minimize stressors in a reactive manner. Coping skills, such as taking a walk when angry, counting backwards from 5 before responding, or using an "I feel" statement, are some strategic actions that individuals can use to deal with stress. Resiliency provides for an outlook that comes from within.

Building and reframing mindsets in support of the agile qualities of a resilient kid begins with demonstrating productive coping skills. The proactive viewpoint of a resilient family member, colleague, or future leader, has the capacity to adjust a course toward success and well-being across a lifetime, through their model of positivity and creativity. Practicing self-care through healthy life choices, self-analysis through discussion of lessons learned from slip-ups, and self-acceptance through publicly and privately accepting our own mixed bag of wins and losses, all help guide the children towards the natural choice of wise and healthful habits, encourages development of a balanced expectation and reaction to life— and creates a positive internalization process in support of motivation, planning, and positivity. These everyday examples, combined with direct teaching of customized coping skills, bolster the development of an internal toolbox of strategies.

In providing supports toward learning and effectively navigating life through proactive coping skills, a springboard is created toward inspiring and nurturing your child's resiliency. A resilient mindset can lead to improved learning and academic achievement, and decreased absences from school or, eventually, the workplace. Additionally, the ability to speedily and efficiently recover and adapt to challenges provides for an increased capacity to bounce back stronger and wiser from life's adversities.

Military service members, by the very nature of their chosen path of helping protect and serve the country, are accustomed to navigating the challenges included in their mobile life of lengthy and recurring deployments and transfers across the map. This highly mobile lifestyle allows their children to experience a unique perspective in life, due to frequent moves, a product of military assignments termed a permanent change of station (PCS). Their perpetual movement provides a lifestyle that goes beyond traditional classrooms and hometown neighborhoods, affording them a viewpoint into an assortment of regional, social and academic settings they would otherwise have missed out on.

THE MILITARY CHILD WITH SPECIAL NEEDS

When a military child experiences educational or physical differences, the everchanging realities of military life take on increased challenges that require specialized supports and resources beyond that of their civilian counterparts. Military installments provide a robust range of services in support of families on the move, including military service members and their families caring for members with special needs. Additionally, federal educational legislation, currently known as Individuals with Disabilities Education Act (IDEA), is law in support of all eligible children with disabilities throughout the nation and ensures special education and related services through an Individualized Education Program (IEP).

When considering the school-based support of the IEP, a synergetic approach toward nurturing qualities that encourage the development of resiliency are foundational to a customized IEP within a well-informed and proactive IEP team. Through the broad strokes of the IEP process, the team has the ability to link home and school-based forces that provide appropriate supports and individualized goals within the least restrictive environment (LRE), based upon a child's individualized profile of strengths, needs and present levels.

Parent perspectives are essential to the team discussion, particularly when a student is highly mobile or new to a school. In addition to military resources that support smooth and equitable transitions for students with special needs, parents provide an important context by providing to the school-based team insight of their child's motivations, needs, and often shifting experiences. Such features included within the IEP document that is presented at the IEP meeting include:

STRENGTHS AND CONCERNS

When determining a student's needs, an essential component to the IEP is to discover and share the student's areas of strength, in order to provide focused understanding that holds promise of continued growth and positive development. Observance and input from current educators and related service personnel, as well as school records, offer academic, social and emotional information based upon categorical points of reference relative to expectations of grade level, or of age, to include possible concerns.

A broader point of view from parents and, as appropriate, the student, adds a measure of comprehensive insight to the areas of competence that can be built upon for greater opportunities of lifelong educational and social/emotional growth and success. Parents are able to share pivotal points of their child's learning experience, as well as engagement insights as to what motivates and fascinates them. Hobbies, special interests, and past successes open up several avenues for generalizing learning in the classroom and on the playground, as well as across a multitude of extra-curricular opportunities that help build a stronger sense of belonging. Parents and educators communicating in a proactive manner results in greater understanding and presents children with a real-life positive model of thoughtful and beneficial collaboration.

APPLICATIONS FOR THE HOME FRONT:

- **Highlight, cultivate and generalize your child's strengths as a launchpad toward proactive problem-solving and a pathway toward self-discovery.** Support their strengths through hobbies and special interests to build passion and confidence. For example, talking about past challenges or hurdles that were successfully navigated when learning a new yoga flow, constructing a kite, or discovering a new star through their telescope may provide opportunities for nurturing a proactive mindset.
- **Praising your child's success to include time spent in practice and problem-solving strategies** encourages them to embrace their accomplishments while bringing preparation and planning to the forefront. Goal setting, stamina and perseverance are primed when kids are involved through their personal experiences.
- **Finding a way to share your mistakes and problem-solving strategies,** appropriate to your child's age and development, helps them understand that they are not alone. For example, sharing that you forgot to buy paper towels at the store that day and offering a simple solution of supplying the family a hand towel on the kitchen counter for hand drying (until you can get to a store again) helps your child learn about problem solving.

PRESENT LEVELS OF PERFORMANCE (PLOP)

Current academic, behavioral and social emotional experiences and levels, are shared at the IEP meeting to provide a comparison of successful areas while sifting through other areas in need of strengthening and building. This has potential to build a goal through utilizing the process of task analysis and breaking down a skill or task to its smallest steps, to plan a path of learning.

APPLICATIONS FOR THE HOME FRONT:

- **Break down chores, family cooking, or other activities into steps at the present level of access,** using visual schedules or checklists to support and grow planning. Ensuring your child's access by starting at your child's present level is a way to provide a scaffold to

work through challenges, and build a repertoire of strategies to draw upon in the future.
- **Play!** Sharing silly kid jokes, enjoying family game nights, or engaging in a fun-filled game of hopscotch or basketball in the driveway, can lead to a wealth of self-awareness and discoveries. The outgrowth of increasing knowledge, physical and mental dexterity and strength, and coping skills through positive play, has the potential to encourage the growth of a personal toolbox of self-assurance that generalizes beyond home and school.
- **Stretch your child's reading and language development beyond current levels by reading together.** Reading high-interest materials together nurtures creativity and sparks exploration of new ideas and perspective-taking. Enjoying lively discussions about ideas, consequences or joys explored together further connects creativity, wonder and even empathy.

SUPPLEMENTARY AIDS AND SERVICES

Accommodations, modifications and supports are individualized and documented within the IEP document, as appropriate, based upon each student's unique profile, in order to provide access to learning within their educational setting. This includes direct services and supports to the child, as well as appropriate support and training for staff members.

APPLICATIONS FOR THE HOME FRONT:

Scaffolds leading to accomplishment are an ever-present reality across the landscape of home, school and job. Providing opportunities for kids to practice a skill at home until they have it mastered, supports learning and generalization of skills within their community, in the classroom, at play, or work. Children learn to internalize fruitful strategies and prune away less productive ones.

- **Include everyone in the joy and bonding of family game night.** Modify, adjust and support your child's game participation. Get creative. Consider generalizing some of the supports or modifications listed within the "Supplementary Aids and Services" section of the IEP. Playing classic board games, card games or guessing games are great ways to unplug and connect, while building self-esteem, teamwork, communication, self-discovery, problem-solving, and coping skills.
- **Make a plan, a checklist or a visual map to support your child's homebased endeavors.** Promoting a broadened collaborative spirit to encourage and support proactive problem-solving approaches—through pitching in at home and discussing other methods or strategies that can be used to complete a project or activity—helps promote self-care and advocacy leading to a growing sense of competence and an ever-burgeoning toolbox for future endeavors.
- **Get crafty.** Teaching children to follow instructions and persevere, or improving their fine motor skills, are natural outcomes of crafting. Quality time and creation of lasting memories fill emotional reservoirs and connectedness. Confidence is boosted as kids see their progress, experiment with their growing talent, or express themselves with originality. Provision of scaffolds offers students practice in using their classroom accommodations and supports self-advocacy.
    - ***Create a board game together.*** *Movies, a favorite book, or a local landmark can spark imaginations beyond expectation, as you explore and discuss possible themes with children.*
    - ***Set up an assembly line where each family member does a part of the craft.*** *Learning and practicing the art of teambuilding and communication is a positive outgrowth that will serve your child across many settings.*
    - ***Create a family tradition.*** *Make greeting cards for family and friends. Communication skills, perspective taking and caring are bolstered, as children design their messages.*

A highly effective mode of reaching and teaching children is accomplished within an authentic environment, such as home and community. Weaving together these three IEP segments within the home, provides focus and generalization across settings, and an entry point toward realizing a strong foundation of resiliency. Such focus provides a starting point and a journey that's customized to meet each family's specific situation.

In addition to the IEP process, transition-related challenges facing each PCS, deployment or post-deployment, can be further met head-on in support of each military family's unique circumstance, through the robust range of resources provided within the military installations. Applying strategies towards achieving an IEP goal provides a roadmap that can be generalized at home and inspire the development of a resilient child to navigate and grow from tough situations throughout their lives.

ABOUT THE AUTHOR:

Angela Shaw is a retired special educator. Her publishing focus is upon special education topics. She synthesizes her diverse teaching experiences and education to support and encourage families as they navigate the special needs of their children across a changing educational landscape. Angela's son-in-law is active-duty military. She and her husband spend as much time as possible adventuring to various PCS locations to enjoy time and be a part of their military family's life.

STAYING CONNECTED WITH YOUR CHILD'S TEACHERS DURING A DEPLOYMENT

BEING THERE: Let your child know that school is important; kids tend to perform better in school when their parents are involved in their education.

No matter where you are around the country or the world, you can still support your child's education. With communication technology and strong interest, you can keep up with their grades and stay in touch with teachers. Let your child know that school and education are important – whether you're home or deployed. Set the stage for success:

- *Meet with teachers prior to deployment. Set up a meeting before you prepare for deployment so you can work out a plan to stay connected.*
- *Use the school's online resources. Department of Defense schools use GradeSpeed* (https://dodea.gradespeed.net) *to keep families up to date on grades and attendance. Civilian schools may have similar services.*
- *Ask your partner for help. Your partner can be your "boots on the ground" for all things educational. Reinforce your partner's role to your children — set your partner up for success.*

Kids tend to perform better in school when their parents are involved in their education.

PLAN AHEAD TO STAY INVOLVED

Make a plan to stay active and involved in your child's education at every stage.

- *Discover technologies. Find out what communication technologies you can access once you deploy.*
- *Talk about how to stay in touch. Ask your child's teachers before you go about the best way to stay in touch. It might be through email, a school website or even texting.*
- *Share when you want to be informed. Tell teachers what specific issues you want to know about, such as a low grade or an unexcused absence. It's a good idea to let your child know, too.*

KEEP IN TOUCH

There are lots of creative ways to stay in touch with your child and support his or her education. Try these ideas:

- *Stay in regular contact with your child's teachers. Check in as frequently as your mission allows via email or telephone.*
- *Send a class gift. Pick up something special from the area of the world where you're deployed. You'll be the kids' favorite parent. If it relates to what the class is studying, you'll be the teacher's favorite parent, too.*
- *Ask your partner or child's guardian for assistance. Your child's designated guardian can oversee homework, talk with teachers and help your child get to school on time. Discuss successes and challenges with your care partner regularly. If your partner or child's guardian has difficulty speaking English, ask the school to provide a translator.*

Find time during your deployment to work on strengthening your connection with your child's school. Your commitment to staying involved can set them up for success in the classroom and beyond.

Contact Military OneSource to speak with an education consultant (www.militaryonesource.mil/confidential-help/specialty-consultations/education). Call 800-342-9647. OCONUS/International? Visit www.militaryonesource.mil/international-calling-options for calling options.

– Military OneSource

GET YOUR CHILD THE RIGHT START WITH SURE START

Sure Start is a Department of Defense Education Activity program for command-sponsored children in military families stationed at overseas installations. If your family qualifies, it could be a great fit for your child. The program provides:

- *Education services*
- *Lunch and snack provisions*
- *Health and nutrition services*
- *Social and parent-involvement services*
- *Dental, medical and developmental screenings*

SURE START: IS YOUR CHILD ELIGIBLE?

Sure Start assists qualified preschool-age military children living overseas. To qualify, your child needs to turn 4 years old by Sept. 1 of the current school year. Your child also must meet one of these requirements:

- *Lives in a single-parent household*
- *Had a low birth weight*
- *Has an older sibling with severe disabilities*
- *Lives in a home with four or more kids close in age*

An eligible child also must have at least one parent who meets one of these criteria:

- *Ranks between E-1 and E-4 or rates the civilian equivalent (Exceptions are possible, but these children receive priority.)*
- *Did not graduate from high school*
- *Was a teenager when the child was born*
- *Speaks anything but English as their primary language*
- *Is on a remote assignment or temporary duty for at least three months*

WHAT'S THE DIFFERENCE BETWEEN SURE START AND HEAD START?

Sure Start is built on the same foundation as Head Start but fits better into the Department of Defense Education Activity culture and regulations.

Both Sure Start and Head Start:

- *Use a four-tiered delivery system: education, health and nutrition, social services and mandatory parent involvement*
- *Run medical, dental and developmental screenings for students and provide follow-up assessments if needed*
- *Provide no-cost, nutritious lunches and snacks*
- *Encourage family involvement*
- *Cater to students' ages, individual needs and cultures in environment, curriculum, materials, routines and daily activities*
- *Follow a full-day program*

How is Sure Start different from Head Start?

- *The Department of Defense Education Activity oversees the Sure Start program.*
- *Sure Start considers a military sponsor's rank its first priority for enrollment, while Head Start uses income to determine eligibility.*
- *Sure Start does not use a child's disability status to determine eligibility, while Head Start reserves at least 10% of slots in each classroom for children with disabilities.*
- *Sure Start staffs two adults for every 18 to 20 students. Local or state licensing boards determine Head Start's staff-to-child ratios.*
- *Sure Start staff works with Department of Defense Education Activity special education staff to determine the best placement and services for a child.*
- *Sure Start programs follow the Department of Defense Education Activity's College and Career Ready Standards and curriculum. Head Start chooses curriculum at the local level.*

If you are interested in the Sure Start program, contact your school liaison, your installation's elementary school or your Military and Family Support Center (**https://installations.militaryonesource.mil/?looking-for-a=program**). Visit the Department of Defense Education Activity's Early Learning page (**www.dodea.edu/Curriculum/eChildhood/sureStart.cfm**) to see if your child is eligible for Sure Start.

– Military OneSource

HEALTHY, ACTIVE CHILDREN & ACADEMIC ACHIEVEMENT

FUEL FOR SCHOOL: Kids need snacks throughout the day that are high in protein and low in sugar to boost their ability to listen, process and remember what they are learning.

We all want our children to enjoy learning, make good grades and achieve success. Nutrition and physical activity are linked to academic achievement, so making sure your children are healthy and active will fuel them to reach their academic goals.

A healthy lifestyle can help improve a child's:

- *Attention span*
- *Thinking ability*
- *Memory*

Here are some tips for making healthy eating and physical activity part of your child's daily life. For more nutrition and physical activity help, contact Military OneSource online, or call 800-342-9647, and set up a specialty consultation for health and wellness coaching (www.militaryonesource.mil/confidential-help/specialty-consultations/health-wellness-coaching). OCONUS/International? Visit www.militaryonesource.mil/international-calling-options for calling options.

YOUR CHILD'S NUTRITION

Hungry kids tend to have shorter attention spans and have difficulty with problem-solving, math skills and memory recall, according to studies from the Journal of School Health. Children need a nutritional breakfast of whole grains, fiber and protein. They also need snacks throughout the day that are high in protein and low in sugar to boost their ability to listen, process and remember what they are learning.

Visit these websites to get tips about healthy food choices:

- *ChooseMyPlate.gov, for tips that you can post at home:* www.choosemyplate.gov/ten-tips-build-healthy-meal
- *Defense Commissary Agency, for recipes, cooking tips and more.:* https://commissaries.com
- *Unlock the Savings and Nutrition Inside Your Commissary, for tips on making healthy choices:* www.militaryonesource.mil/recreation-travel-shopping/commissary-exchange/unlock-the-savings-and-nutrition-inside-your-commissary

PHYSICAL ACTIVITY

According to the Centers for Disease Control and Prevention, children need at least 60 minutes of physical activity every day. Physical activity can include school recess periods, hiking, dancing, playing sports, or walking to and from school.

Check out the following resources for ideas about how to keep your children physically active:

- *Morale, Welfare and Recreation activities on your local installation:* https://installations.militaryonesource.mil/?looking-for-a=program
- *Installation youth centers, to locate a safe, kid-oriented environment:* https://installations.militaryonesource.mil/?looking-for-a=program/program-service=31/focus=program
- *Boys & Girls Clubs of America: Military Partnership, for community participation opportunities:* www.militaryonesource.mil/family-relationships/family-life/for-military-youth-and-teens/boys-girls-clubs-of-america-military-partnership

Boost your child's social and academic success by making healthy eating and physical activity part of your family's daily life.

– Military OneSource

Caregiver Strength

We still have a way to go before we are through this pandemic. But if we make a point to remind ourselves that we are worth advocating for, not just for our children, we'll make it. We'll make it through with our sense of self intact.

I had a dream last night. I was sitting in the corner of my living room in a beanbag chair. I had just woken up. My teeth weren't brushed and my hair still had a dangling, disheveled ponytail where half of my hair was hanging outside of the rubber band. I looked around and my living room started to fill with people. I saw people that work with my husband. I saw people from my son's ABA team, and Hayden's friends. I noticed my windows were open and water started to spill into my house. The water turned into people. People started spilling into my living room and then my kitchen. I yelled, "Get out of my house!" as I ran up the stairs getting away from everyone as they started to climb my walls and stairwell. I finally reached my bedroom, shut the door, and locked it. Then I woke up.

I couldn't get back to sleep. What a crazy dream! Why did I have it? After lying in bed for a while, I realized that my dream was describing how I feel. I am approaching the one-year mark of when the pandemic significantly changed my life as a mom, a wife, and basically a person. Last night, I think I hit rock bottom. I thought I had hit rock bottom a few months ago, but nope. Now, I think I officially hit rock bottom. I mouthed the words, "I miss my life. I want my life back." I didn't realize how much I liked my life until it was taken away from me.

Over a year ago, I had time to myself. After I took Hayden to school and Broden to his ABA clinic, the day was mine. I could run errands, prep for the course I teach, write, go for a run, walk my dogs, go to the grocery store, mail packages, get my hair cut, get my teeth cleaned, or go to a doctor's appointment. My options were limitless. Boy, could I get things done. I was productive and proud of it. Once Broden moved to an in-home program, all of that changed. My freedom became a distant memory and my teaching aspirations were put on hold.

As a mom and caregiver, this is what I'm supposed to do, right? As a mom, I'm supposed to stay flexible, and if it means that I sacrifice my freedom, then that is an expectation that I need to meet. Or is it? I have learned that in order to not lose myself, there needs to be some give and take. That doesn't make me a bad mom. It makes me a mom that survives and sees the importance of holding on to the fact that acknowledging the need to keep my sense of self is sacred. I'm learning that if others do not see this necessity, it doesn't make it less important to me.

Expectations will never go away, but I need to do a better job at not letting them control me. My son, Hayden, normally gets out of school at 3:20 p.m.. After talking with Broden's therapist about how he performs each day, there may be circumstances where it takes a little longer than usual. Yesterday was one of those days. At a stoplight, Hayden texted me at 3:21pm, "Mom! Where are you?" The light turned green so I pressed on to his school. I arrived at 3:30 p.m., "Mom, I texted you. You are always late to get me now. I hate waiting by

myself because everyone is gone. After school, I just want to get home and unwind.”

I smiled at the thought of another unmet expectation. Before putting the car in drive, I turned to him and said, “You’re not my only child. You’re not the only one who has certain expectations of me. You’re going to have to remember that I’m doing the best I can and that’s going to have to be good enough.” I reminded him that I would always remember to pick him up from school, even if I’m nine minutes late.

Caretakers have been truly challenged this year. As a caretaker, I feel like I’m seen as selfish for expressing the need for some relief. When I mouth the words, “I miss my life,” a little voice inside of me says, “You’re not supposed to say that. Your job is to sacrifice for your children.” I don’t believe that little voice in my head anymore. I think we can do our best to be there for our children and also learn to advocate for ourselves. As caretakers, we cannot lose our sense of self. If we do, then we send a message to ourselves that we do not have value. Also, by advocating for ourselves, we are teaching our children that it is not okay to lose yourself, and that there is value in creating boundaries. My health will surely benefit the ones I care for each day.

> “When I mouth the words, ‘I miss my life,’ a little voice inside of me says, ‘You’re not supposed to say that. Your job is to sacrifice for your children.’”

There have been quite a few articles lately on how hard this pandemic has affected moms and caretakers. A few months ago, an NPR article was entitled, “Being a Mom is hard, being a Mom in a pandemic is harder.” I’m going to go one step further due to experience. Being a mom to a special needs child during a pandemic is the absolute hardest. We still have a way to go before we are through this pandemic. But if we make a point to remind ourselves that we are worth advocating for, not just for our children, we’ll make it. We’ll make it through with our sense of self intact.•

PUZZLES & CAMO

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

ADAPTIVE/SPECIAL NEEDS BEDS

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P: 800-574-7880
E: ruthann@kayserbettenus.com
W: www.kayserbettenus.com
Designed to allow the child to be part of the surroundings while being safe and secure in their bed.

BOOKS/PUBLICATIONS

HIGH TIDE PRESS

W: www.hightidepress.org
E: Greetings@HighTidePress.org
Books on Positive Organizational Culture, Leadership, and developmental disabilities for professionals in human services, education, nonprofit management and healthcare.

CLEANING/SANITIZING SOLUTIONS

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

FINANCIAL PLANNING/ EDUCATION

THE AMERICAN COLLEGE OF FINANCIAL SERVICES

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

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Home automation products and devices professionally installed.

NON-PROFIT

IRENE AND ERIC SIMON BRAIN RESEARCH FOUNDATION

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

SCHOOLS/CAMPS/RESIDENCES

THRESHOLD PROGRAM AT LESLEY UNIVERSITY

Cambridge, MD
W: www.Lesley.edu/threshold
P: 800-999-1959 ext. 8181; or 617-349-8181
E: threshold@lesley.edu
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SUPPLEMENTS

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Avmacol's exclusive Sulforaphane Production System® delivers the support your immune and detox systems need to thrive in the modern world.

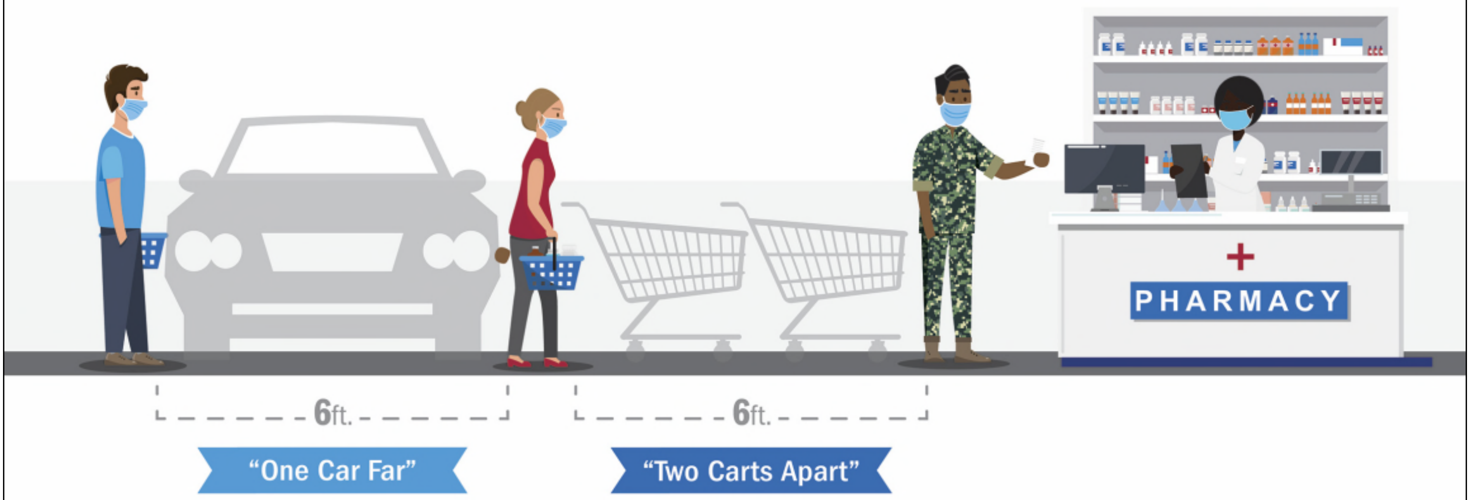
Coronavirus Disease 2019

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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