PLUS: UNITED STATES MILITARY SECTION

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MAGAZINE
DECEMBER 2020
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SEASON'S GREETINGS from the PANDEMIC

IN THIS ISSUE:

CAREGIVING DURING the HOLIDAYS

AND:

CHOOSE ACTION over DISTRACTION

PLUS:

THE BEST CHRISTMAS GIFT EVER

ALSO:

DENVER HAS A HEART of GOLD

FAMILY, COMMUNITY AND

THE HOLIDAYS

AMERICAN ACADEMY OF DEVELOPMENTAL MEDICINE & DENTISTRY
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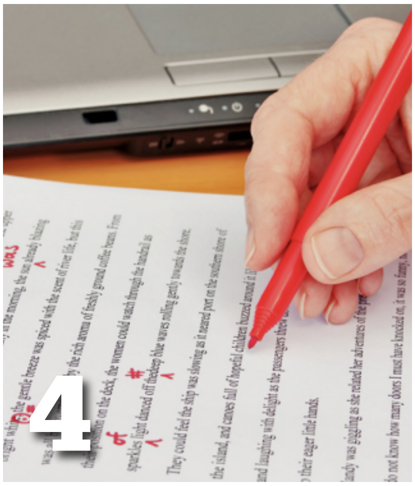

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Information and Support for the Special Needs Community

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— Rick Rader, MD

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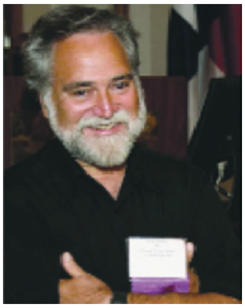
Blood Red

Parents of children with special needs have gotten used to red ink. They've gotten used to seeing red ink circling abnormal lab values on reports, seeing the words "denied" or "ineligible" underlined in red from insurance companies, and seeing maps with redlines indicating where group homes could be built and operated.

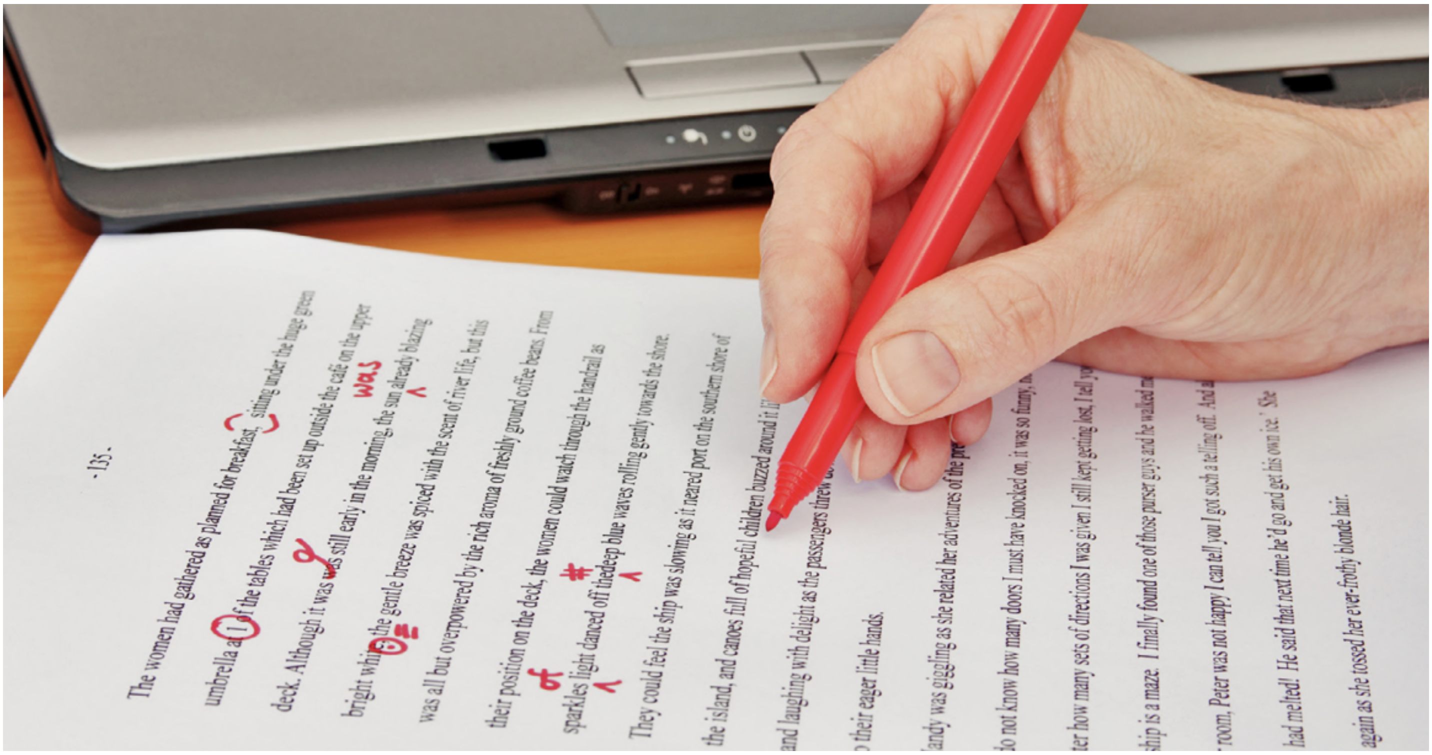


On most weekends I head for my garage to recharge my batteries, both mine and the vintage cars I collect. It's my outlet and my favorite diversion. So, last Saturday, I worked on an old race car, trying to convince it that after 90 years of slumber it was time to get up, growl, and spit fire. Of course, success in the garage is labor intensive. While I was coaxing life back into the speedster, I committed one of the fundamental rules of mechanics – never push on a wrench. It's okay to pull on a wrench, but not to push on a wrench. This was made very clear to me when I was pushing down on a ¾ inch wrench against a bolt that was last touched when a gallon of gas was ten cents, a loaf of bread was nine cents, and the average price of a new house was $590. The bolt was frozen with rust and was humored by my efforts. I gave it my all and pushed down hard and the wrench slipped and my knuckles went flying into the engine block. The reluctant bolt now wore a coat of red, courtesy of the fresh cut on my hand, which to no surprise came in second to the engine in the new guessing game, which thing is more fragile than the other. I was bleeding, not gushing, but enough to get my attention. Red blood can certainly get your attention, especially when it's your own. The red color of blood is among one of nature's most outstanding features.

Linda Crampton, writing in Owlcation, provides an explanation, "In humans, oxygenated blood is bright red and deoxygenated blood is dark red or maroon. The color is due to the presence of hemoglobin molecules in the red blood cells. Hemoglobin is a respiratory pigment. It transports oxygen to the tissue cells, which need the chemical to produce energy. Blood that is not red may indicate a health problem. Human blood may become brown or green due to the buildup of an abnormal form of hemoglobin." It was obvious that my blood was well oxygenated, it was as healthy as blood could be, it just was now residing outside my body.

As medical students, my classmates and I were made aware of the importance of recognizing the different colors of different body fluids. There are approximately 26 body fluids and they all (in both health and disease) have distinct variations in color.

RED SCARE: The mark of death was seeing the following words in red ink on the tests, compositions, assignments, and reports that were returned to me by my teachers: "See me after class."



Stool, urine, sweat, mucus, phlegm, menstrual blood, amniotic fluid, semen, nipple discharge, saliva, tears, cerebrospinal fluid, and others can be identified by their colors.

Shakespeare referenced black bile, yellow bile, green phlegm and red blood as the "four humours" of the human body. It's noteworthy that during a man's mid-life crisis, they typically are found ordering a new sports car and insisting it be "blood red." There are not many orders for a new Ferrari or Corvette in "yellow bile" or "phlegm green."

> "During a man's mid-life crisis, they typically order a new sports car and insist it be 'blood red.' There are not many orders for a new Ferrari or Corvette in 'yellow bile' or 'phlegm green.'"

What is it about red that Mother Nature insisted her blood had to come in that color? Alice Hoffman, the American novelist and children's writer (Practical Magic) provides some provocative insight. "How could I have been so stupid to ignore everything I'd had in my life? The color red alone was worth kingdoms."

Besides the 120 colors in the largest box of Crayola crayons, there are colors that are only known to the most elite Scrabble players. When was the last time you heard someone at the make-up counter at Saks Fifth Avenue or Henri Bendel's asking for cosmetics in the colors of sarcoline, coquelicot, wenge, fulvous or falu?

There are nearly 10 million unique colors, and while not all of them are distinguishable by the human eye, the color red provokes the strongest emotion of any color. Kendra Chery in "The Color Psychology of Red" suggests that "while cool colors like green and blue are generally considered peaceful and calming, red is considered the warmest and most contradictory of the colors. In fact, this fiery hue has more opposing emotional associations than any other color. Red is linked to passion and love as well as power and anger."

It's no wonder that during all the years of my education, the most feared symbol were the comments in red ink on the tests, compositions, assignments, and reports that were returned to me by my teachers.

The mark of death was seeing the following words in red, "See me after class."

Sociologists Richard Dukes and Heath Albanesi of the University of Colorado claim in a paper they've published in the Social Science Journal that when teachers use a red pen to add comments to student papers, students perceive them more negatively than if they use another color pen. They found that the red ink did not have any impact on them if they agreed with the teacher's comments. But, if there was a disagreement between the teacher and the student, the red ink was considered to be very harsh and the students directed their dismay to the teacher and not to their comments.

With so many courses being conducted online, what has happened to the red pen remarks? The modern technological equivalent of red ink for grading appears to be the equivalent of using all caps when writing e-mail or text messages; it's like shouting at a person and causing them to feel abused or being excessively critical.

Parents of children with special needs have gotten used to red ink. They've gotten used to seeing red ink circling abnormal lab values on reports, seeing the words "denied" or "ineligible" underlined in red from insurance companies, and seeing maps with redlines indicating where group homes could be built and operated.

The one sign in red they have worked so hard to find and see is the sign that has eluded them for decades; the sign that says "All are welcome." The one in blood red. •

ANCORA IMPARO

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

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

CONNECT AND DISCOVER

Join EP's Facebook Community

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

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

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

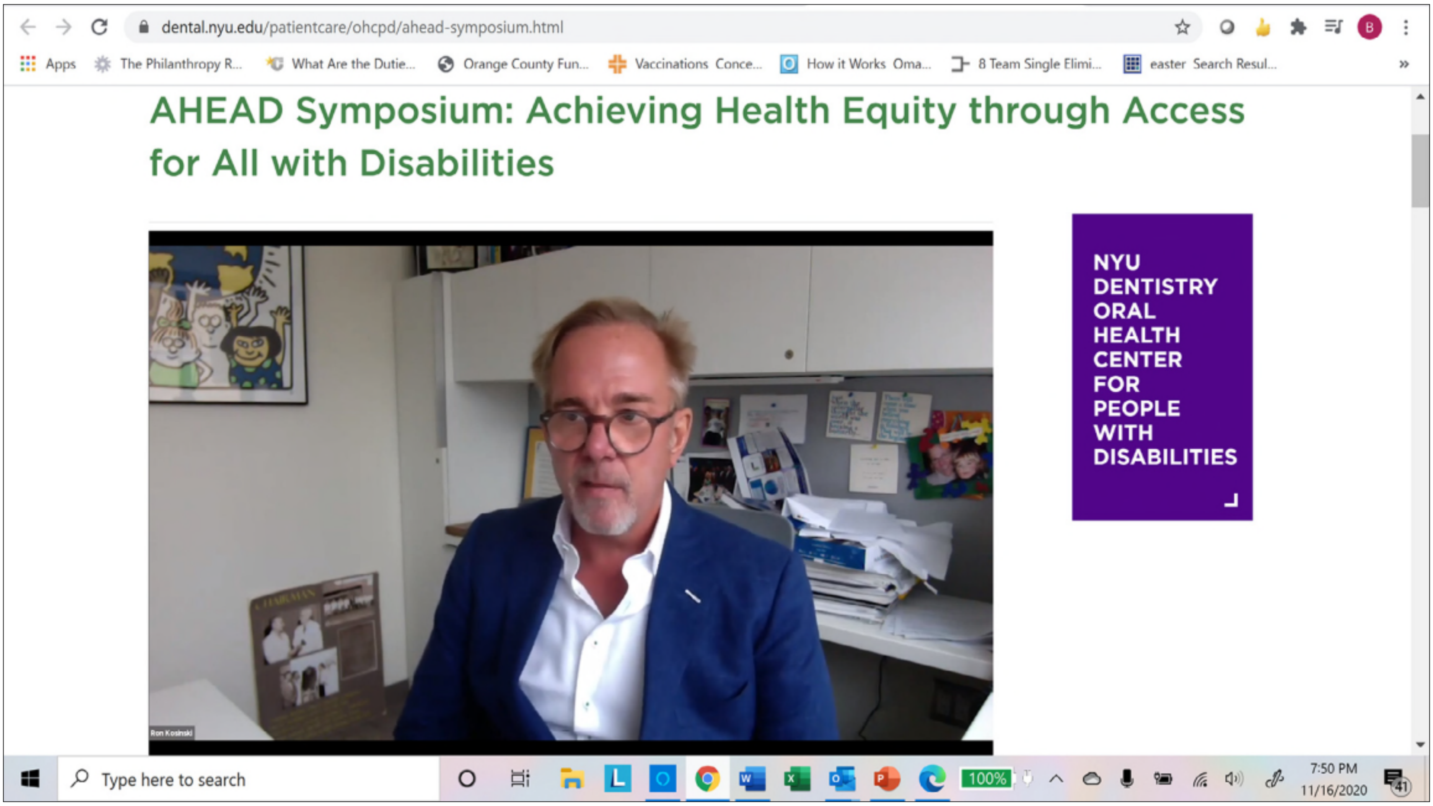
Visitors can access the latest news and articles from recent issues of EP Magazine, and provide feedback and insight of their own.

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

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

WHAT'S HAPPENING

WHEN COLLABORATION LEADS TO AHEAD



AHEAD Symposium: Achieving Health Equity through Access for All with Disabilities

NYU DENTISTRY ORAL HEALTH CENTER FOR PEOPLE WITH DISABILITIES

BY BARBIE VARTANIAN
AND DR. RONALD KOSINSKI

On Friday, October 2, 2020, the NYU College of Dentistry Oral Health Center for People with Disabilities, with the support of Project Accessible Oral Health (PAOH), Henry Schein, Special Olympics International, National Council on Disability, and other key stakeholders, held a one-day "game changing" event.

The Achieving Health Equity Through Access for All with Disabilities (AHEAD) symposium was conceptualized to address the state of oral health care for children and adults with intellectual and physical disabilities.

Determined to not have an agenda similar to many other dental and public health meetings, this event brought together experts and organizations in the areas of health care advocacy, access, and funding that would make a difference. Other important areas of discussion included the family/provider relationship, the impact of COVID-19 on the disability community, and the importance of public-private partnerships in advancing access to care, both locally and nationally. AHEAD drew in almost 500 participants that included a cross-section of academia, industry, insurance payers, providers, and parents.

The impetus behind the AHEAD Symposium was to showcase NYU's Oral Health Center for People with Disabilities. NYU has had a long legacy of addressing health disparities that exist with underserved populations. In the early 1970's, they pioneered a Special Care Clinic in which students rotated through and were exposed to the challenges that patients with special needs were present with. Fast forward to 2017, when Dean Charles Bertolami observed a patient in a wheelchair who had their head strapped to the dental chair. He thought to himself, we can do better. That experience planted the seed which was to become NYU Dentistry's Oral Health Center for People with Disabilities. After providing President Hamilton of NYU with a Summary of Problems and Solutions, a team comprised of architects, contractors, vendors, IT and other disability experts were assembled to design and determine how to best utilize the 8,000 square foot space that was allocated to the Center.

Today, the Center houses nine large treatment rooms, a sedation area that includes two large suites, a nurse's station, recovery area, large sterilization space, as well as a spacious waiting room that includes a

MOVING AHEAD: Ronald Kosinski moderates the Family/Provider Relationship panel during October's AHEAD Symposium

IMAGE PROVIDED BY BARBIE VARTANIAN

multi-sensory area. This innovative multi-sensory section was a collaborative effort between many of the other schools within NYU where prototypes have been developed to decrease anxiety and promote desensitization.

Our most recent collaboration was the development of a Virtual Reality Application which provides the patient with the ability to spend time virtually in the Center. NYU is the largest dental school in the nation and a leader in a paradigm shift in the way dental students are trained to embrace this patient population with the behavioral guidance options to avoid unnecessary sedation. The result has been astounding! All fourth-year dental students rotate through the Center where they are exposed to a myriad of patients with Intellectual and Physical disabilities many of whom have complex comorbidities.

The Center has a dedicated faculty and staff whose mission it is to ensure that all patients are treated with dignity and respect. The impact on the community as well as the dental students has been mutually beneficial. The hope is that graduates practicing in the community will be able to treat and triage these patients with support and confidence. Every specialty is represented in the Center, from endodontics to oral surgery. Multidisciplinary and interdisciplinary care is offered to all of the patients without needing to refer out of the Center.

> ***NYU is a leader in a paradigm shift in the way dental students are trained to embrace this patient population with the behavioral guidance options to avoid unnecessary sedation. The result has been astounding!***

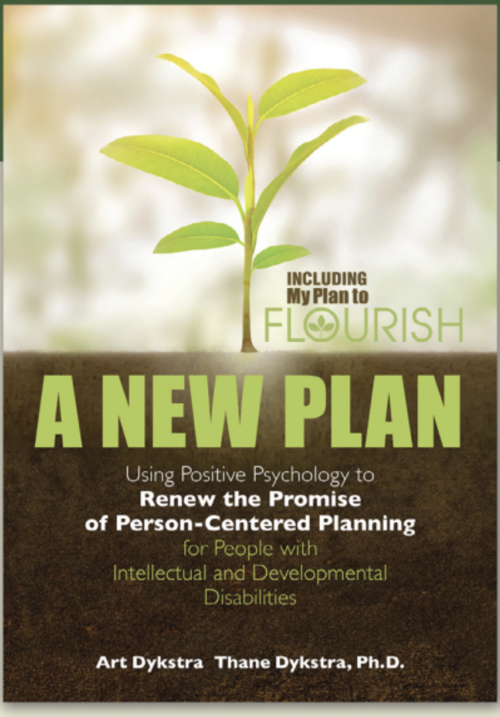
Even as the Center continues to evolve, it would never be where it is today had it not been for its partnerships. One which is most significant is the partnership with Project Accessible Oral Health (PAOH). PAOH is a is a global public-private partnership, and the first to nationally assemble and connect a consortium of dental and medical professionals, corporations, organizations, policymakers, educators, people with disabilities, caregivers, and other stakeholders in the pursuit of equal access to culturally competent oral healthcare. Collaboration is vital, and NYU Dentistry and PAOH are committed to ensuring that all individuals, including the disabled, have equal access to quality oral healthcare. •

ABOUT THE AUTHORS:

Barbie Vartanian is Executive Director, Project Accessible Oral Health at The Viscardi Center Advisory Board, Oral Health Center for People with Disabilities.
Dr. Ronald Kosinski is Clinical Director, NYU Dentistry Oral Health Center for People with Disabilities.

Worried About Your Son or Daughter?

Suffering too many sleepless nights worrying about how to help them flourish into adulthood? What we need for people with intellectual and developmental disabilities is not simply a "new normal" but a "better normal." What we need now is A New Plan.



INCLUDING My Plan to FLOURISH

A NEW PLAN

Using Positive Psychology to
Renew the Promise
of Person-Centered Planning
for People with
Intellectual and Developmental
Disabilities

Art Dykstra Thane Dykstra, Ph.D.

From two values-based leaders in the field Art Dykstra and Thane Dykstra PhD.

- Why things can be both bad and better at the same time
- Why planning is so important
- The 10 Principles of Person-Centered Planning
- The importance of Positive Psychology for people supported
- How to craft MY PLAN TO FLOURISH
- The importance of a positive outlook
- Future possibilities

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-Dykstra & Dykstra

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WHAT'S HAPPENING

THE FOURTH EDITION OF DEVELOPMENTAL DISABILITIES IN ONTARIO

BY SHIRLEY MCMILLAN, RN, PHD, CDDN

This is a review of the 4th edition of Developmental Disabilities in Ontario. I would like to acknowledge from the outset that I have co-authored Chapter 32 (Physical Health and People with Developmental Disabilities) with the late Dr. Thomas Cheetham. Despite the book's title of Developmental Disabilities in Ontario, the reader will discover throughout the chapters the book is a valuable resource for anyone working in the field of Developmental Disabilities.

It should be noted the term developmental disabilities is used, and this is due to the legislation in Ontario. In other jurisdictions, the term intellectual disabilities and learning disabilities may be used. The central issue of this book is on the most relevant and up-to-date information and research that will assist in the work of those in the field to support individuals with developmental disabilities.

I will not comment specifically on a chapter, however will review the quality and breadth of the topics that are covered in this book. The forward of the book is written by Mark Benner, who began his career in the field of developmental disabilities as a social worker in a provincial institution, and currently is a professor in the Developmental Services Worker Program at Fanshawe College in London, Ontario.

Developmental Services Worker is the title given to workers who support individuals with developmental disabilities in Ontario. However, the term is synonymous with direct support professional, as may be found in the United States. The role of these individuals is very similar and vital in the care of individuals with developmental disabilities.

The first edition of this book was published during the time I was teaching in the Developmental Services Worker program at the col-

lege level in Ontario. This was the first textbook that was specific to the work in Ontario, and when the book became available, it was placed on the required list of textbooks used in the majority of college programs in the field.

In total, as the reader will find in this edition, there are 50 chapters that speak to the issues throughout the lifespan. As an example, there is a chapter on the first 1000 days of fetal and infant development, and the final chapter is devoted to aging in people with developmental disabilities. The book's first chapter provides a definition of developmental disabilities, thus setting the stage for the reader regardless of where he/she is working in the field in the world.

The book covers, as identified above, a wide range of topics, and the editors sought to have the experts who have extensive knowledge, as well respect in their specific area in the field, to contribute content that reflects their expertise. It should be noted, as one browses the book, the authors of the chapters are not limited to Ontario and represent knowledge across Canada, the United States, and the United Kingdom. The main focus of this book is to update the reader on a wide variety of topics that are pertinent to enhance their support of individuals with developmental disabilities.

Title: **Developmental Disabilities in Ontario — 4th Edition**

Editors: **Ivan Brown** and **Maire Percy**

Publisher: **Delphi Graphic Communications**
Publication Date: **August 2020**
Paperback: **833 pages**
ISBN-13: **978-1-7771637-0-9**
Available at: www.oadd.org

ABOUT THE ONTARIO ASSOCIATION ON DEVELOPMENTAL DISABILITIES:

Ontario Association on Developmental Disabilities

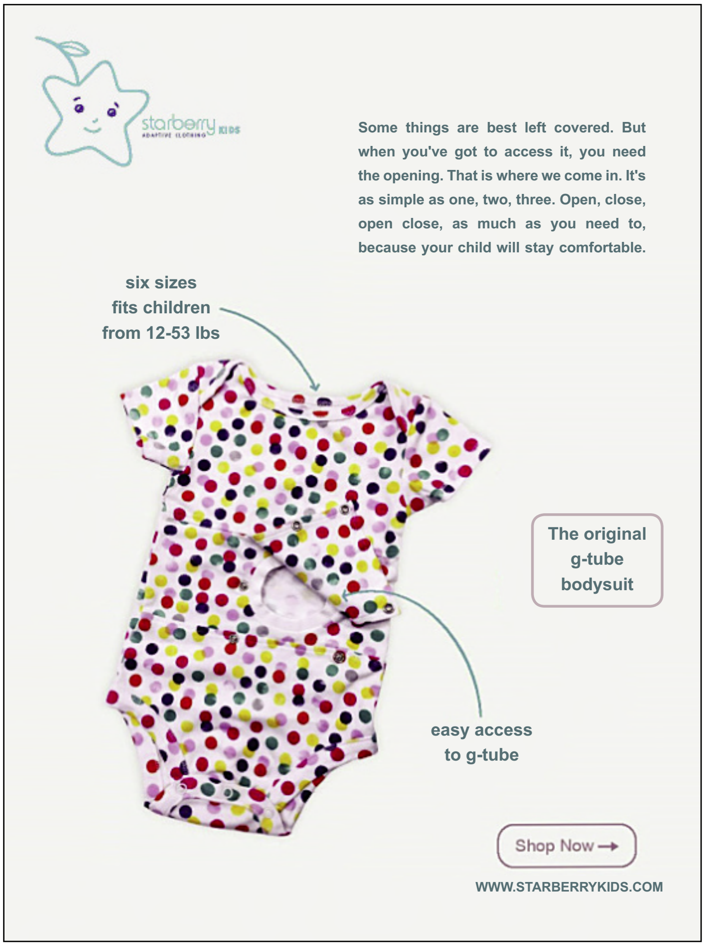
The Ontario Association on Developmental Disabilities (OADD) is a professional organization of people working and studying in the field of developmental disabilities, throughout Ontario. OADD's members include agencies and organizations; university and community college students and instructors; service provider direct care staff and managers; family support workers; case managers; psychologists; social workers; and other dedicated individuals. Developmental Disabilities in Ontario, fourth edition, is the new edition of the pre-eminent comprehensive text specifically for Ontario readers. This complete book of 50 chapters — covering a broad range of topics and issues about developmental disabilities in Ontario today — is an essential resource for both professional and everyday use.

Each chapter covers the particular subject in a balanced fashion and there is effective presentation of the theme. The subject of the chapter is approached in a topical analytical and descriptive manner as possible. It provides the reader with an unbiased understanding of the topic being covered in the chapter. The argument in each chapter offers evidence to the reader in the form of the most recent literature review, and the evidence is convincing.

In summary, this book offers information that is relevant to a wide range of individuals in the field of developmental disabilities at whatever level of knowledge, ranging from novice to expert. This this book is of assistance to the student in the Developmental Services Worker field who is beginning his/her career there, to those who are teaching in the education field of developmental disabilities, to the clinicians in the field. I have each edition sitting on my book shelf and often will refer to a chapter for information or guidance, not only for my own knowledge, but also for a nursing student I may be mentoring. I encourage anyone in the field to peruse this book and appreciate the knowledge and experience that is shared by the authors. •

ABOUT THE AUTHOR:

Shirley McMillan, RN, PhD, CDDN is Clinical Nurse Specialist - Adult Program, Surrey Place, Toronto, Ontario.



Some things are best left covered. But when you've got to access it, you need the opening. That is where we come in. It's as simple as one, two, three. Open, close, open close, as much as you need to, because your child will stay comfortable.

IMAGE COURTESY OADD

AMERICAN ACADEMY OF DEVELOPMENTAL MEDICINE & DENTISTRY

ADHD and Substance Use Disorder

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

Attention-Deficit/Hyperactivity Disorder (ADHD) is one of the most common ***neurodevelopmental*** *disorders of childhood. It is usually first diagnosed in childhood and often lasts throughout adulthood. Children with ADHD may have trouble paying attention, controlling impulsive behaviors (may act without thinking about what the result will be), or be overly active.*[1]

Note: *Children with Attention-Deficit-Disorder (ADD) – also known as ADHD with inattention – are not hyperactive. They do not have high energy levels like other children with ADHD and may seem shy or as if they are often daydreaming. Children with ADD are harder to diagnose because their symptoms may be mistaken for daydreaming, shyness, or timidness.*[2]

According to the 2016 National Survey of Children's Health report, the estimated number of children who were diagnosed with ADHD was 7.4 million (9.4%).

- *388,000 children aged 2–5 years*
- *4 million children aged 6–11 years*
- *3 million children aged 12–17 years*

Boys are more likely to be diagnosed with ADHD than girls (12.9% compared to 5.6%).[3]

In 2016-2018, for the first time, a U.S. survey found that black children appear to be more likely than white youngsters to have been diagnosed with ADHD and learning disabilities; 17% of black, 15% of white and 12% of Hispanic children. [4]

In 2016:

- *Almost two thirds (62.0%) of children with current ADHD, were taking medication and slightly less than half (46.7%) had received behavioral treatment for ADHD in the past year.*
- *6 in 10 children with ADHD had at least one other mental, emotional, or behavioral disorder.*
- *Other conditions affecting children with ADHD include: depression, autism spectrum disorder, and Tourette syndrome.*[5]

Among children 2-17 years in 2011, in states with the **highest prevalence** of ADHD, the proportion ranged from 12.2% in Rhode Island (including [Alphabetically] Alabama, Arkansas, Indiana, Louisiana, Mississippi, North Carolina, Ohio, South Carolina, Tennessee) to 16.6% in Kentucky. [6]

AMERICAN ACADEMY OF DEVELOPMENTAL MEDICINE AND DENTISTRY

The American Academy of Developmental Medicine and Dentistry (AADMD) was organized in 2002 to provide a forum for healthcare professionals who provide clinical care to people with neurodevelopmental disorders and intellectual disabilities (ND/ID). The mission of the organization is to improve the quality and assure the parity of healthcare for individuals with neurodevelopmental disorders and intellectual disabilities throughout the lifespan.

WHY ARE PEOPLE WITH ADHD MORE LIKELY TO USE DRUGS AND ALCOHOL?

> *"People with ADHD tend to be more impulsive and likely to have behavior problems, both of which can contribute to drug and alcohol abuse, researchers say. Also, both ADHD and alcoholism tend to run in families. A child with ADHD who has a parent with alcoholism is more likely to also develop an alcohol abuse problem. Researchers have pointed to common genes shared between ADHD and alcoholism."* [7]

It is more common for children with ADHD to start using alcohol during their teenage years. Studies have found that at a mean age of 14.9 years, 40% of children with ADHD began using alcohol, compared to 22% of children without an ADHD diagnosis. ADHD is five to 10 times more common among adult alcoholics than it is in people without the condition. Among adults being treated for alcohol and substance use disorder, the rate of ADHD is about 25%. [7]

> *"Researchers have also found links between ADHD and the use of marijuana and other recreational drugs, particularly in people who also have other psychological disorders (such as obsessive-compulsive disorder). What's more, people with ADHD typically start having problems with drugs and alcohol at an earlier age than people without the condition."*[7]

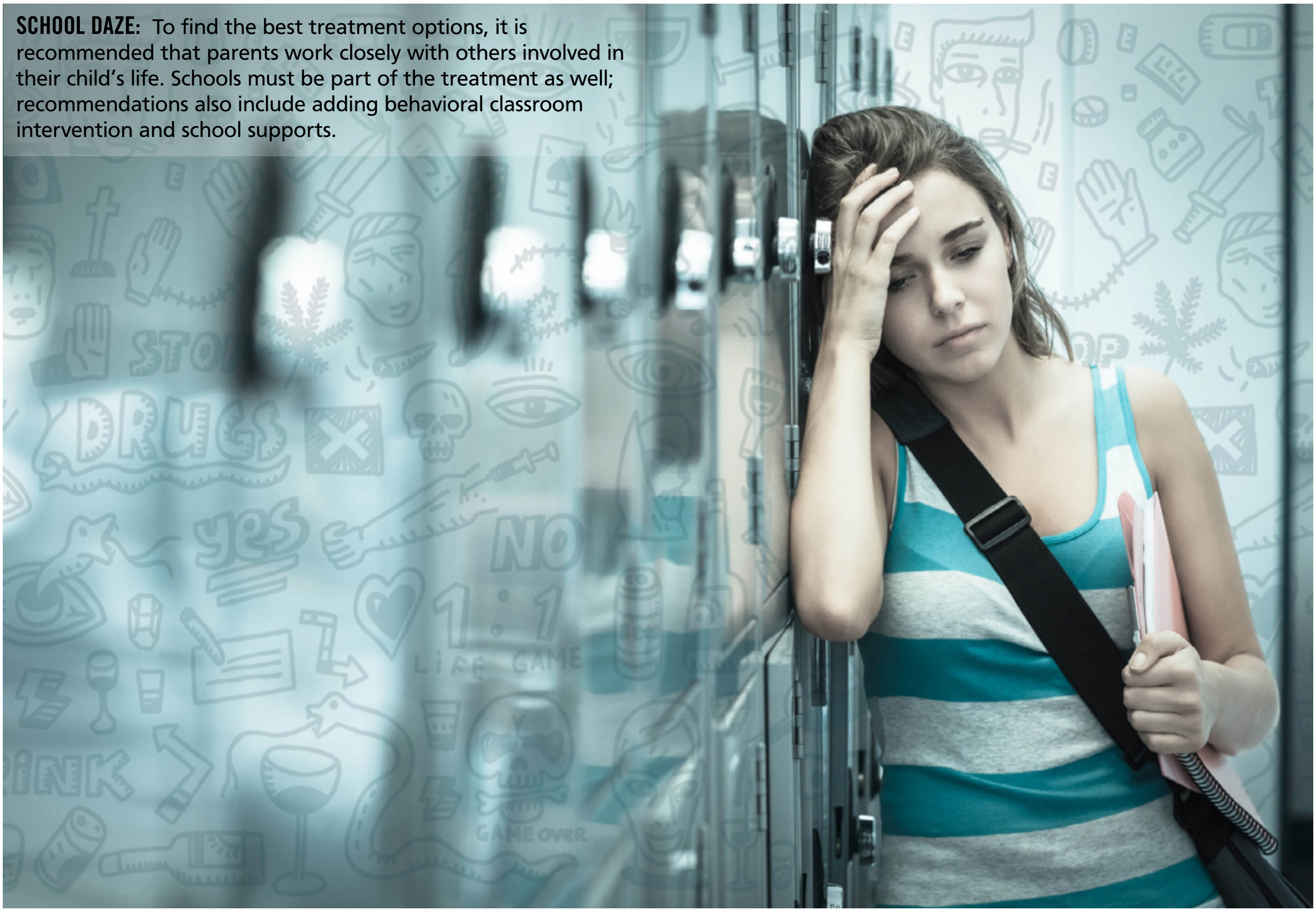
However, contrary to characteristics of the use of recreational drugs, many with ADHD who also have substance use disorder, do not illicitly use substances in an attempt to "get high" or achieve a euphoric state, rather, they are using drugs or alcohol as a means to self-medicate symptoms associated with their disorder. "Only 30 percent of young adults surveyed used substances for the pleasurable effect, in comparison to the 70 percent who used them to improve their mood, to sleep better, or for other reasons. They need something to calm their brain enough to be productive." [8]

> *"Stimulant medications work differently on the brain of an individual with ADHD versus that of a non-ADHD individual. The latter individual experiences a pleasurable effect, whereas the former–those in need–experience an adjustment to their thought process by becoming more balanced and focused, while not experiencing the euphoria illicit drug users seek. Administration of stimulant medications may actually help to prevent the occurrence of a SUD, (substance use disorder) especially in youth."*[8]

TREATMENT FOR ADHD

When a child is diagnosed with ADHD, parents often have concerns about which treatment is right for their child. ADHD can be effectively managed with the right treatment. There are many available options and what works best can depend on the individual child and their family. To find the best options, it is recommended that parents work closely with others involved in their child's life – healthcare providers, therapists, teachers, coaches, and other family members.

Children with ADHD younger than 6 years of age: The American Academy of Pediatrics (AAP) recommends parent training in behavior management as the first line of treatment, before medication is tried.



SCHOOL DAZE: To find the best treatment options, it is recommended that parents work closely with others involved in their child's life. Schools must be part of the treatment as well; recommendations also include adding behavioral classroom intervention and school supports.

Children 6 years of age and older: The recommendations include medication and behavior therapy together – parent training in behavior management for children up to age 12 and other types of behavior therapy and training for adolescents. Schools must be part of the treatment as well; recommendations also include adding behavioral classroom intervention and school supports. [9]

Young (and older) adults: Approximately 10 million adults have ADHD. Adults with ADHD often cope with difficulties at work and in their personal and family lives related to ADHD symptoms. Many have inconsistent performances at work or in their careers and may have chronic feelings of frustration, guilt or blame. [10]

Parents sometimes worry whether the stimulant drugs their children are taking to treat ADHD (such as Ritalin and Adderall) are themselves addictive. Stimulant medications work by raising levels of a chemical messenger called dopamine in the brain, which helps improve focus and attention – skills that people with ADHD often find difficult to master.

> “Contrary to characteristics of the use of recreational drugs, many with ADHD who also have substance use disorder, do not illicitly use substances in an attempt to “get high” or achieve a euphoric state, rather, they are using drugs or alcohol as a means to self-medicate symptoms associated with their disorder.”

“Dopamine also affects emotion and the feeling of pleasure, creating a ‘high’ that makes people want more. Because cocaine and other street drugs also raise dopamine levels, there has been concern that ADHD stimulants might be similarly addictive. Ritalin’s ability to increase energy and focus has even led some people to refer to it as the ‘poor man’s cocaine.’” [11]

> ***“In large doses – greater than what is typically prescribed for ADHD – Ritalin does have effects similar to those of cocaine. However, researchers have found marked differences between the two drugs”*** [10] (emphasis added).

Most important, to avoid the risk of substance use disorder accelerating into an addiction, appropriate treatment, including ADHD medications, is essential both for youth and adults. In many instances, this may be best supported when used within the context of medication-assisted treatment, either during instances of abuse or addiction. As ADHD is, in part, a behavioral disorder, certain behavioral therapies that impart behavioral modifications may be particularly beneficial.[11] For example:

Cognitive behavioral therapy (CBT) is a psycho-social intervention that aims to improve mental health. CBT focuses on challenging and changing thoughts, beliefs and attitudes. It emphasizes behaviors, improving emotional regulation and the development of personal coping strategies that target solving current problems. Originally, it was designed to treat depression, but its uses have been expanded to include treatment of a number of mental health conditions. CBT is a “problem-focused” and “action-oriented” form of therapy, meaning it is used to treat specific problems related to a diagnosed mental disorder. [12]

If you think there is substance abuse, Shatterproof, a national nonprofit organization dedicated to reversing the addiction crisis in America, created “National Principles of Care”, standard of care for addiction treatment to provide guidance to those and their loved ones as they seek addiction treatment. Additionally, individuals or their loved ones, can visit **www.treatmentATLAS.org** where they can take an assessment to understand the type of care that may be needed and can search for high-quality services.

YOUR CHILD’S FUTURE

“I think everybody in the field agrees, if you can get a toehold on the addiction, you should think about treating the ADHD relatively quickly. If you treat ADHD aggressively and you monitor for substance abuse, you’re going to reduce delinquency.” [13] •

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BOOK REVIEW

THE EMPATHY ADVANTAGE

COACHING CHILDREN TO BE KIND, RESPECTFUL, AND SUCCESSFUL

REVIEWED BY LAUREN AGORATUS, M.A.

Although this book isn't specifically about children with special needs, it will benefit all children, including those with disabilities and special healthcare needs. There is also information regarding bullying of children with disabilities.

CHAPTER 1:

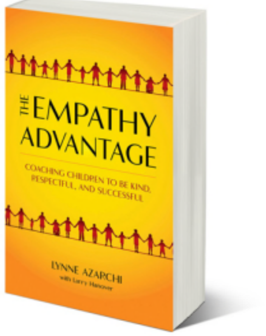
WHY YOU SHOULD CARE ABOUT EMPATHY

It is noted in the preface that racist attitudes and behaviors, for example, can be seen as early as age three. Early and consistent appropriate learning opportunities must be given to children. Teasing, which is sometimes seen as a childhood rite of passage, can follow children over time, well after the event. Lack of empathy may be increasing, as there is an increase in bullying, self-centeredness, and a decline in interaction in person. This is exacerbated by the media, especially the adult media, to which too many children are exposed. The main message of this book is that empathy can be taught. "Empathy can transform 'otherness' into inclusiveness." Without empathy, there is a lack of understanding of differentness and diversity. Too much screen time results in focus only on oneself. Empathy and social emotional skills can help counteract this.

CHAPTER 2:

EMPATHY CAN BE TAUGHT

Children can learn not to be bystanders but, rather, UPstanders and stand up for others. They can learn to cheer other children up, not to bully, and how to help others. Children who are targets need to realize that they should be treated respectfully and that they have the power to speak up and get help from adults to make bullying stop. Bystanders need to recognize that doing nothing is wrong and learn what they can do to stop bullying. The Tolerance Center at Kidsbridge uses evidence-based practices utilizing scripts resulting in measurable attitude shifts.



Title: **The Empathy Advantage: Coaching Children to be Kind, Respectful, and Successful**

Author: **Lynne Azarchi** with **Larry Hanover**

Publisher: **Rowman & Littlefield**
Publication Date**: November 2020**
Paperback: **324 pages**
ISBN-13: **978-1538143704**
Available at: amazon.com and www.barnesandnoble.com

CHAPTER 3:

THE SCIENCE AND BIOLOGY OF EMPATHY

The author describes the science behind empathy in animals and humans. Quite simply, empathy is essential for survival of the species. Activities in this chapter include "walking in someone else's shoes."

CHAPTER 4:

EMPATHY 101 – DEFINING HOW EMPATHY FITS IN WITH OTHER EMOTIONAL SKILLS

An UPstander is someone who is motivated by empathy and choses to get involved, which is the opposite of a bystander. A good description of empathy is to focus first on listening, then focusing on being listened to. Empathy is seen as the foundation of social-emotional skills. Emotional intelligence is important to get along with all kinds of people, and empathy is part of emotional intelligence. The difference between empathy and sympathy is also discussed.

CHAPTER 5:

EMPATHY, MEDIA, AND SOCIAL MEDIA

Children, teens, and young adults average three hours a day on social media. This is time misspent on not interacting in person. Media violence and "reality" shows desensitize kids. Some children are sleep-deprived due to excessive gaming or social media. Media literacy is one way for children to use critical thinking about what they're seeing. Virtual reality exercises can help students see what it was like for others and can be used to teach empathy. Tips for

IMAGES COURTESY LYNNE AZARCHI/ROWMAN & LITTLEFIELD

families include limiting social media, turning off all communications to avoid disrupting sleep, reducing exposure to violence, and ensuring that what is seen is developmentally appropriate.

CHAPTER 6:

PARENT TIPS – STRENGTHENING MORAL COMPASSES

Parents can model appropriate skills for children. "People skills" can be taught, which will also help later with employment. Topics such as physical violence, cheating on tests, etc., can be discussed. Kids seem more distracted and less respectful. Children with appropriate social-emotional skills, including empathy, have less substance abuse, obesity, and criminal activity according to the data. Parent tips include face-to-face talks, which allows children to understand tone of voice, body language, facial expressions, and other nonverbal clues. Empathy can grow over time, and children with this mindset will volunteer to help others. Family meetings and discussing activities such as museum visits, articles read, etc. are helpful. Parental nurturing is key, as children learn empathy when their own emotional needs are met. Cultural empathy can be taught, again, using "walking in another's shoes" activities. Children will also learn that they are more alike than different from others.

CHAPTERS 7-11:

TEACHING EMPATHY (ACROSS THE YEARS)

The next four chapters cover teaching empathy based on the child's age. For *infant to three years,* restrict screen time for toddlers, don't use shaming because shaming communicates that the child is bad, and there shouldn't be toys or food used as bribes as motivation should come from within. From *three to six years,* reading books (*The Little Engine that Could, The Giving Tree, Chicka Chicka Boom Boom*), doing puppet shows, praising kindness, teaching self-compassion vs. self-esteem, and sharing toys, will help. For *elementary years,* children learn by using mindfulness, apologies that are heartfelt, and participating in family meetings. They learn that it is ok to be different and to use people-first language rather than by disability. For *middle school years,* students learn through historical empathy (e.g. Abe Lincoln), role-plays, and awareness of stereotypes. Finally, for *high school years,* teens can discuss implications of school shootings, that social emotional skills also improve academic skills, and depression warning signs. They can also learn about social media and privacy rights, First World vs. Third World problems, and community service (food kitchen) vs. service learning (actually going hungry). Teens will learn not to judge by disability and to have appropriate role models (not just celebrities).

CHAPTER 12:

EMPATHY - CRITICAL FOR BULLYING PREVENTION

In keeping with not labelling children, the terminology that is used is "target" rather than "victim", and "those who bully or harm" rather than "bully." Children who bully often lack empathy. Activities in which they role-play the role of target and solving the problem helps. Schools can be an ally for bullying prevention. Children who are targeted for bullying need to understand that they don't deserve to be bullied and that the bullying can be stopped.

MUSCLE MEMORY: An illustration from the Chapter 2 of *The Empathy Advantage;* "Empathy is like building a muscle: it grows stronger and stronger the more it used and exercised."

THE FINAL CHAPTERS

Chapter 13 covers parents' point of view. Chapter 14 goes over self-compassion. Mindfulness and stress-reduction exercises may be helpful. Teens learn to focus on breathing and repeating thoughts such as "May I be happy, may I be safe, may I be at ease." Then they use those phrases while thinking of loved ones, friends, then to those with whom they may have conflict. In this way, they first learn self-acceptance, then empathy towards others. Active listening, and actually getting down to the level of the child at eye level is covered in Chapter 15. Key phrases can be "I hear you" or "tell me more." Parents must be nonjudgmental (unless there is a safety issue.) Chapter 16 discusses gender and empathy. Chapter 17 goes more in depth on social-emotional skills. Chapter 18 covers teaching empathy using documentaries, stories, and pictures. Pets and empathy show up in Chapter 19. Chapter 20 covers heroes and Chapter 21 covers empathy and paying it forward.

All children can benefit from learning empathy, as it is a learned skill. In this world of narcissism, me-me-me, and the era of selfies, children (and adults!) can learn to think of others. This will make them successful in school, relationships, jobs, and life.•

ABOUT THE REVIEWER:

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.

The Best Christmas Gift Ever

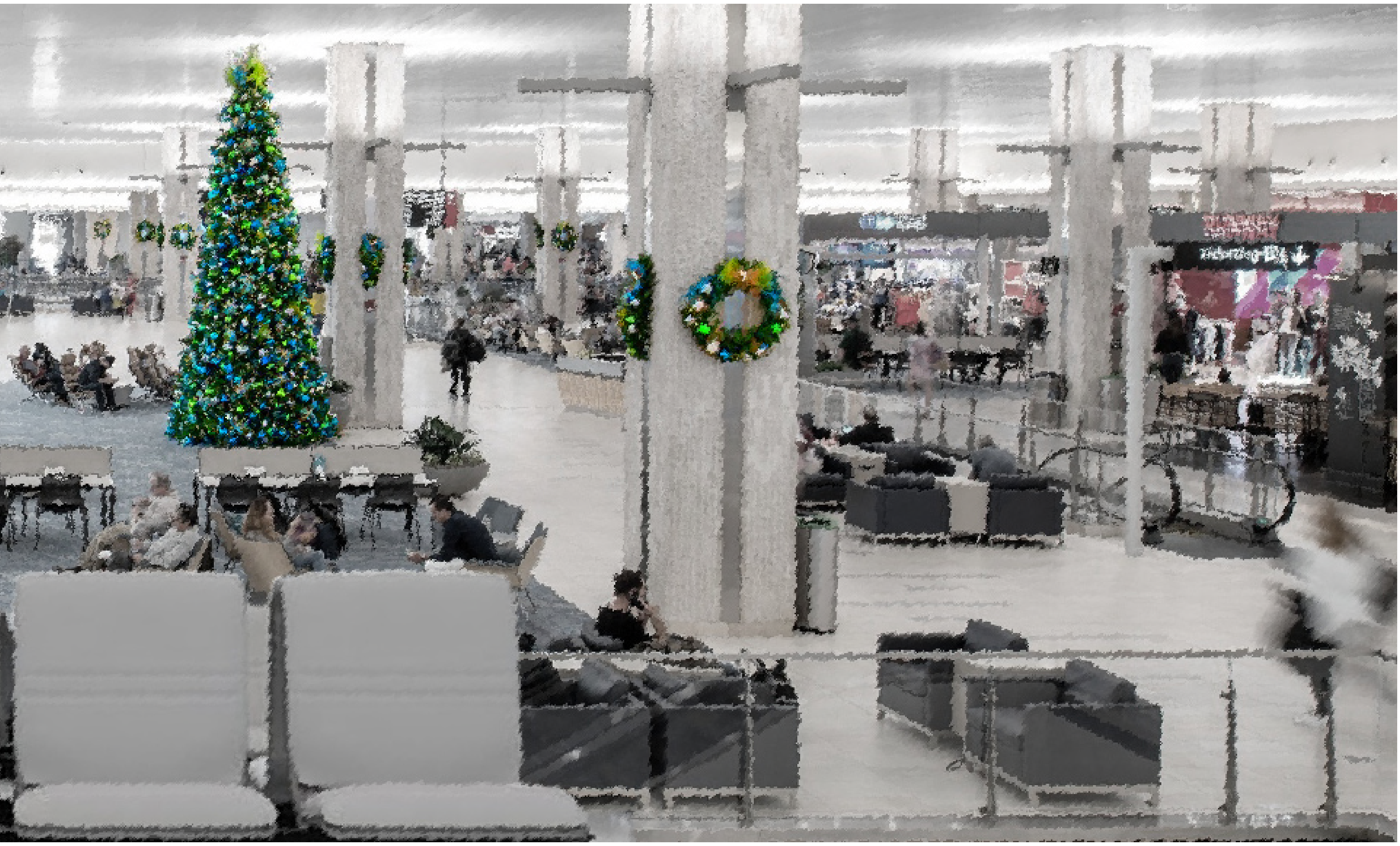
Finally, we arrived in the US. For the first time, I was greeted with cold winds I'd never experienced in my nine years of being alive. "So that's why we needed extra bulky winter jackets," I thought. With this weather, I thought my eyeballs were going to freeze and come off their sockets before I could even see the doctor.

BY JEM MABALOT

Christmas for me has always been a time for happiness, a time to spend together with the family at home. The smorgasbord of special meals and delightful treats in every corner of the house entices our bellies to feast more. Melodies from Christmas albums by Michael Bublé and Pentatonix enthrall the family about the winter wonderland.

The gigantic Christmas tree, abundant with presents, projects the spirit of giving, love, and laughter. Even the elves sitting beside the fireplace seem to be perennially dancing. As a child, I always looked forward to the clock striking twelve to signal Christmas Eve. This was the time I could open and enjoy all my presents.

In 2006 however, Christmas was not normal. Instead of presents, we had luggage, lots and lots of luggage. We didn't stay up late to spend Christmas Eve around the tree. We slept early to wake up before sunrise to catch a ride waiting to take us to Ninoy Aquino International Airport. There, we would hop on a plane bound to the land of the free. Sure, a 36-hour adventure



A WEARY TRAVELER: Again, I tried my best to make the most out of the toy. But, by the time we were called to board, I felt like my soul got impatient and left my body to go ahead, leaving my physical form plopped on a bench like an abandoned wrinkled coat with a ghostly arm, listlessly holding the toy flag.

could be exciting for a bright-eyed and bushy-tailed nine-year-old trooper like me, but all I could think of during this unusual Christmas was, "Are we there yet?" Truly, it was an unforgettable time for my family and me.

We enjoyed a good life in the Philippines. But, according to my parents, due to the lack of medical advancement, I was in danger of losing my sight down the road. My uncle advised my mom to consult an eye doctor in the United States. He knew a glaucoma specialist in New York who was an expert in aniridia. So, we had to fly to America. As for me, I couldn't wrap my head around the fact that I had to leave behind my toys which mom said I couldn't pack, my best friend who we also obviously couldn't pack, and my fun daily routine. I thought, what's the point of going to an eye doctor in America if I'm already seeing one in the Philippines? Besides, among my relatives that have aniridia, my vision was the strongest. My glaucoma condition was also the most stable. The more my mom tried to explain that doctors in the US could help me better than the ones at home, the more I conjured up scenarios in my head of what an eye checkup in America would be like. Were the docs going to look like mad scientists? What if they acted like Yzma from *The Emperor's New Groove,* who tricked the emperor into drinking a llama potion? Would they take me away from my parents for an unknown amount of time? Were they going to give me bitter-tasting concoctions that would allegedly be the cure for aniridia? If so, would I have to take it for the rest of my life? After the checkup, would I still be able to look at the world the same way? What if something bad happened and I lost my sight, just like one of my older cousins who was already in the US?

Would the doctors take me away from my parents for an unknown amount of time? Were they going to give me bitter-tasting concoctions that would allegedly be the cure for aniridia? If so, would I have to take it for the rest of my life? After the checkup, would I still be able to look at the world the same way?

Before I left, I remember meeting Zackary, a transfer student who came from America. He was Filipino too, but the fact that he grew up in the US instantly made him like Justin Bieber during his debut. Every other kid couldn't get enough of him. All the stories he told enchanted my classmates, as if he just came back from Atlantis, or a land flowing with milk and honey. I was skeptical. What did he have in America that I didn't? Just because someone came from the US doesn't automatically make him better than the other kid bragging about his monkey bar skills. Still, I couldn't help but wonder if this trip was going to make or break it for me. The growing uncertainty about its outcome was killing me.

In transit to the US, I managed to find ways to entertain myself when I wasn't tormenting my parents and older brother with the dreaded "Are we there yet?" question. I was enchanted by my cabin crew's coordinated suits and movements, and I wanted to know more about them. Their suits were green, so I assumed they were going for the modern-day elves on wings kind of style, and I interviewed them about everything whenever I found an attendant willing to talk to me. Of course, I would also get extra snacks and attention with my cheerful charms, which I was happy about since it helped pass the time. Then there were the other passengers. I would ask people why they were spending Christmas day traveling instead of opening their presents. Some would ignore me, but there were others who shared a bit of their story. Unfortunately, no one was going to the US for medical reasons like I was.

Stopovers were the worst. It was as if I was waiting to hop on a Disney World hit ride on a Saturday afternoon during peak season, without a fast pass – multiplied by ten. At least I was sitting on a bench with air conditioning. The only toy I had available was a light-up contraption that showed a moving image of the American flag by spinning the top half. Again, I tried my best to make the most out of the toy. But, by the time we were called to board, I felt like my soul got impatient and left my body to go ahead, leaving my physical form plopped on a bench like an abandoned wrinkled coat with a ghostly arm, listlessly holding the toy flag.

Looking back now, what I thought was the worst Christmas of my life – filled with waiting, anxiety, and unwanted changes – ended up as the Christmas that gave me the best gifts ever. Because we stayed in the US, I had the gift of good healthcare. I maintained and even improved my vision.

Finally, we arrived in the US. For the first time, I was greeted with cold winds I'd never experienced in my nine years of being alive. "So that's why we needed extra bulky winter jackets," I thought. With this weather, I thought my eyeballs were going to freeze and come off their sockets before I could even see the doctor.

So what awaited me after my flight to America? More waiting. Christmas had already passed but, at this point, I already registered the last two days as the worst Christmas of all time. I just wanted to go back home.

Fast forward to the doctor's visit. To my surprise, my doctor didn't look anything like the threatening mad scientist that I had imagined. He was a jolly man who looked more like Old Saint Nick, if you added a white beard. It was his wife, the secretary, who scared me a little. I think it was because back then, I wasn't used to the way New Yorkers communicated. The gadgets and lights he used to check my eyes were uncomfortable, but not too outlandish compared to the contraptions I was used to. The checkup was anticlimactically normal except for one thing – the doctor's verdict.

"If you take her home to the Philippines, she will lose her vision like you did," he told my mom.

What the doctor said broke my mother's heart. Yet, she made the decision to leave everything behind to stay here. On this very first visit, the doctor altered the path to our future. Words really do hold weight.

Looking back now, what I thought was the worst Christmas of my life – filled with waiting, anxiety, and unwanted changes – ended up as the Christmas that gave me the best gifts ever. Because we stayed in the US, I had the gift of good healthcare. I maintained and even improved my vision. I can continue to enjoy life seeing the beauty of the world around me (of course, that includes my Korean dramas and anime). I left behind my toys, but now I can get the latest and greatest high-tech toys in the market, such as my iPad Pro and enjoy using it with high-speed internet. I left my old friends behind but gained life-long relationships while also developing my uniqueness. I left behind my lifestyle, but I gained a healthier physical, mental, and spiritual way of living. Furthermore, I was gifted with an abundance of wonderful memories with friends and family around me. I wouldn't be who I am today if my parents decided to go back to the Philippines, and for that I am grateful. The doctor's words on the day of the check-up transformed my future and my whole family's life.

This year, 2020, has been filled with fear, uncertainty, and loads of pain and hardships. Our lifestyles have changed. Several people we hold dear have passed away. Many have also lost their jobs, their feeling of security, as well as their freedom to travel and get together that they had in years past. Plans are deferred indefinitely.

If you're like me, you might be thinking that Christmas 2020 will be the worst one ever. But, just like the holiday disaster I initially thought I went through in 2006, this holiday could still bring us the best gifts. As one man put it, "it's where you sit that determines what you see. And it's what you see that determines what you do."

We can choose to label this year as a time of hopelessness and loss. We could sit on our couch thinking of the what-ifs and negatives while wasting the precious time we have on earth to make our lives more impactful and positive. But we could also use our experiences this year as stepping stones toward a better and higher future. Who knows, 2020 might actually be the best thing that ever happened to us. Really. We won't know until it's over. But while we still have the chance, we also have the power to change the future.•

ABOUT THE AUTHOR:

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

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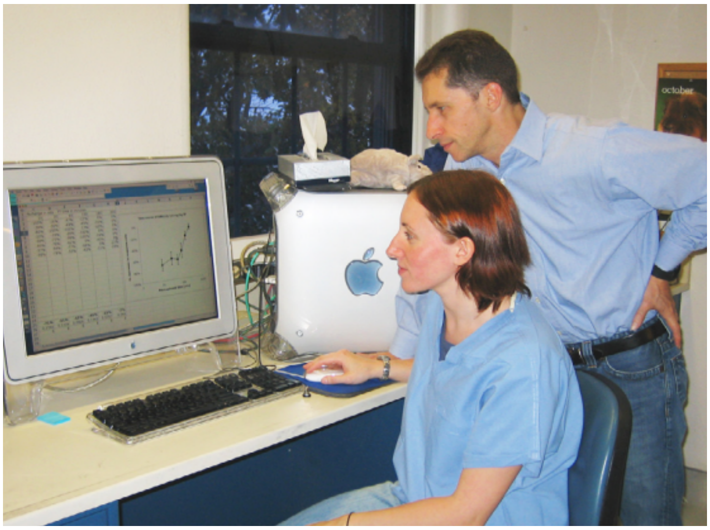

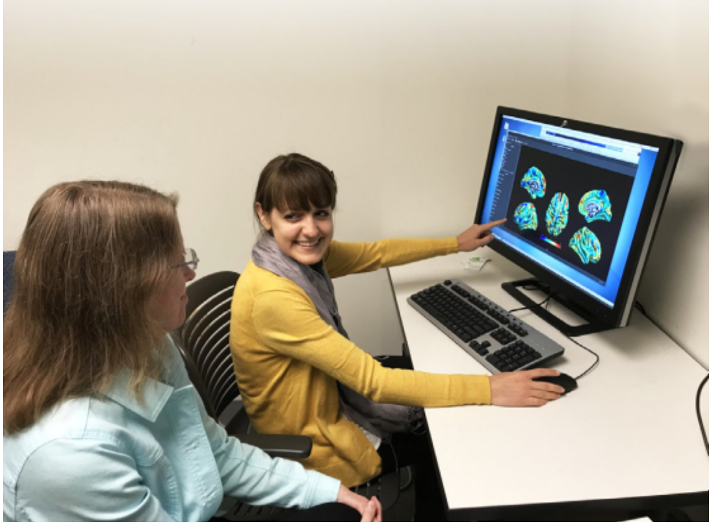

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SEASON'S GREETINGS FROM THE PANDEMIC

'TIS THE SEASON TO SOCIAL DISTANCE AND DON A MASK!

BY ELIZABETH J. LUCAS, MD, CARA COLEMAN AND MALLORY CYR

As families approach the holidays, many are looking to adopt old traditions or create new ones to cultivate the joy associated with the holiday season while maintaining a reasonable degree of safety. Here, we hope to present some strategies that can help everyone stay safe.

As we near the most wonderful time of the year, families with adults and children with complex medical conditions are thinking about how to enjoy the holidays amid the worldwide severe acute respiratory syndrome coronavirus-2 (COVID-19) pandemic. Individuals with complex medical conditions are considered high risk for severe disease with infection with COVID-19, so families have already witnessed dramatic shifts in their day-to-day lives.

For all of us, this holiday season will look different than previous years. At the time of writing this article, several European countries are resuming rigid lock downs, rolling back the opening of restaurants, bars, and other spaces where large groups of people can gather.[1] The number of new cases in the US are similarly on the rise, with the last week of October reporting the highest rate of new cases of COVID-19 among children and adolescents.[2] Over the past two weeks, Governors from several states have stepped up to implement and/or tighten a variety of restrictions on activities such as gatherings and wearing masks. We know from data collected here in the US that holidays observed during the summer led to peaks in new cases, driving more hospitalizations and unfortunately, COVID-19 related deaths (CDC).

ZOOMING HOME: Host a virtual holiday meal with friends and family who don't live with you. Schedule a time to share a meal together virtually, and have people share recipes and show the dishes that they prepared.

Many health care providers are concerned that the upcoming winter holidays could lead to even higher numbers of cases as families engage in travel and participate in large gatherings.

As families approach the holidays, many are looking to adopt old traditions or create new ones to cultivate the joy associated with the holiday season while maintaining a reasonable degree of safety. Here, we hope to present some strategies that can help everyone stay safe. The CDC (https://www.cdc.gov/coronavirus/2019-ncov/daily-life-coping/holidays/thanksgiving.html) just released guidance as to how to approach Thanksgiving planning during the surge.

One theme that will consistently resurface throughout these recommendations is that this year will require more planning and attention than years past to reduce the risk of spread of COVID-19. Other strategies will be familiar, with an emphasis on maintaining social distance wherever possible, wearing personal protective gear, and practicing frequent hand hygiene. Families of children and adults with special healthcare needs and disabilities can always reach out to their health care providers to have honest discussions about the risk for their loved one, and to use shared decision making to develop creative, flexible and responsive accommodations to holiday traditions that minimize risk of COVID-19 transmission and balance the need for love, laughter and life!

Travel: Should we go over the hills and through the woods to grandmother's house in 2020?

The gold standard of protection from risk is to forgo travel altogether. Before making any travel plans, it is suggested that you review the guidelines and COVD-19 cases at your destination (https://www.cdc.gov/coronavirus/2019-ncov/travelers/how-level-is-determined.html). Every state is in a different phase of shut down, that may further restrict you from gathering with people other than those in your household, or even traveling to that state.

If travel cannot be avoided by families, be sure everyone has their flu shots and plan for the most direct route. If driving, choose the shortest distance and plan your route carefully. Where possible, avoid stopping for food or gas along the way to minimize contact with other travelers. Packing meals along with plenty of hand-washing, sanitizing and cleaning supplies for the trip is one strategy to reduce potential exposures. If flying or taking another form of mass transit, look for flights with the fewest seats sold or flights at less desirable travel times. Airports and transportation centers tend to be less crowded during the early morning and later evening, allowing for more effective social distancing. When on the plane, remaining seated for the duration of the flight, wearing a cloth facial covering or a facial mask, and relying on food brought with you will reduce potential exposures.

If you plan to travel on any form of mass transit, wearing a cloth facial covering or a facial mask is essential for minimizing the risk of COVID-19 infection transmission. Despite the socio-political controversy around wearing masks, the scientific evidence is clear.[3] Masks primarily reduce infections by capturing respiratory and aerosol droplets that disperse from breathing, talking, or coughing.[4] COVID-19 virus particles hitchhike rides on droplets to spread successfully and it has been demonstrated that cloth facial coverings greatly reduce the number of droplets that can scatter. Masks do not reduce blood oxygen levels in people, including vulnerable populations, and allow for the normal exhalation of carbon dioxide.[5]

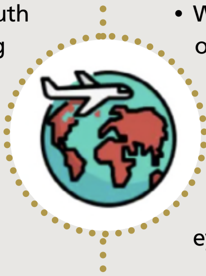
When all measures are strictly followed, travel is made safer and so far, the numbers of infections related to air travel have been small (CDC). Most important, if you or anyone in your family feels sick or starts showing any symptoms consistent with COVID-19, then the best way to help your extended family, community, city, state, and country is to cancel planned travel and stay home.

The Holidays are NOT cancelled… just adapted:

Outside of travel, families with adults and children with complex medical conditions likely look forward to holiday traditions that may need adjusting during the COVID-19 pandemic.

DURING YOUR TRIP : PROTECT YOURSELF & OTHERS FROM COVID-19

- Wear a mask to keep your nose and mouth covered when in public settings, including on public transportation and in transportation hubs such as airports and stations.
- Avoid close contact by staying at least 6 feet apart (about 2 arms' length) from anyone who is not from your household.

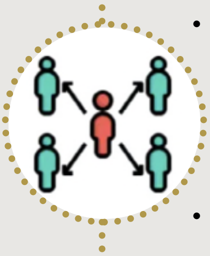


- Wash your hands often or use hand sanitizer (with at least 60% alcohol).
- Avoid contact with anyone who is sick.
- Avoid touching your eyes, nose, and mouth.

CDC Travel guidance: https://www.cdc.gov/coronavirus/2019-ncov/travelers/travel-during-covid19.html

COMING TOGETHER : PRECAUTIONS FOR HOSTING AND GATHERINGS

- Limit number of guests (10 or less) and have clear conversations with guests ahead of time as to expectations.
- Gather outside or in very well-ventilated areas and sit 6 feet apart.
- Bring your own food, drinks, plates, cups, utensils.



- Use single-use items, such as condiments or sauces, and disposable food containers.
- Limit people in food preparation area.
- Disinfect surfaces often.

CDC Holiday guidance: https://www.cdc.gov/coronavirus/2019-ncov/daily-life-coping/holidays.html

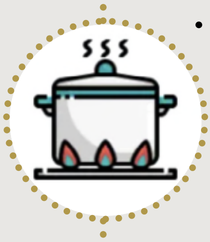
Some festive fun like touring neighborhood light displays in a private vehicle, holiday tree shopping, and holiday home decorating can be done without any changes. Depending on the climate in which you live, moving some activities outdoors can also help.

These risk assessments are not absolute and do not take into account differences in vulnerability between certain complex children and adults; so, families must still use their judgement about how much risk is acceptable. You can work with your child's healthcare provider, using the shared decision-making process to determine what the safest options are for your family to continue your favorite holiday traditions.

It has been a long year, and it is understandable, the strain that social distancing has had on the mental and emotional health of many people. It is difficult to think of not spending the holidays with loved ones. However, making these sacrifices for one year, may lead to the ability to have future holidays with those who may be more at risk.

FLEX TIME : TIPS FOR ADAPTING HOLIDAY TRADITIONS

- Leave a surprise – flowers, homemade cookies, a nice note – on a neighbor's doorstep.
- Pick out and donate a toy for a holiday gift drive.



- Record a happy song or dance and send it to friends or family who need a pick-me-up.
- Cook a meal together, and video-chat a family member who can't be with you.

PBS: www.pbs.org/parents/thrive/adapting-holiday-traditions-during-coronavirus

For families looking to keep their risk for COVID-19 transmission as low as possible, but maximize their fun potential, now is the time to tap into one's creativity. Many families with adults and children with complex medical conditions are long-term innovators as they have found solutions to their unique child's needs.

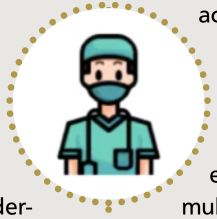
As eventful as 2020 has been, we have learned a lot that can help us move forward and out of the pandemic. Uncertainty swirls all around us as if we are in the middle of a snow storm and the landscape seems to change daily. Hold on to your skills as families of children with health care needs; you know how to adjust, make accommodations, be flexible and nimble. Lean in to your experience balancing risk, health and living life this Holiday season.

We wish all of our readers a joyous and safe holiday season! •

TEAM EFFORT : GUIDELINES FOR SHARED DECISION MAKING

Shared Decision making to resolve difficult decisions in health care, education, child care, and community life, balancing risk reduction with other ongoing needs, specific to the needs of the child and caregivers (especially, but not limited to, families), respecting and valuing the concerns of multiple stakeholders (health care providers, educators, school nurses, and others) to achieve consensus for needed accommodations. Practical steps include:

- Develop shared goals and objectives.
- Identify personal and cultural preferences, priorities, and concerns of all parties actively involved.
- Collaboratively review risk-reduction strategies and creative, flexible, and responsive accommodations under consideration, specific to the needs and risks of the child and contacts.



- Determine which individual(s) are responsible for carrying out the actions required to achieve the shared goals.
- Acknowledge that evidence to inform these decisions during the pandemic is limited, evolving, and often subject to multiple interpretations.
- Continue to re-evaluate decisions as new data become available.

American Academy of Pediatrics: Caring for Children with Special Health Care Needs During the COVID-19 Pandemic: https://services.aap.org/en/pages/2019-novel-coronavirus-covid-19-infections/clinical-guidance/caring-for-children-and-youth-with-special-health-care-needs-during-the-covid-19-pandemic

ABOUT THE AUTHORS:

Elizabeth J Lucas, MD is a Complex Healthcare provider at Nationwide Children's Hospital in Columbus, Ohio. She has board certifications in Internal Medicine, General Pediatrics, and Pediatric Infectious Diseases. She plans to spend this holiday season eating holiday cookies, mostly, but is open to including holiday donuts in this diet.

Cara Coleman is the mother of four (one of whom, Justice, had disabilities and medical complexity until she died in 2017) and Program Manager at Family Voices National. The Coleman family will spend their holidays in cozy pajamas, playing games inside and out, watching movies and eating way too much food!

Mallory Cyr is the Project and Communications Coordinator for Family Voices National, a subject matter expert on healthcare transition for CYSHCN, and navigates life as an adult with medical complexities. Mallory will be spending the holidays with her husband and dog, using Zoom to share her favorite traditions with her family in New England!

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WHY LILY TAKES GREAT PICTURES

THE AUTISM SPECTRUM “PETS THING”

Our pets are constant reminders that we don’t know everything, and that we have a responsibility to more than just ourselves. These are real, reciprocal relationships – bonds that never stagnate, love affairs wherein we shape one another as we travel – for our dogs get taught more than “sit” or “heel” from us.

BY MICHAEL JOHN CARLEY

I have what some people would call a very photogenic dog. She takes great pictures, and most would assume that such a talent originates in an interesting face coupled with the luck of the camera. But in truth, Lily suffers from a separation anxiety that requires her to constantly monitor me (or Kathryn).

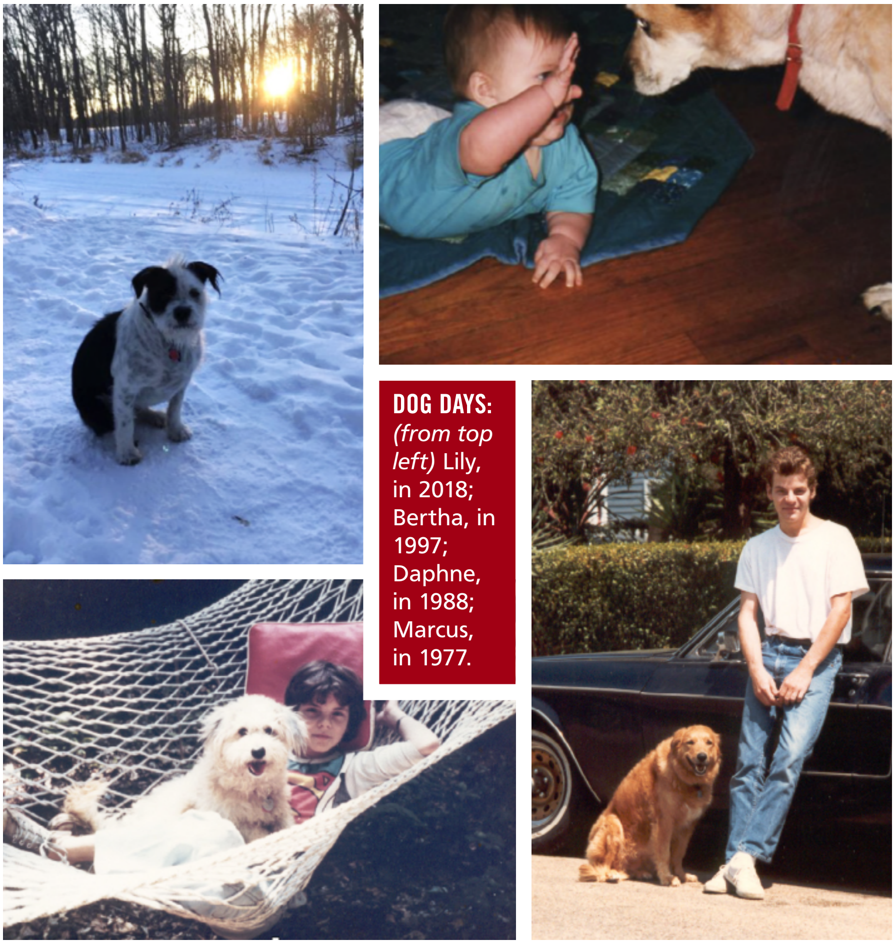
Many dogs can’t sit still. Not Lily. When your dog is constantly looking at you, they simply become a lot easier to photograph. Our efforts to reassure her that she will never be abandoned go for naught. She’s happy, and well-behaved for sure, but there’s a lack of trust somewhere that we cannot seem to heal.

Many pets come to us from rotten first experiences with humans. Humans have been taking their frustrations out on animals since the dawn of man; worse still, for entertainment – setting fire to cats was common practice in the middle ages. Lily, like Bertha and Daphne before her, needed soulful restoration upon

PHOTOS PROVIDED BY MICHAEL JOHN CARLEY

becoming “my dog.” But I’ve come to know the benefits of animals like this. They take longer to bond, but when they choose to bond, the bond is ten times stronger than what would occur had there been no prior trauma.

In the autism world alone, many of my spectrum brothers and sisters have been cited for an elevated knowledge of pets. Whether Temple Grandin making a career from her knowledge of how cattle think, Liane Holliday Willey with horses, Dawn Prince-Hughes with gorillas, Jerry Newport with birds, or the scads of undiagnosed, elderly “cat ladies” that are out there, we spectrumfolk take these relationships a step more seriously than most. I myself am even known to many family and friends as a fantastic judge and trainer of dogs – a “whisperer,” in the current lexicon.



DOG DAYS: *(from top left)* Lily, in 2018; Bertha, in 1997; Daphne, in 1988; Marcus, in 1977.

But it’s not because spectrumfolk are spiritually-gifted or have some kinetic association with the animal world. Like anyone, we have a lot of love to give. And sometimes it just isn’t working out with fellow humans. So we invest our energies more wisely into something that can better reciprocate.

I think I did a pretty good job of figuring fellow humans out. But it took a while. And that process probably got kick-started when I was ten, and my mother finally brought home the pet I’d wanted all my young life. Suddenly I had a dog, Marcus, who among other things got up with me every morning at 4 a.m. to deliver newspapers.

And then there was Daphne, who posed a problem when it was time for college as my mother had married an Englishman, and would live in London. Due to strict overseas pet laws, Daphne couldn’t go with her. So I had to choose a college that allowed pets. I and two others eventually even ran the entire campus pet system at Hampshire College. But whatever extra work it entailed was worth it, as I would exit classes to find my “roommate” sitting patiently on the ground outside the building. Daphne would eventually come with me to grad school in New York, and accompany me for the five months I played an eighth-rate Jack Kerouac and lived out of my car, working odd jobs to pay for food and gas.

And in the fourteen years we had Bertha, I became a father.

I’ll never forget the day I read that fatherless children eventually made for poor fathers. I was horror-stricken, and I panicked. That “won’t happen to me.” And I think that’s why I never refused when my dogs wanted to play.

Kathryn and I are a very affectionate couple. But do we greet each other at the door the way our dogs greet us? Does any couple?

It was also during our Bertha years that the rest of the world seemed to learn an increased value in pets beyond protection, rodent killing, and drug sniffing. The concepts of service dogs for people with eyesight challenges, therapy dogs to soothe the memories of our veterans, or the loneliness of old age… pets burst onto the scene as low-cost, highly effective treatments for trauma and anxiety.

By the time we lost Bertha in 2004, I interpreted that my dogs had served me as a preparer for fatherhood, a job I love, and that was in high gear at the time. Couple that with living in 4th floor Brooklyn walkups (i.e. no elevator) and I was content to be petless for a while. We were without a dog for almost 12 years, and that was a mistake.

Even today, when Kathryn and I sit down to watch a movie, and Lily decides she wants to play-fight with me, Kathryn gets frustrated because she knows the movie has to go on hold. And thanks to Lily and the companions before her, I have tried, as a parent, never to say the words, “Not now,” to my children.

Our pets are constant reminders that we don’t know everything, and that we have a responsibility to more than just ourselves. These are real, reciprocal relationships – bonds that never stagnate, love affairs wherein we shape *one another* as we travel – for our dogs get taught more than “sit” or “heel” from us.

- All my dogs have hated leashes, and I have worked hard to place them in spaces where they don’t need them (stupid cars…).
- None have been that interested in other dogs despite the many dog parks I take them to. As one friend joked, “Gee, wonder where she got that from?”
- Our loyalty is *shared* with others, for unless taught *not to,*

dogs enjoy all people, not just us. And were it not for humans, dogs really wouldn't have many "breeds." Ever wonder why mixed-breeds, or "mutts," are so much more emotionally-stable?

As I've written about plenty of times, I've had more adventurous experiences than most fellow spectrumites.[1,2] Seen war, death, extreme poverty and suffering in the preferably limited doses that did not overwhelm. I've cried over it, but I've also seen the best of human behavior amidst the same experiences. When you live a comfy life, and have experienced or seen no hardship, you protect yourself from the suffering of traumas, but it's also really hard to have confidence because you don't really know who you are. You haven't been tested.

At 13, Marcus was missing one night, and I went out to look for him. His bloodied and crushed body lay mystically under the light of a streetlamp on Elmgrove Avenue (stupid cars…).

I howled as hard as I could as I carried Marcus over my shoulder. I walked slowly, steadily, and not on a sidewalk but in the direct middle of the road. In the dark, three blocks home, lights went on in the windows to see what the screaming was all about, but no one left their house, no one approached me. They knew the uselessness inherent in asking if I needed help.


DOG YEARS: *(from top left)* A therapy dog; Lily in 2018; Lily in 2020; and the Carleys in 2018

Why was *that* the most painful day of my life? And why can so many of us relate to the experience of mourning pets so disproportionately – even when we have beloved friends or family that pass suddenly? This experience does not compare to a significant other, or a child's passing (or does it?). But still…

This piece has been a pleasure to write, but not because our pets are cute or that their love heals better than most therapy. It's been a pleasure because I have been a hypocrite in turning this article in to my editor. I constantly preach that no one needs us to write, or speak about something we're going through. People need to know or hear about what we've *been through*. We get it that people are overwhelmed and angry. There's nothing more to be learned therein except that people need more help than we think.

But here, in this piece, I am the hypocrite; another flawed set of contradictions, a disappointment to the true animal-loving communities… still figuring it out. I'm not a vegetarian, but I won't kill the food myself. I deplore animal testing for cosmetics and yet I've worn leather. I once thought myself humane because I threw the fish I caught back in the water, believing as I was told that fish feel no pain when the hook goes through their mouth. Now it appears that was nonsense.[3] So, I don't fish anymore. I have no desire to hunt and never did. But so long as the kills are eaten, hunting really doesn't offend me either.

I find arguments that guilty humans are better than innocent animals, or vice versa, to miss the point. Such semantics seek a simplistic answer that the natural world is forever telling us will not happen. We still don't know what exists in the ocean's depths, whether trees are communicating with each other when, unseen underground, their roots entwine, or whether there are limits to the real estate of our galaxy.

Meanwhile, while we're figuring it all out, true, reciprocated love and family, just for the asking, is offered to us all. We don't even have to deserve it.•

ABOUT THE AUTHOR:

Michael John Carley is the Founder of GRASP, a school consultant, and the author of *Asperger's From the Inside-Out* (Penguin/Perigee 2008), *Unemployed on the Autism Spectrum* (Jessica Kingsley Publishers 2016), the upcoming *Book of Happy, Positive, and Confident Sex for Adults on the Autism Spectrum... and Beyond!*, and the column, "Autism Without Fear," which for four years ran with the Huffington Post. Currently he is the Consultant for Disability Inclusive Culture at New York University, a writer for many, and on Mondays he sees individual clients. For more information on Michael John, or to subscribe to his free newsletter, visit www.michaeljohncarley.com

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CAREGIVING DURING THE HOLIDAYS,THE YEAR 2020

BY PATTI WADE

A NEW NORMAL: Do not focus on what you or your loved one is not able to do this year. Enjoy what they can still participate in.

There is no denying that 2020 has not been a typical year. This will include the Holidays. We all thought COVID-19 would be long over by now. We were wrong. This will cause a shift in holiday traditions for many folks, but most will adapt. For people with intellectual or developmental disabilities (IDD), this may be a bit harder. There are ways we can help.

TAKING CARE : TIPS FOR MANAGING THE HOLIDAYS WHEN YOU'RE A CAREGIVER

Focus on what is **MOST MEANINGFUL** or important to your family. Let some things go and just try to go for the activities that have the deepest meaning. Perfection is not the goal, calmness and happiness are.

EXPLAIN what will change and why – even if you think the person won't understand. Holidays can already cause anxiety for some, due to the disruption in daily routines. But the loss of usual traditions, like visiting family, or seeing Santa at the mall, may require a more thorough explanation for the person with those expectations.

SIMPLIFY your holiday activities. It does not have to be all or nothing. Decorate, but don't worry about putting everything out or meeting anyone else's standards. Send holiday cards a little at a time or send e-greetings. Encourage the person you support to help with decorating. It may be best to add a bit at a time and gradually layer in more if they want to. Making holiday cards can be more fun than shopping for the perfect commercial card and we still need to minimize shopping trips.

Start **NEW TRADITIONS.** Do not focus on what you or your loved one is not able to do this year. Enjoy what they can still participate in. Maybe you watch holiday videos or look at pictures from holidays past. Maybe you decorate and they just supervise where things go. Maybe you buy cookies instead of baking, or you bake and then invite a friend or family member over to share.

ADJUST MEALS. Simplify the menu. Prepare what you have time for or purchase all or part of the food premade. Ask other family members to bring some of the items if they are coming over. Allow for current tastes and texture requirements. Old favorites are better than fussy new dishes. Eat earlier (lunch rather than dinner) to avoid issues with fatigue or people who are too hungry and cranky. Sometimes their (and our) ability to cope wanes as the day goes on. It is okay if you choose not to have a traditional holiday feast. What ever works for your family is what you do.

GIFT GIVING. Give other family members lists of things the person can really use or currently enjoys. Many family members may want to give a gift, but just don't know what. Shop online if going out to the stores is too taxing for you or the person you are caring for, or if it still isn't safe. Buy small gifts for them to give to others. Use gift bags instead of wrapping, it's easier on you and easier for them to unwrap. When receiving gifts, if it becomes overwhelming for the person, put some gifts aside and open them over several hours or days.

REMEMBER SELF CARE. Allow time for rest and relaxation. You are a better caregiver if you are not over-stressed. Enjoy holiday treats, but remember to eat healthy meals and not overdo it. Be careful of over stimulation for you and for the person you are caring for. Slow down and breathe. You and the person you are caring for need rest, so you are better able to cope with the occasional, unavoidable holiday chaos. It is okay if you or your child (young or adult) wants to take a time out if things are becoming frustrating or tiring.

ASK FOR HELP WHEN YOU NEED IT. It's okay to say "no" to others' requests or to ask other family members or friends to help out. When others offer help, don't be a martyr - smile and take them up on whatever they are offering. Have a list of what others can help with (shopping, cleaning, visiting, or sitting with the person while you go out). Help others when you can (virtual volunteering can be fun) but only commit to what you truly want to do and enjoy the season.

Sometimes the Holidays can add extra joy, but sometimes they can add extra stress, especially if you strive to make everything "perfect."

Relax, reset your expectations, and try to enjoy the little moments. Remember, you and the person you care for will both be happier if you learn to go with the flow, expect the unplanned and enjoy what you can. Let the rest of it go.

Happy Holidays! •

ABOUT THE AUTHOR:

Patti Wade is the Director of the Orange Grove Center on Aging, Dementia and Longevity. She has devoted her professional pursuits in supporting people with intellectual and developmental disabilities. She has a particular interest in Alzheimer's disease and creative methods to teach caregivers how to support those individuals in "their world."

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ISSUES FACING PARENTS OF CHILDREN WHO ARE DEAF

BY TERI YUNUS

In 1985, when my third son was born, routine hearing testing was not being done in hospital for newborns. Michael was a good baby, likely due to being the third boy and having two brothers who made sure all his needs were met with the slightest squeak. He was a quiet baby, and I remember telling my friends that he was such a good sleeper that I could vacuum under his crib during his nap and he slept right through the noise.

As he grew, his frustration grew with him. He would point at things he wanted, there was no verbal communication other than grunts or cries. I often would empty out the kitchen cupboards to locate the item that he wanted. The pediatrician said he would talk when he was ready. His brothers and I doted on him, so why should he talk? When he was two years old, on a beautiful fall day, we were all playing ball in the front yard. The ball was thrown into the street and Michael went after it. I saw a car coming toward him and I yelled loudly for him to stop. I knew instantly that he did not hear me. Luckily, the car saw this little one and stopped in time for me to retrieve him. I packed up all the kids and drove straight to the doctor's office. I demanded a hearing test and, no surprise, Michael was profoundly deaf.

By that time, I was a single mom with three boys, ages six and under. What did I know about raising a son who was deaf? He was the first deaf person I ever met. The local school district, at the time, provided an Early On program for kids with special needs. We had the assessments done through the school system and were lucky enough to have a teacher come to the house to work with Michael and me. She taught us some sign language words so we could finally begin to communicate in a meaningful way. Debbie was fantastic, I will never forget her kindness and willingness to help. She was a lifeline for us then, and when Michael was just three years old, he went off to school. I still remember putting him on the bus when he was so little and so cute. By then, he had hearing aids and I would pin them with a string to his shirt so he didn't lose them. He still managed to lose many sets over the years.

Michael attended the deaf class at the local elementary school where he had four to five classmates. Some of his closest friends were in that class, and he remains in touch with a couple of them over 30 years later. His teacher in the earliest years who worked very well with the kids used sign language and taught social skills.

Michael went on to a mainstream classroom when he was about seven years old. He did well in the beginning with special seating and an interpreter. Yet, he was always the outsider. His only method of knowing what was happening in the classroom was through his interpreter; that left him isolated and, over time, unhappy. His memory now at age 35 of his mainstream years is that of the one friendship with a hearing boy, Kyle. Kyle made the effort to befriend him. One hearing classmate. Just one. Of his experience in mainstream elementary he says otherwise, "It's not cool to go there."

SILENT SCARE: Luckily, the car saw this little one and stopped in time for me to retrieve him.

BEST DECISION

When he was 10, I started pushing the school system to allow him to attend the state school for the deaf. It was a battle. I fought for about a year and a half and I will never forget the call I received on Christmas Eve that year. The fight was over. They approved his attendance and, at age 11, after Christmas break, Michael moved into the dormitory at the school that was over an hour away from our home. It was the hardest but the best decision I ever made for Michael. He was no longer the outsider. His "dorm" was a stand-alone house on the school property where five other little boys lived with the houseparent. It was homey and Michael shared a room with another boy his own age. One of my most profound memories is that Michael began wearing out the knees in his jeans after he moved to the school. He was now playing like a normal kid and his clothing was evidence of his inclusion. I still tear up thinking about it. He became a happier kid overnight.

The years leading up to the move to the school for the were not easy. Michael "living" away at school offered a whole new set of challenges. I was a single parent working multiple jobs to provide for my kids. My other sons often felt like secondary citizens as Michael's needs were greater than theirs. They were independent and probably had too much freedom because I was either working or attending a school event over an hour's drive away. The boys and I all took sign language classes during almost all the years of raising Michael. When the kids were young, I did my best to provide sitters who had sign language skills. Two of our longer-term sitters were fluent signers, one had deaf parents and the other was deaf herself. One of our neighbor girls taught herself sign language with books from the library (pre-internet days) and went on to earn her degree in Deaf Education.

> **"Allow your child to be different and unique while including him as much as possible in every conversation. Use signs whenever your child is present. This is inclusion."**

Looking back, it was a real challenge in many ways raising a child who was deaf in a hearing family. Children learn so much via incidental learning and, without it, every single thing must be taught. At one point, everything in the house was labelled…signs on the door, the windows, the curtains, the coffee pot, the blankets. Every word had to be taught as Michael did not have the benefit of hearing these words over and over like hearing kids do. It is something most people have no concept of – one of the things most of us take for granted.

I was astounded when I realized when Michael was nine years old that he did not realize that my mom was his grandma, and my sister was his aunt. He did not know this because he had not been taught this concept that we all "just know." It blew my mind. I felt inadequate as a parent of a child with different needs. I felt overwhelmed intermittently while raising Michael. I now can look back and give myself the grace that I wish I had allowed myself then.

Ninety percentage of deaf children are born to hearing families. Most of us are unequipped to make the big decisions. When my son was little, cochlear implants were in the experimental stages and were not an option for him. He wore hearing aids over the years and finally, at age 15 when I found that he was using them as expensive earplugs, he stopped wearing them all together. They did not help him hear voices and were a significant distraction for him. He still finds high pitched, loud noises painful.

COMMUNICATION IS KEY

I often wondered had Michael been given hearing aids earlier in life, if he would have been less hypersensitive to sound. I will never know if the delay contributed to this. My recommendation is to get hearing aids as soon as you know there is a hearing deficit that is significant enough to require them. Sign language and new technology changed my son's world. Cell phones have made connection with friends so much better. When he was in school, his friends were spread over hundreds of miles, and play dates were a huge deal, but we did it. We did the best we could to ensure some level of "normalcy" for our family and for Michael.

Bottom line for new parents of deaf children is that communication is number one. Learn sign language as soon as you learn your child cannot hear. Use your voice when you sign and be expressive in your facial appearance. Access to learning sign language is so abundant now. There are many free American Sign Language options available online. Know that it will all feel awkward and uncomfortable, and you may wish that your child was "normal" like the other kids. Your child has a different normal. Michael has always said that the only thing he cannot do is hear. Otherwise, he is our "normal".

Allow your child to be different and unique while including him as much as possible in every conversation. Use signs whenever your child is present. This is inclusion. Talking to another person while your child is present without signing is excluding the child. This can be a tough one for many hearing people. It is imperative for the sense of belonging that is sometimes absent for a deaf child in a hearing family. That may be your biggest challenge. It has been for us.

YOUR INTUITION WILL GUIDE YOU

The best advice I can offer is to listen to your heart. Your intuition, your gut wisdom will guide you. If recommendations are made for your child that do not sit right with you, do not agree to proceed. Your body will tell you if you listen. Pay attention to what comes up in your body when recommendations are made. If you feel excited and hopeful, that's a great sign. If you feel reluctant and feel like you need time to think about it, that is your no.

Getting help will make your life less chaotic. Seek help from your doctor, your local health department, the school system, social media groups and on the web. Knowing that people may be very opinionated and "know" what is right for your child may help you understand that they are truly trying to support you but, ultimately, you are the parent and your wisdom is the best guide. •

ABOUT THE AUTHOR:

Teri Yunus is a Family nurse Practitioner and nationally board-certified health & wellness coach with health up with teri! she recently retired from her work as a nurse practitioner and devotes her time to coaching with emphasis on transitioning to a whole food plant-based lifestyle. she empowers her clients to take their power back and the results she sees with her clients is transformative! www.healthupwithteri.com contact teri at healthupwithteri@gmail.com

THE IMPORTANCE OF CONNECTION IN DEAF-BLINDNESS

BY MEGAN COTE, PEGGY MALLOY AND ANN BISWAS

When my son was first diagnosed with deaf-blindness, it was difficult to find information to support his and our family's educational, medical, and emotional needs. We felt despair, desperation, alone, and unconnected. Once our family became involved in the deaf-blind network, we met families, interested friends, educators, and professionals—a community of trusting relationships and effective partnerships that will last a lifetime and allow us never to feel alone again."

– Patti McGowan, President of the National Family Association for Deaf-Blind

WHAT IS DEAF-BLINDNESS?

Although the term deaf-blind implies a complete loss of vision and hearing, in reality, it refers to individuals with varying degrees of vision and hearing loss. The types and severity differ from individual to individual, but the key feature of deaf-blindness is that the combination of losses limits access to auditory and visual information.

Approximately 10,000 children and youth (birth through 21) have been identified as deaf-blind in the United States. Within this population there is great variability in terms of age, race/ethnicity, cause of deaf-blindness, severity and type of hearing and vision loss, and whether they have additional disabilities (e.g., physical, cognitive) or health challenges.

There are many causes of deaf-blindness. Those that are present or occur around the time of birth include prematurity, childbirth complications, and numerous congenital syndromes. Deaf-blindness may also occur later in childhood or during adulthood due to causes such as meningitis, brain injury, or inherited conditions.

Because deaf-blindness significantly impacts an individual's ability to access information and communicate with others, children who are deaf-blind have a unique experience of the world. Therefore, it is critical that both families and educators have access to training and support to know how to best support the growth and development of the child with deaf-blindness. Creating predictable routines in safe environments with trusted communication partners is critical for their development.

IMPORTANCE OF THE FAMILY

"I never really realized how alone I was until I found my tribe of people that understood me and my child." – Minnie Lambert, Board Member of the CHARGE Syndrome Foundation

Because deaf-blindness is a low-incidence disability, families usually carry the burden of educating others about the impact that their child's disability has on his or her unique learning needs. They often feel isolated because it is not typical to have others living nearby who also have children with this rare disability. As a result, families often find themselves in the dual role of care provider and educator. This not only creates exhaustion but also a sense of loneliness. Connecting families to high-quality resources and to other families of children with deaf-blindness is essential to fostering a sense of support and community.

RESOURCES FOR FAMILIES OF CHILDREN AND YOUTH WITH DEAF-BLINDNESS

"Providers who work with and for your child should be willing to explore additional options while keeping the health and development of your child and family a priority. We look for therapists and doctors who see us as valued partners and refer to others when needed." – Rita Fredericks, Mother to Liam and Miles and Advocate

Numerous agencies and organizations are available for families of children with deaf-blindness in the United States that provide a range of services and supports including information, referrals, services, and opportunities to interact with other families. Some are relevant to all families regardless of the cause of their child's deaf-blindness. Others focus on specific causes of deaf-blindness such as CHARGE syndrome, peroxisomal disorders, and Usher Syndrome.

State Deaf-Blind Projects: The primary resource for most families of children age birth through 21 in the United States is their state deaf-blind project. There is one in every state, as well as Puerto Rico, the District of Columbia, the Pacific Basin, and the Virgin Islands. These projects are funded by the U.S. Department of Education's Office of Special Education Programs (OSEP).

The types of services offered vary from state to state, but typical-

PHOTOS PROVIDED BY THE NATIONAL CENTER ON DEAF-BLINDNESS

ONLY CONNECT: *(Clockwise from top left)* Aryan and Krishangi Shroff; Jackie Freeman; Parker Chen; and Miles (in chair) and Liam Fredericks. Connecting families to other families of children with deaf-blindness is essential to fostering a sense of support and

ly include resources, guidance, and annual workshops or other events. Most state deaf-blind projects include a staff member in the role of family engagement coordinator who works directly with families. To find your state deaf-blind project, visit the National Center on Deaf-Blindness website at www.nationaldb.org and click on "Contact Your State Deaf-Blind Project" in the upper right corner of any page.

National Center on Deaf-Blindness: The National Center on Deaf-Blindness (NCDB) works closely with state deaf-blind projects and other partners to improve educational results and quality of life for children who are deaf-blind and their families. Its primary mission is to support state deaf-blind projects as they work to increase the knowledge and skills of educators and families and promote sustainable services.

Most of NCDB's goals are aligned with four national initiatives designed to address key needs of children with deaf-blindness, their families, and service providers:

- ***Family Engagement*** *– Increasing the quality of family support and helping families acquire knowledge and skills to help them partner with service providers and advocate for their children's needs*
- ***Identification and Referral*** *– Increasing the identification of children and youth who are deaf-blind so they can begin receiving appropriate services as early as possible*
- ***Interveners and Qualified Personnel*** *– Building the knowledge and skills of educators serving children who are deaf-blind through expansion of personnel development opportunities and adoption of interveners and teachers of the deaf-blind*
- ***Transition*** *– Improving transition outcomes so that students successfully move from high school to post-secondary education or employment and community life*

Like the state deaf-blind projects, NCDB is funded by OSEP. In recognition of the complexity of the disability of deaf-blindness, the U.S. Congress has authorized programs for children who are deaf-blind as part of education legislation since the late 1960s. NCDB and state deaf-blind projects are the most current programs and are funded under the Individuals with Disabilities Education Act.

NCDB does not provide direct services to families, but it has an extensive website with an "Info Center" containing information about deaf-blindness, resources on educational practices, data on the population of children and youth who are deaf-blind, and resources in Spanish. The website also has a special "For Families" section with information to help families learn and connect to agencies and organizations. This section also includes "Key Topics for Families," with tips, strategies, and supports that families of children with deaf-blindness can use to help them navigate their child's services and their family's everyday life. The NCDB website is www.nationaldb.org

National Family Association for Deaf-Blind: The National Family Association for Deaf-Blind (NFADB) is the largest national nonprofit organization empowering families with individuals who are deaf-blind. NFADB believes that people with deaf-blindness are valued members of their communities and should have the same opportunities and choices as others in the community. As such, they seek to empower the voices of families with individuals who are deaf-blind and advocate for their unique needs. NFADB's purposes include:

- *Advocating for families with individuals who have deaf-blindness*
- *Fostering family-to-family relationships*
- *Promoting partnerships*
- *Providing information and resources*
- *Offering training opportunities*

NFADB also has an Affiliate Network of family organizations with which it partners on activities that improve opportunities and services for individuals who are deaf-blind. The NFADB website is www.nfadb.org

Helen Keller National Center for Deaf-Blind Youths and Adults: The Helen Keller National Center (HKNC) provides training and resources to people age 16 and older who have combined vision and hearing loss. Its headquarters is in Sands Point, New York, but it also has offices in ten regions across the United States. HKNC's services include:

- *An on-campus comprehensive vocational rehabilitation program*
- *A virtual comprehensive vocational rehabilitation program. Consumers can take an individual class or a full program online.*
- *Peer-learning groups*
- *Virtual youth programs offered in the summer and during school vacation weeks as well as a group for teens 14 and 15 years old*
- *Regional services (e.g., consultation, advocacy, assessment, training, referrals). These services include ten regional representatives and eight deaf-blind specialists currently in eight states and growing. Deaf-blind specialists can assist with training needs and job development and training in these states. (For more information, visit helenkeller.org/hknc/deaf-blind-specialists.)*
- *Two comprehensive community services programs that provide services to individuals locally in New York City, Westchester, and Long Island as well as in California from Bakersfield to San Diego*
- *Online classes for consumers, families, and professionals who work with individuals who are deaf-blind and online learning tools and resources. Please visit their online courses and resources for additional information:*
- *Online classes:* www.helenkeller.org/hknc/online-courses
- *Learning tools:* www.helenkeller.org/hknc/onlinelearningtools

The HKNC website is www.helenkeller.org/hknc and HKNC Regional Services can be found at www.helenkeller.org/hknc/nationwide-services

The CHARGE Syndrome Foundation: The mission of the CHARGE Syndrome Foundation is to lead and partner to improve the lives of people with CHARGE syndrome locally, nationally, and internationally through outreach, education, and research. The primary goals of the Foundation include:

- *Growing outreach and support programs*
- *Increasing the knowledge base*
- *Promoting awareness*
- *Building networks and partnerships*
- *Investing in leading edge research*

Fundraising activities allow the CHARGE Syndrome Foundation to support families through conference and recreation assistance grants, a director of outreach, and a state family liaison program to keep families connected and informed. The Foundation also invests in research and spreads awareness through webinars, e-news, a newsletter, social media sites, and a biennial international conference. The CHARGE Syndrome Foundation website is www.chargesyndrome.org

Global Foundation for Peroxisomal Disorders: The mission of the Global Foundation for Peroxisomal Disorders (GFPD) is to improve the lives of individuals with these disorders by funding research, championing scientific collaboration, and empowering families and professionals through educational programs and support services. GFPD supports and connects families in 40 countries and 50 states through:

- *Educational conferences*
- *Regional meetups*
- *Online support groups*
- *Webinars and virtual events*
- *Parent to parent mentoring programs*
- *Access to trained family support facilitators*
- *A medical equipment exchange program*
- *Bereavement support*
- *Advocacy training*
- *Medical research funding*

The GFPD website is www.thegfpd.org

Usher Syndrome Coalition: The Usher Syndrome Coalition (USH) provides information and support to individuals and families affected by Usher syndrome worldwide. Their focus is to raise awareness of and accelerate research on the syndrome. USH's specific goals include:

- *Hosting the annual USH Connections conference*
- *Maintaining an international registry to connect the Usher community*
- *Providing education via "USH Talks," a video podcast series on the latest research developments and community stories*
- *Networking through the USH Blue Book email forum*
- *Providing local information and support through USH ambassadors*

The USH website is www.usher-syndrome.org and USH's "Just for Parents" page is www.usher-syndrome.org/our-story/just-for-parents.html •

ABOUT THE AUTHORS:

In her more than 25 years in the field of deaf-blindness, Megan Cote has worked as a classroom teacher, coordinated multiple state-level grants, taught graduate coursework at the University of Kansas, and directed the Kansas Deaf-Blind Project. She has worked for NCDB since 2015 as the initiative lead for Family Engagement.

Peggy Malloy is NCDB's Information Services and Technology Coordinator and has worked for technical assistance and dissemination projects on deaf-blindness since 1997. Her areas of expertise include product development, implementation science, and library research and management in the fields of deaf-blindness, disabilities, and health care.

Ann Biswas is a Project Specialist - Writer for NCDB. Prior to joining NCDB, she was a principal lecturer at the University of Dayton, where she taught medical and professional writing. Over the years, she has written numerous publications and media programs for health organizations, medical schools, and health professionals from a variety of disciplines.

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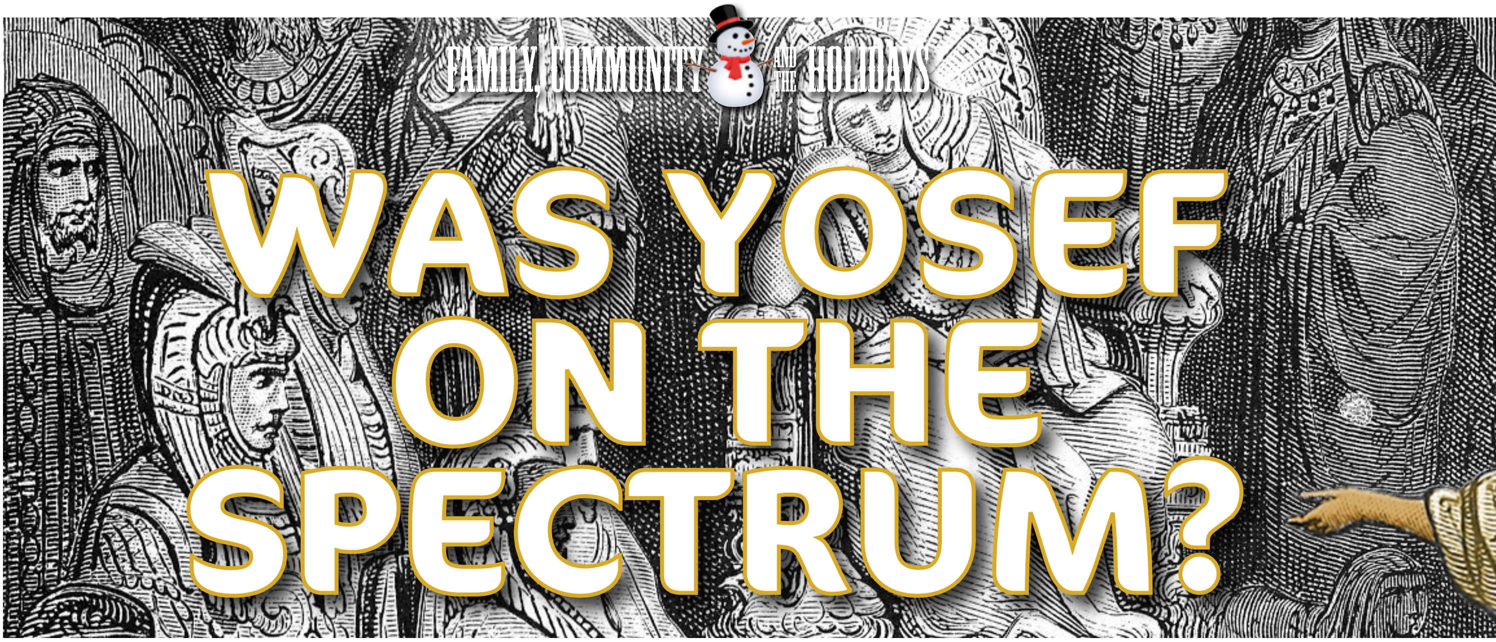

WAS YOSEF ON THE SPECTRUM?

BY SAMUEL J. LEVINE

The story of Joseph (the title of my book uses the Hebrew "Yosef") presents a fascinating and memorable narrative, which has been the focus of careful study for countless generations of readers and scholars of the Bible, as well the subject of a wide range of art and literature, from the visual arts to acclaimed novels, to Broadway and Hollywood productions. Much of this interest, among both religious adherents and broader culture, likely stems in large part from the challenging questions that arise in the course of the story.

Joseph's behaviors, interpersonal relationships, and personal journey and development are often difficult to understand, and at times seem to defy explanation, as he faces concomitant and interconnected challenges and opportunities, and as he experiences, often at once, both surprising success and unexpected failure. Over the years, I have read the biblical story of Joseph numerous times, and I have studied the text through the prism of the works of classical Jewish commentators, spanning thousands of years and geographically disparate locations across the world.

A number of years ago, as I read the opening verses of the story, it occurred to me that many of Joseph's characteristics and behaviors are consistent with those of an individual on the autism spectrum. As I continued to reread the events through the lens of contemporary understandings of autism, I observed that throughout the story, in one episode after another, Joseph's behaviors and experiences closely resemble those common among individuals who are categorized with high-functioning autism or Asperger's syndrome. Upon further examination, I realized that understanding Joseph as an individual on the spectrum helps illuminate not only the text of the Torah but also many comments and teachings about Joseph found in the classical Jewish sources I had previously studied.

On this basis, through a close reading of both the biblical text and classical Jewish commentators, my book attempts to achieve a coherent and cohesive understanding of the story that offers a plausible account of Joseph's behaviors toward others and those of others toward him, while at the same time accounting for both his successes and his failures. Although, of course, individuals with autism spectrum disorders vary widely in their symptoms and their behaviors, common characteristics include many of the behaviors Joseph exhibits and the interactions he experiences.

For Joseph, these include: social challenges, punctuated by an inability to read social cues, understand and anticipate the feelings and reactions of others, and navigate social settings; attachment to animals or to inanimate objects in place of interpersonal relationships; heightened intellectual capacity and creativity in narrow areas of interest; repetitive and inflexible behaviors and routines; an obsessive and compulsive focus on a personal vision and a private way of viewing the world; and a rigid and literal understanding of truth, ethics, and morality that sees virtue in extreme terms rather than allowing for nuance.

In terms of Joseph's behaviors, the biblical text uses the Hebrew word na'ar, often translated as "lad," to describe a seventeen-year-old Joseph's interactions with his brothers who marginalize him. Noting that this term is ordinarily reserved for a young child, some suggest that Joseph engaged in seemingly childish activities, such as tending to his eyes and his hair. Building on these suggestions, Joseph may have been engaging in self-stimulatory and repetitive behaviors, playing with his eyes and twirling his hair in a manner that is not uncommon for an individual on the spectrum, but deemed by his brothers to be immature and off-putting. Likewise, Joseph is portrayed as a particularly skilled shepherd, exhibiting a talent and interest in animals often found among children and others on the spectrum.

Similarly, picturing Joseph as being on the spectrum may help explain some of his otherwise puzzling and problematic interactions with his brothers. Indeed, viewed through this lens, Joseph

GUSTAVE DORÉ: JOSEPH INTERPRETS PHARAOH'S DREAM; COMMONS.WIKIMEDIA.ORG

BRILLIANT AND CHALLENGED: I realized that understanding Joseph as an individual on the spectrum helps illuminate not only the text of the Torah but also many comments and teachings about Joseph found in the classical Jewish sources I had previously studied.

emerges as a more familiar and less enigmatic individual, exhibiting both strengths and weaknesses commonly associated with autism spectrum disorder. For example, near the start of the story, Joseph tells his father, Jacob, about his brothers' misdeeds, sparking their resentment. Biblical commentators attribute Joseph's determination to bring this information to his father's attention as a reflection of Joseph's dedication to truth and morality, notwithstanding the social repercussions of his actions. Likewise, Joseph insists on recounting his dreams to his brothers, depicting his ambitions of ruling over them, not surprisingly evoking their hatred and jealousy. Joseph's apparent compulsion to share his thoughts and visions with others, without anticipating or recognizing the effects that his words and action have on them, is also consistent with characteristics of individuals on the spectrum.

Indeed, as a result of Joseph's brothers' inability or unwillingness to understand him, their relationship quickly and precipitously deteriorates, such that the brothers repeatedly demonize, ostracize, and marginalize him. Although Jacob tries to mediate, his attempts to indulge Joseph only breed further resentment and isolation on the part of his brothers, to the point that they remove Joseph entirely from among them, selling him into slavery in Egypt. Notably, during his time in Egypt, Joseph constantly speaks truth to power and displays both his talents and his commitment to morality, albeit in ways that are often lacking in social skills and awareness.

In addition to explaining Joseph's experiences, this understanding of the story may offer positive perspectives, encouragement, and important lessons for children and adults on the spectrum and those who interact with them, including their families, friends, and caretakers, as well as others who are unfamiliar with autism spectrum disorder. For example, during his initial encounter with Pharaoh, the King of Egypt, Joseph interprets Pharaoh's dreams and prescribes a response to the forthcoming famine, expressing himself in ways that demonstrate, at once, both his brilliance and some of his social challenges. Pharaoh recognizes Joseph's potential value to his kingdom, but he also anticipates that, on a social level, Joseph may be vulnerable to the maneuverings and attacks of others. To accommodate his deficits, Pharaoh provides Joseph with dignified clothes, an honorable name, servants, and a wife from a distinguished family to protect him and help him navigate his social surroundings. With these supports in place, Joseph is safe to go out on his own, leaving the protective watch of Pharaoh and traveling throughout the Land of Egypt.

It is not uncommon for individuals with disabilities, once they receive the appropriate services, structure, and supports, to be able to exercise the talents they possess and achieve the goals that would otherwise continue to elude them. As Pharaoh recognizes, like many who are on the spectrum, Joseph's deficits are in areas relating to social expectations and interactions. Unencumbered by these external concerns, Joseph is now free to focus on his areas of strength, constructing and implementing his masterful plan to save Egypt and the surrounding lands.

Finally, at the end of the story, having attained great success as the viceroy of Egypt and after the death of Jacob, Joseph speaks one last time with his brothers. Contrary to their fears of possible vengeance on his part, Joseph responds in a thoughtful, gracious, and heartfelt manner, which may offer a message of optimism for individuals on the spectrum, their families, and their friends. Joseph assures his brothers that they have no reason to fear, and that he will continue to provide for them and for their children. Accordingly, the text concludes with the declaration that Joseph "consoled them and spoke to their heart." As this verse emphasizes, Joseph now speaks to them in a way that shows his ability to see their perspective and to touch their heart, and likewise, Joseph's brothers seem to understand and accept him. Now, outside of the protective watch of either Pharaoh or Jacob, Joseph is truly reconciled with his brothers. •

ABOUT THE AUTHOR:

Samuel J. Levine is Professor of Law & Director, Jewish Law Institute, Touro Law Center.

“I feel so blessed to have Denver as my son because there is no way I would have been able to understand all these differences to the degree I do today without having him a significant part of my life. Here’s to you Denver, my special blessing.”

DENVER HAS A HEART OF GOLD

“When a father gives to his son, both laugh; When a son gives to his father, both cry.”
– William Shakespeare

BY DR. KEITH DRESSLER

For the first 36 years of my life, I had effectively zero interactions with special needs children and knew virtually nothing about their needs, other than the biology that may have created their disorder. I was totally uneducated about them, even though I went to dental school and received a masters degree in orthodontics. I had never had a special needs child as a patient and I grew up in an era where special needs children were stigmatized and isolated in their own classroom and never allowed to interact with the “normal” children.

My entire life and perspective of differences amongst all human beings changed on August 3, 1994, when my son, Denver, was born. Special needs took on real meaning in my life. Denver was born almost totally deaf, with a little hearing in his right ear, which he wears a hearing aid in. He is totally deaf in his left ear and can’t really hear anything unless his right hearing aid is in. My wife and I were told to learn sign language as he would never talk.

Being hearing impaired was not Denver’s only issue as a newborn. His left eye was turned inward towards his nose. He had three eye surgeries to correct his crossed eye before he was six months old, then he wore corrective glasses. We were told by his doctors he would never see well and being that he couldn’t hear, he would be severely intellectually disabled, a softer term for “mentally retarded”.

My wife and I were determined to give Denver the best chance to develop to his best potential. He went to the speech and and hearing center preschool when he was 18 months through six years old. They taught him sign and speech. He was also seeing physical therapists, occupational therapists, sensory integration therapists, and many other doctors. He had to be taught to walk as his muscles never developed properly. He never crawled on his hands and knees. His crawling was like doing the backstroke, it was always on his back.

I had never heard the word sensory integration in my life before, let alone understood what that meant for Denver and his

PHOTO COURTESY DRDRESSLER.COM

life and the world he lived in. His life was teaching me so much and opened my eyes to a world I knew nothing about.

Somewhere around Denver was five, we were told he was autistic as well. Another category he was put in that I had never heard of before. ADD, ADHD, autism were new buzz words you might hear, but I knew nothing about what they really meant.

Well, Denver defied all odds, for he learned to walk, talk, and could see, even though each eye worked separately and not together, which meant he had zero depth perception. He had no fine motor skills, so writing with proper letter size and space orientation was and still is very difficult for him. However, thank goodness for computers. He types wonderfully, which gives him a great tool for communicating.

I would like to share with you what all these things meant in Denver's world and in mine. I'm sure my wife has way more stories than me, but these are the ones I remember best. Denver interprets the world as black and white and no gray. He was four years old when once, I was bathing him in the bathtub. He had asked me earlier why he had to take a bath. I explained he was dirty. While in the tub, he started drinking the water and I said, don't drink the water, it is dirty. He asked me, how am I becoming clean by taking a bath? Another time when Denver was seven, I bought an SUV, and when I picked Denver up, I said jump in the back seat. He opened the back door and said, Daddy don't leave me; I can't jump this high. When he was 12 years old, we were on vacation; while bathing, Denver got into a hot tub with a huge sign – 10-person limit. The next thing I knew, I heard him screaming at a lady who got into the hot tub holding her infant. She made 10, and the infant 11.

> "When Denver was seven, I bought an SUV, and when I picked Denver up, I said jump in the back seat. He opened the back door and said, Daddy don't leave me; I can't jump this high."

Because of Denver's sensory integration, he does not like to be touched, and textures of foods, clothes he wears, and others really matter to him. As strange as this may seem with him being virtually deaf, he cannot stand to be in a loud room. It over-sensitizes him. Eating out used to be difficult as he freaked out if different foods touched each other, or the restaurant was too loud. He would tell the waitress to bring him each food item on a separate plate – or ask if they could make an announcement and tell everyone in the restaurant to whisper, as the noise was bothering him. Or he might just suddenly stand on his chair and get everyone's attention in the restaurant and lecture them that they needed to be quieter as the noise was driving him nuts. He has outgrown and better understands how to cope now as an adult – because he loves eating out. But for most of his developmental life, eating out was a challenge, and I never knew what to expect from him.

While on the topic of not understanding social norms or behaviors, we were all at a political fundraiser and waiting on the introduction of the political figure. All of a sudden, we (thousands) heard a bell ringing signaling for us to stop talking and the introduction of the political figure. Much to my amazement, it was Denver on stage getting everyone's attention so he could tell them about his brand-new digital hearing aid and to be careful around him, as he could not get it wet and it would cost him $5,000 to get a new one and his parents would be very upset.

Some of the toughest times as a parent come because these conditions are in their infancy of being understood and controlled. What this means is trial and error with medications and, in my experience, medications work for a period of time and, for whatever reason, stop working and need to be changed. Because you never know when they may stop working, you cannot accurately predict behavior or perceived misbehavior. Making things tougher: behaviors also vary, or become erratic every change of a season. In Denver's case, he becomes very manic when the seasons change, even today.

HEART OF GOLD

What I can tell you about Denver, is that he has a heart of gold. When in middle and high school, he used to bring every member of the football team chewing gum and hand it out each day before practice. Every player loved him. At 16, I taught him how to write a check and got him a checking account that required two signatures, mine and his, to be valid. It had a few hundred dollars in it, but was overdraft-protected by my account. I got a call from the bank saying Denver had overdrawn his account by $4,500. I said that is impossible, I have his checkbook locked up and I didn't counter-sign anything. They told me he bought $4,700 of oranges online from a band fundraiser. The bank told me they couldn't control online purchases and they didn't need double signatures. When I got home, Denver explained he did buy them and wanted to give some to poorer children at school, and that he wanted to take some to the homeless shelter, Chattanooga food bank, and give some to the work out facility where he works out so everyone would be able to enjoy a free Orange after their workout. My heart melted but I had to try my best to explain excessiveness. Denver said, we can afford it so why not? He bought 100% of the band's allocation of Oranges.

> "Denver's gift is math and science and he will never deviate from rules he is given. He has been doing my accounting in my office since he graduated high school. He does what I was having a full-time accounting person do in two half-days a week, telling me I do not have enough work for him to do."

MAINSTREAMED

Denver was mainstreamed in public schools, which always provided him an interpreter. He used that individual as a personal assistant as he didn't want that individual signing to him. He wanted to try and listen. He was found to be more of an auditory learner. That makes things tough as we may be talking about teeth and he thinks/hears feet and misinterprets the conversation. What we learned and asked of the school was to stay with same assistant every year to provide stability and consistency. There was too much of a learning curve if they changed this person every year. The school agreed, and I feel this led to the best outcome for him.

I have a passion for tennis and nothing thrilled me more when Denver asked me, when he was 10 and a half, if he could take tennis lessons. I knew this was going to be a real challenge due to his sight and lack of fine motor skills. The pro told me the best way to teach him would be for him to hold the racket with both hands on all shots. After six months of tennis lessons, his eye doctor said to us Denver's vision had really improved and both eyes are working together for the first time and he was beginning to see some depth. We had tried four years of vision therapy a few years earlier, with no improvement and now, major improvement with six months of tennis lessons. Denver continues his weekly lessons and I have enjoyed being his doubles partner in various leagues we have participated in. We have even enjoyed winning one league twice.

Back to his heart of gold, he participated in a tournament as a teenager and bought grip (wrapping over handle of racket) that he handed out to every boy and girl participant. It was something he wanted to do and thankfully, was only $150, so I told him I thought that would be nice.

INDEPENDENT LIVING SKILLS

As his high school days were ending, my wife and I became concerned about Denver's independent living skills and how was he going to be able to learn these. He didn't drive, he didn't last at any volunteer job he tried, as most did not understand how to manage a special needs individual—and more important, did not want to learn how. We were blessed that a house with a guest house came on the market that we purchased.

Denver has lived independently in that house for almost eight years now. He can cook for himself, take his meds on his own, buys what he needs online, is much better budgeting but can go crazy buying stuff when he gets manic during the change of the seasons. His gift is math and science and he will never deviate from rules he is given. He has been doing my accounting in my office since he graduated high school. He does what I was having a full-time accounting person do in two half-days a week, telling me I do not have enough work for him to do. He goes into his office, closes the door, follows all the rules he was taught, writes checks, does payroll, pays all taxes, reconciles all checking/savings accounts, as well as all credit card statements and very rarely makes a mistake. This only occurs during medication adjustments.

I feel so blessed to have Denver as my son because there is no way I would have been able to understand all these differences to the degree I do today without having him a significant part of my life. I credit him with me becoming a much more spiritual, empathetic human being, and a better healthcare provider of and for very special human beings. Here's to you Denver, my special blessing.•

ABOUT THE AUTHOR:

Dr. Keith Dressler is an orthodontist living in Chattanooga with his wife Laura Lea and son Denver. His son has served as his personal tutor and mentor in furthering his understanding of neurodiversity. He is the Chairman and CEO of Rhinogram, a virtual care platform that promotes patient and provider communications.

DYSPHAGIA DOES NOT HAVE TO BE A HARD DIAGNOSIS TO SWALLOW

AN OVERVIEW OF DYSPHAGIA IN PATIENTS WITH INTELLECTUAL DISABILITY/DEVELOPMENTAL DISABILITY

BY MISSY LEWIS AND BAMBI L. TROXELL, MCD/CCC-SLP

The most frequently asked question in the Orange Grove Center (OGC) Speech/Language/Swallowing Department is "Can I have some coffee?" We know how all of our patients like their coffee and what their favorite snacks are, too.

Having a special treat and time with friends is something our patients look forward to. Mealtime is a social time and it is meant to be enjoyable; everyone has different preferences when it comes to what they enjoy eating/drinking.

Humans swallow between 500-700 times a day, around three times an hour during sleep, once per minute while awake and even more during meals.[1] What happens when swallowing is difficult to accomplish?

- *Difficulty swallowing (dysphagia) means it takes more time and effort to move food or liquid from your mouth to your stomach.*
- *Aspiration occurs when a person accidentally inhales particles into their airway. In the ID/DD population, those particles are most commonly foods, beverages, or bodily fluids such as saliva or vomit. Aspiration is a major medical concern because it may lead to pneumonia, infection, pulmonary edema or other issues.*
- *Choking (asphyxiation) occurs when the airway is blocked by food, drink, or foreign objects. Any choking incident can put someone at a risk for aspirating.*

NOURISHING RELATIONSHIPS: Bambi L. Troxell, MCD/CCC-SLP *(left)* and Missy Lewis *(right)* visit with a patient at the Orange Grove Center. Several of their patients are residents of our Supportive Living or Residential programs and have been a part of OGC for most of their lives.

PHOTOS BY DENNIS WILKES

When aspiration occurs, many people with ID/DD have difficulty identifying or reporting symptoms. Signs that aspiration has happened may not be visible until after the fact and may appear to be unrelated, so it often goes undetected. Repeated trace amounts of aspiration over a long period of time can cause serious respiratory complications and permanent damage to the lungs.

In addition, dehydration, constipation, aspiration and seizures make up the "Fatal Four." These conditions have the potential to severely impact a person's quality of life and, in some cases, can be deadly.[6]

All individuals that receive services through Orange Grove Center have an Intellectual Disability/Developmental Disability (ID/DD), a diagnosis that can be paired with additional contraindicating congenital conditions. According to the TN Department of Intellectual and Developmental Disabilities, these co-committing disorders can lend to the following medical and behavioral factors make an individual more likely to choke or aspirate include:

- *Dysphagia*
- *Difficulty (or absence of) chewing*
- *Vomiting after meals*
- *Throwing head back to swallow*
- *Difficulty controlling head or neck muscles*
- *Mobility limitations that prevent sitting up straight*
- *Impaired consciousness or awareness*
- *GERD (Gastroesophageal Reflux Disease)*
- *Eating too quickly or putting too much food in one's mouth*
- *Dental problems that prevent adequate chewing*
- *Anatomical variation such as a small airway or a large tongue*
- *Having pain while swallowing (odynophagia)*
- *Being unable to swallow*
- *Having the sensation of food getting stuck in your throat or chest or behind your breastbone (sternum)*
- *Drooling*
- *Being hoarse*
- *Bringing food back up (regurgitation)*
- *Unexpectedly losing weight*
- *Coughing or gagging when swallowing*

COMMON SENSES: Visual aids, such as picture symbols, help patients to better understand steps toward mealtime safety.

ANOTHER BITE : ADDITIONAL ROLES FOR SPEECH LANGUAGE PATHOLOGISTS

- Identifying the signs and symptoms of dysphagia
- Identifying normal and abnormal swallowing anatomy and physiology
- Identifying indications and contraindications specific to each patient for various non-instrumental and instrumental assessment procedures
- Identifying signs of potential disorders in the upper aerodigestive tract and making referrals to appropriate medical personnel
- Performing, analyzing, and integrating information from non-instrumental and instrumental assessments of swallow function collaboratively with medical professionals, as appropriate
- Providing safe and effective treatment for swallowing disorders, documenting progress, and determining appropriate dismissal criteria
- Identifying and using appropriate functional outcome measures
- Understanding a variety of medical diagnoses and their potential impact(s) on swallowing
- Awareness of typical age-related changes in swallow function
- Providing education and counseling to individuals and caregivers
- Incorporating the client's/patient's dietary preferences and cultural practices as they relate to food choices during evaluation and treatment services
- Respecting issues related to quality of life for individuals and/or caregivers
- Practicing interprofessional collaboration as an integral part of the patient's medical care team
- Educating other professionals on the needs of individuals with swallowing and feeding disorders and the SLP's role in the diagnosis and management of swallowing and feeding disorders
- Advocating for services for individuals with swallowing and feeding disorders
- Advancing the knowledge base through research activities
- Maintaining competency of skills through reading current research and engaging in continuing education activities
- Determining the safety and effectiveness of current nutritional intake (e.g., positioning, feeding dependency, environment, diet modification, compensations).[5]

IMAGES COURTESY DAVID A TESINI DMD, MS

THROUGH THICK AND THIN: Gel-based thickeners such as SimplyThick are used to create a more palatable thickened liquid viscosity.

- *Having to cut food into smaller pieces or avoiding certain foods because of trouble swallowing*
- *Eating non-edible objects*
- *Hoarding foods for later consumption*
- *Taking foods when no one is watching*
- *Quickly grabbing food from plates or counters*

Some of these factors, such as eating too much too quickly or general mobility limitations, are common across the Intellectual and Developmental Disability population. Other factors may be disability-specific. For example, individuals with cerebral palsy (CP) may have difficulty swallowing or controlling their head and neck due to the impact of CP on their muscle tone.[2] Respiratory disease is the most common cause of death for those with severe intellectual impairment.[1]

OGC's mission statement is "to recognize, support, and celebrate the qualities of the individual." Our department is part of the Morton J Kent Habilitative Center. We are unique in the way that we provide service delivery for patients with Intellectual Disability /Developmental Disability. Several of our patients are residents of our Supportive Living or Residential programs and have been a part of Orange Grove Center for most of their lives. Our speech therapy patients cannot always participate in therapy or make progress in the traditional way. Our patients require consistent monitoring and assistance by trained caregivers during all meals/snacks to ensure safety and to decrease risk of choking/aspiration.

OGC provides a training model for Direct Support Professionals (DSPs). Our DSPs are the frontline workers that work diligently with our patients on a daily basis. DSPs provide support, companionship and dedicated, compassionate care. When MT Instruction Plans are written, our DSPs are trained to assist individuals appropriately during all meals/snacks. The DSPs are integral to mealtime/swallowing safety and risk prevention. Staff/Caregivers typically note and report changes/decline in swallowing skills, as they know our individuals the best. We rely on our dedicated support staff to monitor for s/s that may present while eating meals/snacks.

A MATTER OF TASTE : OGC RECOMMENDED TEXTURE/VISCOSITY GUIDELINES

REGULAR

This diet consists of all foods (with needed alteration). Foods should be cut into ½" to 1" pieces. This diet is for individuals with good chewing skills.

SUB FOR HARD TO CHEW

This diet consists of foods that are mostly regular consistencies, with the exception of very hard, sticky, or crunchy foods. Foods should be in ½" pieces or smaller. All foods on a mechanical soft diet are allowed on this diet. This diet is for individuals with compromised chewing abilities.

MECHANICAL/SOFT WITH GROUND MEATS

This diet consists of foods that are moist and soft. Meats are ground or minced to pieces 1/8 or smaller. All other foods are chopped into ¼" pieces or smaller and moistened. All foods on a pureed diet are allowed on this diet. This diet texture is for individuals with mild to moderate dysphasia and requires some chewing ability. Individuals need to be assessed for tolerance of mixed consistencies.

GROUND MECHANICAL/SOFT

This diet consists of foods that are moist and soft. All foods are ground/minced to 1/8" pieces. All foods on a pureed diet are allowed on this diet. This diet texture is for individuals with moderate dysphagia that demonstrate decreased to absent chewing skills, but with some oral prep present. Individuals need to be assessed for tolerance of mixed consistencies.

PUREED

This diet consists of pureed foods. The food should have a smooth, pudding-like consistency and should contain no lumps. This diet is for individuals with moderate to severe dysphagia. Close or complete supervision is required when an individual is on this diet.

- **Thin/Regular:** All beverages allowed with no modification
- **Nectar - Liquid (after being thickened):** Coats and then drips off the spoon.
- **Honey - Liquid (after being thickened):** Flows off the spoon in a ribbon (like honey).
- **Pudding - Liquid (after being thickened):** Stays on the spoon

SETTING THE TABLE : A DYSPHAGIA CASE STUDY

JD is a 50-year-old man with Down syndrome. JD has been a group home resident since he was 22 years old. He enjoys watching Alabama football games, working at his recycling job, and looks forward to going to summer camp with his friends.

While watching television one night, JD choked while eating supper. His best friend and DSP performed the Heimlich Maneuver successfully and JD spit up an unchewed bite of pizza crust. Before JD could be seen by his PCP, he spiked a fever and started having difficulty breathing. He was admitted to the hospital with a diagnosis of aspiration pneumonia.

While in the hospital, JD was temporarily placed on a ventilator to assist with breathing (while being treated with medication). Following ventilation removal, JD underwent a Modified Barium Swallow Study (MBSS). JD tolerated ingestion of different food textures and liquids with barium mixed in, so that his oral prep and swallow function could be observed via x-ray (fluoroscopy). In the summary, collaborated on by the hospital SLP and radiologist, JD is noted to demonstrate decreased oral/motor preparation skills, including decreased tongue range of motion, absence of chewing. In addition, JD demonstrated multiple instances of trace penetration (with coughing/clearing) leading up to one instance of aspiration while drinking thin liquids. The SLP made discharge recommendations for Mechanical/Soft foods and Nectar-thickened liquids.

Once discharged from the hospital, staff filled out a referral for me to complete a chairside Clinical Swallowing Evaluation (CSE) to develop a mealtime instruction plan and complete additional training with staff.

During chairside, I completed a background/history with staff (ex-house manager/DSP(s)/work site staff/etc). Staff reported that that JD has had changes in cognition/understanding, increased frustration, and new challenges while completing Activities of Daily Living (ADLs). JD loves to eat Krystal hamburgers, but prior to choking incidence, he had started overstuffing his mouth, forgetting to chew, and coughed/cleared frequently while eating/drinking. Staff further reported that they have been helping him more with the task of eating – providing reminders to keep eating, guided tactile assistance (due to fatigue), and verbal cues to not overstuff mouth. During the examination of the oral/motor function, I noted that JD is missing several teeth, including molars, and has poor oral hygiene. He had oral residue around gum lines and pocketed in both cheeks. When asked to complete simple exercises with tongue/lips, JD was unable to follow simple commands with full model provided by SLP, instead he smiled his big smile and said “I love you.” Since MBSS showed aspiration with Thin liquids, Nectar-thickened liquids are trialed (with proper viscosity thickening demonstrated/discussed).

Thickened liquids provide better control of the liquid in your mouth. The thickened viscosity helps to slow down the flow rate of liquids, which lessens the chance of liquid going into your airway or “going down the wrong pipe.” As previously discussed, liquids that go into your airway end up in your lungs.

During food trials, the goal was to determine appropriate alteration of Mechanical/Soft foods. While trialing different sizes of foods, I was looking at how to create future choking/aspiration risk prevention for JD.

After JD chose a soft breakfast bar and pudding, he was given ¼” chopped pieces and asked to finger feed 1 piece at a time. JD attempted to overstuff his mouth and held food in his mouth while waving at his house manager and saying “Hi.” JD was provided with redirection (verbal/visual prompting) back to the task of eating. Observed chewing was minimal to absent with some mashing to roof of mouth with tongue, as well as some tongue thrusting observed. After swallowing, SLP used flashlight to look in JD’s mouth and there was moderate oral residue observed in both cheeks, on roof of mouth, and around gum lines. JD was encouraged to use his tongue to clear; however, he could not follow the command. JD was encouraged to take a sip of liquid to aid in further clearing oral cavity. JD was unable to self-monitor size of drink and he gulped a too large drink and coughed immediately. Due to increased risk for aspiration, straw sips are not recommended; however, the SLP recommends using a cut-out “nosy” cup in order to promote neutral head position (rather than throwing head back/gulping). SLP further recommended pouring small amounts of liquid in cup at a time (replenishing throughout meal) to aid in smaller sips. SLP educated caregivers about the need for small and frequent sips to aid in clearing oral residue and in creating a good digestion pattern.

JD then trialed the breakfast bar (ground up into 1/8” pieces) with added milk to further moisten crumbly texture. JD held the bite in his mouth (while looking around office) before demonstrating typical pattern of decreased oral preparation (mashing/munching). After swallowing, SLP observed oral cavity with flashlight once more and oral residue was present, but minimal. When cued to take a sip of his drink, JD was able to clear oral cavity with the liquid wash. JD’s decreased chewing combined with the further altered (i.e. “chewed”) texture was safer and more appropriate when paired with JD’s existing risk factors. SLP determined that texture recommendations and implementation of MT Instructions with compensatory strategies will likely promote safety and wellbeing.

The SLP asked additional questions about JD’s preferences, additional risk factors, caregiver’s typical level of assistance. The SLP provided additional education on possible continued decline/maintenance goals.

Since JD loves Krystal hamburgers, special preparation (of his preferred food) was discussed. The SLP further recommends JD’s involvement (so he can see that although it looks different, he is still getting the Krystal burger and condiments he enjoys).

JD’s Mealtime Instructions Plan was developed during the appointment. Staff completed a written test and was trained to appropriately assist JD during all meals/snacks. SLP sent all the results to JD’s PCP, along with a texture clarification order. SLP placed JD on caseload for mealtime/swallowing monitoring/intervention strategies/training. JD will have a follow-up MBSS in a few months to determine improvement/maintenance/deviation of baseline skills.

NO THANK YOU : HIGH RISK CHOKING FOODS

- Bacon
- Meat
- Breads
- Corn
- Dry Crackers
- Doughnuts
- Dried fruits
- Fried foods
- Granola
- Hard/sticky candy
- Hot dogs
- Ice cubes
- Sandwiches
- Peanut Butter
- Nuts/seeds
- Popcorn
- Raisins
- Raw vegetables
- Refried beans
- Vienna sausages
- Whole grapes
- Gummy candies
- Rice
- Cornbread

At OGC, we have the unique position of taking care of our individuals for the whole lifespan; several of our patients have been students in the school program and then transitioned into various adult programs. Having the same patients for years is an opportunity that provides us with the ability to notice changes in baseline mealtime/swallowing skills and to provide additional strategies and intervention.

Speech Language Pathologists (SLPs) have extensive knowledge of anatomy, physiology, and functional aspects of the upper aerodigestive tract for swallowing and speech. In addition, SLPs have expertise in all aspects of communication disorders that include cognition, language, and behavioral interactions, many of which may affect the diagnosis and management of swallowing disorders. Because of the complexities of assessment and treatment in most persons with swallowing disorders, SLPs work collaboratively with other professionals, individuals, families and caregivers. Interprofessional practice (IPP) is critical to successfully achieving the desired improvements and outcomes.[5]

During speech therapy/mealtime safety monitoring appointments, the goal is to observe each individual in a comfortable and typical setting with safe mealtime/swallowing skills being carried out consistently. SLPs consider health and safety, patient/caregiver report, risk prevention and quality of life while striving for the safest and least restrictive texture/viscosity recommendations. At OGC, we use MT Instructions plans that are unique to each patient served by our department. During ongoing appointments, it is typical to revise plans of care and manage maintenance (or decline) of baseline mealtime/swallowing skills.

Additional suggestions/precautions may include:

- *Provide calm/clear directives that are consistent and in context.*
- *Empathy matters.*
- *Limit background noise/distractions*
- *Provide assistance with correct positioning (encourage upright position at 90 degrees, hips should be straight/level and to the back of the chair (or wheelchair)*
- *Provide support for arms and feet (ex. small footstool, pillows or block supports)*
- *Provide adaptive mealtime equipment*
- *Have knowledge of high-risk choking foods*
- *Being aware of sensory processing overload*
- *Be aware of decreased self-monitoring, impulsivity (ex. grabbing inappropriate foods from peer's plates)*
- *Assist with good oral hygiene/check for oral residue around gum lines, on roof of mouth, under tongue, and in cheeks. If patient is unable to adequately clear with tongue or by swishing liquid; while using a flashlight, gently use a moistened soft toothbrush or toothette swab to clear oral residue.*

TOOLS OF THE TRADE : EQUIPMENT & THICKENERS

www.simplythick.com

www.pamperedchef.com

www.ninjakitchen.com

www.thickit.com

www.arktherapeutic.com

See more adaptive equipment resources at
https://swallowingdisorderfoundation.com/adaptive-feeding-devices

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BOOK EXCERPT: PART II OF II

HONEST MEDICINE:

The Ketogenic Diet for Epilepsy

Author's Note: *In Part 1, November, 2020* EP Magazine, *you learned how Hollywood writer/director Jim Abrahams' son Charlie was saved from suffering with almost constant seizures – as well as from a cocktail of mind- and body-altering anticonvulsant medications – by the Ketogenic Diet. This life-changing experience led Jim and his wife Nancy to found the Charlie Foundation, through which they educate medical professionals, parents, and patients throughout the world about the diet. In Part 2, you will learn the "rest of the story."*
Jim's chapter was taken from Julia Schopick's book, HONEST MEDICINE: Effective, Time-Tested, Inexpensive Treatments for Life-Threatening Diseases. *It has been updated for EP Magazine by Jim and Julia.*

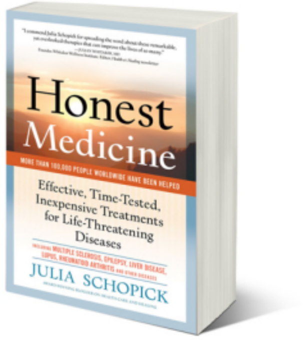
CHAPTER 7

JIM ABRAHAMS: CHARLIE'S DAD, DIRECTOR OF THE CHARLIE FOUNDATION

Because the diet had been in existence for so many years, we began to hear from other families who had had success with the Ketogenic Diet. One of the stories that was particularly dramatic occurred in 1975. Connie Intermitte wrote us about how her then four-year-old son Tim had gained seizure- and drug-freedom with the diet – but not until her family was forced to go through incredible measures. With her permission and input, in 1997, we made an ABC television movie, "First Do No Harm," starring Meryl Streep. Millions watched (https://youtu.be/HyeC9IiFKpw) Our goal was to spread the word about the Ketogenic Diet. An unintended consequence was that Connie's story and Meryl's incredible performance empowered so many to take control of their own children's medical destiny.

At the same time, we worked through the scientific and medical communities in an effort to facilitate research into the diet's mechanisms and knowledge of its application. To that end, we sponsored meetings among physicians and dietitians and helped support research.

We have held, and continue to hold, educational events for professionals, from our first seminar in September 1995, which was attended by over 100 neurologists, dietitians and nurses, to the first, third, and fifth Global Symposia on Dietary Therapies for Epilepsy and Other Neurological Disorders in 2008, 2012, and 2016.



Title: **Honest Medicine: Effective, Time-Tested, Inexpensive Treatments for Life-Threatening Diseases**

Author: **Julia E. Schopick**

Publisher: **Innovative Health Publishing**
Publication Date**: January 2011**
Paperback: **310 pages**
ISBN-13: **978-0982969007**
Available at: amazon.com and www.barnesandnoble.com

Awareness ticked dramatically upward. Other parents and parent groups began to spring up around the world. Other families came forth with their success stories.

In 2006, Beth Zupec-Kania, RD, CD, who had been working with the Ketogenic Diet since 1993, joined the Charlie Foundation. Thus far she has trained over 300 hospital personnel and 40,000 professionals globally in this therapy. She has also developed ketodietcalculator, a professional app for computing meal plans, which has over 50,000 subscribers worldwide.

Matthew's Friends, a sister organization in England, began in 2004 when Emma Williams' son Matthew was finally offered the diet, six years after she saw "First Do No Harm," and began asking for it. He attained over 90 percent seizure reduction. But by then Matthew had experienced substantial, irreversible brain damage from the years of pummeling by seizures and drugs.

Blogs, chat rooms, and other support groups have sprung up worldwide.

The diet itself has been refined in terms of initiation, reduced adverse effects, and palatability. As doctors and dietitians implemented the diet over the years, they developed pre-diet screening procedures to ensure safety and rule out metabolic contraindications, as well as side effects that would interfere with efficacy. Hospitals have developed a team approach in which neurologists, dietitians, nurses, and pharmacologists collaborate on the diet as it is applied to each new patient. Dietary supplements have been added prophylactically to ensure nutritional adequacy and to prevent constipation, the most common adverse effect of the diet. Two new versions of the diet were developed – the Low Glycemic Index Treatment and the Modified Atkins Diet – less restrictive diets for older children and adults. New infant formulas have made the diet accessible to infants and tube-fed children.

And, as the diet has grown in awareness, popularity and understanding, it is beginning to be used with other neurological disorders. Some patients with ALS, early onset Alzheimer's disease, Parkinson's disease, and certain cancers including malignant brain tumors have improved dramatically with the Ketogenic Diet.

Our progress was summarized in a June 17, 2009 article published in *The Journal of Child Neurology*:

STAYING POWER: Charlie *(left)* with parents Nancy and Jim Abraham; and with Meryl Streep *(above)* at the 2012 Global Symposium on Dietary Therapies for Epilepsy and Other Neurological Disorders. "Beyond promoting public and medical awareness of a therapy that fits like a square peg in the round hole of Western medicine, The Charlie Foundation has an added message. Today, among our top priorities, is empowering parents with the information they need to trust their instincts and battle for their children."

> *"The past 15 years have witnessed an enormous growth of interest in the ketogenic diet. At this writing, a PubMed search indicates that nearly 750 peer-reviewed articles on the ketogenic diet have been published since 1994. In 2006, symposia at both the International Child Neurology Association and Child Neurology Society annual meetings were the first sessions ever held devoted solely to the ketogenic diet. In April 2008, a 4-day international conference devoted to the use of dietary treatments brought 270 attendees to Phoenix, Arizona. The ketogenic diet is now available in over 50 countries, in all continents except Antarctica. As a direct result of this growing interest, an expert consensus guideline was commissioned by The Charlie Foundation, written by 26 neurologists and dietitians from 9 countries, endorsed by the Child Neurology Society, and published in Epilepsia in November, 2008. This consensus guideline was designed not only to suggest the optimal management of children receiving the ketogenic diet but also to highlight aspects of dietary treatments that were unclear and potentially areas of future research."*
>
> – Dr. Eric Kossoff, Beth Zupec-Kania, RD, Dr. Jong Rho

One year earlier, in 2008, Dr. Helen Cross from Great Ormond Hospital in London published a Class 1 randomized double-blind study concluding: "42 percent of children with epilepsy who were following a Ketogenic Diet for three months had a greater than 50 percent reduction in seizure frequency with 19 percent reporting a reduction in seizures of 75 percent or more."

The science has continued to document the reality. According to a 2016 Cochrane Review of Ketogenic Diets' Efficacy, "We identified 11 randomized controlled trials (RCTs) that generated 15 publications. The 11 studies recruited 778 patients; 712 children and adolescents and 66 adults. Reported rates of seizure freedom reached as high as 55% in a classical 4:1 KD group after three months and reported rates of seizure reduction reached as high as 85% in a classical 4:1 KD group after three months."

Today, there are over 275 hospitals worldwide with Ketogenic Diet programs. The Charlie Foundation has sponsored and run numerous Ketogenic Diet seminars and training programs, and has contributed to many books about the Ketogenic Diet for epilepsy, as well as for other conditions. Our website, **www.charliefoundation.org** is a comprehensive source of Ketogenic Diet resources, including medical opinions, a list of Ketogenic Diet FAQs, keto centers, diet implementation, recipes, other families' stories, and chat rooms.

Most importantly, thousands of children have gotten better.

So, I don't want this chapter to read like I'm some angry parent who's still grinding his axe 27 years later. Every day we are overwhelmingly grateful for getting Charlie back, and every day we are overjoyed to hear from other parents who have now had the same experience, in part because of Charlie.

But sadly, as I write this chapter, the Ketogenic Diet for epilepsy remains woefully underutilized. The disconnect between good health and other powerful influences in Western medicine is blatant. The billions being made annually by pharmaceutical and medical device companies; the additional billions being pocketed by the sugar and processed foods industries; the reluctance of insurance companies to reimburse hospitals for Ketogenic Diet trained nutritionists; hospital systems that profit handsomely from surgeries, tests, devices and medications but make no money from Ketogenic Diet therapies; as well as physicians who are not taught about diet therapies all work in concert to obscure this information.

PHOTOS PROVIDED BY JIM ABRAHAMS

In 2008, medical guidelines were published advocating that the "Ketogenic Diet should be strongly considered after the failure of two or three medications regardless of age or gender." This was considered a giant step forward for a therapy that had been largely considered a "last resort." In a second version, published in 2018, they changed the wording to "after the failure of two medications regardless of age or gender."

But it's not enough. Just imagine how many millions of lives would have been improved, even saved, if physicians were willing to share two uncontested facts:

Fact 1: *After the failure of a first anti-epileptic medicine there is a 13% chance a second will stop a person's seizures and a 1% chance a third will have this effect.*

Fact 2: *The Ketogenic Diet reduces seizures by at least 50% in over half the people who try it and eliminates seizures completely in 20%.*

Both facts are as true in 2020 as they were in 1993 when Charlie first got sick.

What is the point of real evidence-based medicine when the evidence is ignored? What happened to "...first do no harm?"

I have great admiration for anyone who would choose to spend his or her life helping children with neurological disorders. Pediatric neurology is very low on the "glitz scale"; it's toward the bottom of the medical specialties list in terms of financial rewards; the responsibility and dedication must feel overwhelming. The neurologists and epileptologists on the Charlie Foundation's scientific advisory board, as well as so many others I've met over the years, are among the most dedicated people I know.

So I do not feel that what happened to Charlie and countless other children like him is due to any one, or a handful, of practitioners. As I mentioned earlier, our health care system frequently rewards tests, procedures, and medications rather than patient outcomes. Dietary therapy, though successful, is time intensive and does not generate revenue. What may be news to many is that physicians are not taught about nutrition, or dietary therapies during their formal training.

Charlie's primary neurologist, Dr. Donald Shields, was incredibly candid when he was asked on "Dateline NBC" about Charlie and the Ketogenic Diet:

Dateline NBC: "Why are modern doctors ignoring this diet? Charlie's own doctor has a surprising answer."

Dr Shields: "There's no big drug company behind the Ketogenic Diet and there probably never can be unless somebody starts marketing sausage and eggs with cream sauce on it as a drug."

Dateline NBC: "You're saying that, in a sense, one of the reasons that the Ketogenic Diet is not popular at this point is that there's not a big drug company behind it selling it to the doctors?"

Dr. Shields: "I think that's probably true. I hate to say that. But I think that's probably true."

(*The entire interview can be seen on our website at* **www.charliefoundation.org**)

So, beyond promoting public and medical awareness of a therapy that fits like a square peg in the round hole of Western medicine, The Charlie Foundation has an added message. Today, among our top priorities, is empowering parents with the information they need to trust their instincts and battle for their children. There is a tendency when we walk into a doctor's office to want to hand over our problem and say, "Here it is; please fix it." It's comfortable, it's easy, and more often than not, it works. Just as we take comfort in deferring to them, many doctors are unwilling to confide in us that we may have stepped into one of Western medicine's black holes. Clearly, most children with difficult-to-control seizures have stepped into one of them.

What does this mean? It means that our medical problems and our children's medical problems are precisely that – ours. At first, that's a pretty intimidating and perhaps a seemingly foolish concept, both to us and to some physicians. After all, they went through years of education. They've seen countless patients in their practices. And then we walk into their offices with a disease we probably don't even know how to spell. How presumptuous and perhaps foolish of us, the parents, to ask and then pursue the hard questions, learn the side effects, get the second opinions, do the research, and participate in an informed joint decision with our doctors – in short, to become proactive. Ironically, the "side effect" of participating in our own medical destinies and those of our children may not only lead to getting better sooner. It is also empowering. Though I would do almost anything to go back and have Charlie not suffer epilepsy, the experience has been empowering. Regardless of whether responsibility for informing ourselves confirms what we learn from our physicians, it's nevertheless empowering to become informed.

We take control of so many lesser issues in our families' lives – meals, bedtimes, TV hours – why not have that same attitude with the most important issue, our families' health? In the worst case, we have learned something new; in the best case, we have improved both our lives and the lives of our children. Isn't that each of our ultimate missions?•

[The following comment is by Julia Schopick, in whose book Jim's story appears:
"I am frankly in awe of Jim for his years-long, day-in-and-day-out dedication to helping parents who want the diet for their children to get it. Jim has read letters to me from parents who were told – wrongly – by their doctors that the diet would not work for their children, and that even if it might work, it would be just too difficult to administer. Jim helps each and every parent he can help – even though it brings back such painful memories for him – and even visits many of these children. And in several instances, especially in cases where the diet is being administered incorrectly, he calls hospital personnel to help them get on the right track. Without Jim, I am positive the diet would have died. Without Jim, millions of people with conditions ranging from cancer and many neurological conditions would never have heard about the Ketogenic Diet – not to mention the millions of weight-conscious people who are on the diet today."]

ABOUT THE AUTHOR:

Julia Schopick is the creator of the award-winning blog, HonestMedicine.com, and has been a published writer and a public relations consultant for more than thirty years. When her husband Tim Fisher became ill in 1990 with a cancerous brain tumor, Julia became his medical advocate and began writing on topics relating to health and medicine. Her articles and columns were published in *American Medical News* (the AMA publication), *SEARCH* (the newsletter of the National Brain Tumor Foundation) and *Alternative and Complementary Therapies.* Her work and essays have been featured in the *British Medical Journal, Modern Maturity* and the *Chicago Sun-Times.*

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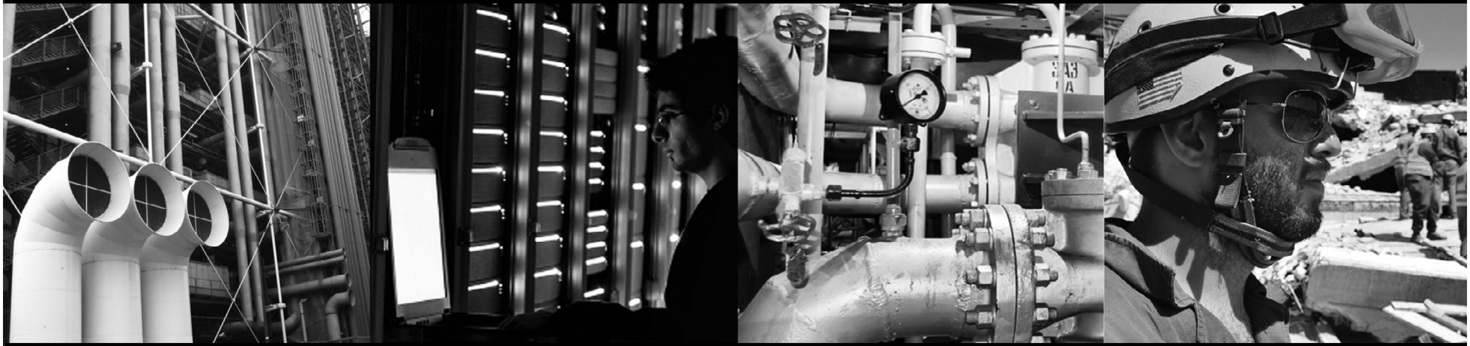

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WOMEN'S HEALTHCARE

AN OUNCE OF PREVENTION

BY VINCENT SIASOCO, MD, MBA

The disparity in health risks and outcomes between people with I/DD and those in the general population is accounted for, at least in part, because individuals with I/DD face multiple barriers to receiving quality healthcare within their communities.

HEALTHCARE IN THE NEW NORMAL

As we settle into the new normal, health care facilities need to navigate a means to continue providing necessary clinical services in the safest way possible. State and federal agencies took steps to make it easier for health centers to provide telehealth services, which allows for safer provision of care. Health centers need to change the way they triage and evaluate care for patients to ensure appropriate use of telehealth and in-person visits. Many preventative care services that were put on hold during the height of the pandemic must now be addressed to ensure non-COVID medical issues are addressed. For example, women's healthcare and cancer screening need to be maintained in order to prevent serious disease from developing.

WHAT IS PREVENTATIVE CARE?

Preventive care and counseling help manage health and detect or prevent issues before they become significant. According to the U.S Preventive Services Taskforce, "preventive services, such as screening tests, counseling services, and preventive medicines, are tests or treatments that your doctor or others provide to prevent illnesses before they cause you symptoms or problems." Prevention activities are mainly categorized by the following three definitions:

- **Primary Prevention** is meant to intervene before health conditions occur. This is done through vaccinations, proper nutrition, exercise, and avoiding risky behaviors and substances known to be associated with a disease or health condition.
- **Secondary Prevention** include screenings to identify diseases in the earliest stages, before the onset of signs and symptoms, through measures such as mammography and regular blood pressure testing.
- **Tertiary Prevention** involves managing a disease after its diagnosis to slow or stop disease progression through treatment, rehabilitation, and monitoring for other complications.

Primary and Secondary Prevention in Women's Healthcare is crucial. Cancer is the second leading cause of death in the United States, exceeded only by heart disease. One of every four deaths in the United States is due to cancer. The American College of Obstetrics and Gynecology recommends cervical cancer screening start at the age of 21 years. Women of average risk of breast cancer should be offered screening mammography starting at age 40 years.

ILLUSTRATION COURTESY STUDIO G STOCK

Although individuals with intellectual and developmental disabilities (I/DD) have similar rates of breast cancer and cervical cancer compared with women in the general population, women with I/DD have higher cancer related mortality and lower screening rates. According to several studies that researched cancer screening rates among women with disabilities, breast cancer screening rates ranged from 67% to 79% among women with disabilities and 70% to 83% among women without disabilities. Cervical cancer screening rates ranged from 77% to 82% for women with disabilities, and 83% to 87% for women without disabilities.[1] The type of disability also affected screening rates. For example, breast and cervical cancer screening rates were found to be lower among women with intellectual and developmental disabilities, cognitive disabilities, and multiple disabilities than among women with other disability types. Breast cancer and cervical cancer are both very treatable when detected early. Therefore, increasing screening rates among women with I/DD is extremely important.

BARRIERS AND CHALLENGES

The disparity in health risks and outcomes between people with I/DD and those in the general population is accounted for, at least in part, because individuals with I/DD face multiple barriers to receiving quality healthcare within their communities. Healthy People 2010 and Closing the Gap, both stressed the importance of eliminating health disparities for people with I/DD, especially through enhancing access to primary care and prevention. In order to avoid health risks and maintain a healthy lifestyle, persons with I/DD and those that care for them need to receive information and have access to care that will empower them to better understand and manage their health.

Assumptions/ Education: Because of the lack of understanding, some providers or caregivers may not feel certain screenings are warranted, such a cervical cancer screening, as the risk factors may not apply to those with I/DD. Parents or caregivers unaware of their own needs for preventative care may not then be able to advocate for those they care for.

Communication: Critical preventative information (as simple as healthy nutrition and exercise) is often not provided due to healthcare providers' inability to engage I/DD patients in their own healthcare.[2] This inability to successfully engage patients may be due to poor communication between patient and provider. Challenges may occur when a provider is faced with a patient with I/DD who may be non-verbal, dysarthric, or utilize a communication device. Lack of information may be an issue if the accompanying caregiver isn't knowledgeable about the patient or doesn't act as their advocate.

Behavior: Routine medical visits can be particularly stressful for patients with I/DD and especially for those who have co-occurring mental health conditions. As a result, patients who are unable to communicate their discomfort may present as difficult and uncooperative. For a provider inexperienced in working with this population, this behavior can result in frustration and negatively affect the patient's clinical experience. Due to the lack of communication, the provider may also fail to provide critical information that is necessary to promote healthy behaviors and reduce the patient's risk of chronic medical conditions.

Physical/Equipment: Despite the enactment of the American with Disabilities Act (ADA), many healthcare facilities still lack the specialized equipment and supplies needed to accommodate a wide range of patient function and ability. This lack of appropriate equipment, such as height adjustable exam tables – and support staff and inadequate training – combine to create significant access problems for people with disabilities. For example, one report revealed women who are unable to stand for 10 minutes or climb 10 stairs are far less likely to have received a Pap smear in the last three years (63.3% compared to 81.4%), and also less likely to have received a mammogram in the last two years (45.3% compared to 63.5%).[3] Another report found that a third of all women surveyed reported being denied services at a doctor's office solely based on their disabilities and 56% reported giving birth at a hospital that did not have specialized equipment to accommodate their disabilities.[4]

All these barriers and others can negatively affect a patient's relationship with a primary care provider. Research has shown that patients who do not have an ongoing relationship with a primary care doctor had more frequently missed appointments, were less likely to receive preventive care, and had worse overall health outcomes.

OVERCOMING BARRIERS

Even prior to the pandemic, preventative care for women with I/DD has always been a concern and a challenge. However, despite the barriers, there are ways to overcome them. For the provider, understanding the patient's needs, disabilities, and support is key. It is important to prepare for the visit ahead of time, taking into consideration mobility issues and/or potential behavioral concerns. This allows providers to ensure that any necessary equipment and support staff are available during the visit. It is also important that provider schedules are flexible enough to allow for longer visits when needed. One of the biggest challenges is managing appropriate follow-up. For example, following up on mammogram referrals is important, especially since these screens can be challenging for some women with I/DD to successfully complete. Educating patients on what to bring to each visit (medication lists/pertinent outside contacts, etc.) and asking about any special needs when calling to confirm appointments can make visits more successful.

SUMMARY

Benjamin Franklin famously stated, "an ounce of prevention is worth a pound of cure" in reference to Boston's fire prevention methods that he observed during in a visit to the city in 1733. This quote is of course applicable in many different situations. Ensuring that women with I/DD are educated about preventative care screening is crucial. Providers, patients, and caregivers all need to work together to ensure we can prevent any future "fires" from occurring with our underserved population.•

ABOUT THE AUTHOR:

Vincent Siasoco, MD, MBA, Family Physician is the Chief Medical Officer at Metro Community Health Centers; Assistant Professor, Department of Family Medicine and Pediatrics at Albert Einstein College of Medicine at Montefiore; Board Member, American Academy of Developmental Medicine and Dentistry; Board Member, Mercy Home, Brooklyn, N.Y.; Chair, Special Olympics New York Health Advisory Council; Co-Chair, Cerebral Palsy Associations of NYS Medical Director's Council.

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A Lucky-Finer can grasp anything that is within their vicinity, but, more than that, they will tell you that they also have the unique ability to reach for the stars.

FEARFULLY AND WONDERFULLY CREATED

BY CARL LANGE, MD

Roger: I'll take Human Anatomy for one thousand.

Host: Symbrachydactyly.

Roger: What is an upper limb disability?

Host: Correct for one thousand dollars.

BZZZZ... pause.

Host: I'm sorry. Our judges cannot accept this answer as the community over at the Lucky Fin Project would take exception to the term "disability."

So, before I would urge Roger to engage his attorney and file suit against the game show, my best advice would be for him to get a plane ticket to Royal Oak, Michigan to see exactly what is going on there. This is the birthplace of the Lucky Fin Project.

In 2007, Molly Stapelman gave birth to her beautiful daughter, Ryan. Healthy in every way, Ryan was also born with the unique condition called *symbrachydactyly*. This is a rare congenital condition which affords its inheritors a single upper extremity disparity. Typically, on the affected hand, the fingers are abnormally shortened, webbed, or conjoined. The underlying anatomy, including bones, joints, muscles and nerves are also affected, causing functional disparities as well. A spectrum of presentations includes anything from a functional thumb and no fingers, or nubs to a functional thumb and little finger only. Several causes are theorized, including disruption of "normal" development in the womb, exacerbated by lack of blood flow.

I am reluctant to use words like normal, abnormal or disability, particularly around the folks involved in the Lucky Fin Project. After the initial shock of realizing that their daughter had a limb

TEN FINGERS ARE OVERRATED: Lucky Fin CEO/Founder Milly Stapelman with daughter Ryan. Ryan entered the world with an unexpected hand difference. The growth of her right hand had been stunted, her palm small and no fingers except a tiny thumb.

PHOTO COURTESY LUCKYFINPROJECT.ORG

disparity, Molly and her husband Dan discussed their fears and the "what ifs". What if she can't play the same games as the other children? What about the monkey bars, the piano, or throwing a ball?

Believe it or not, that tipping point discussion between Molly and Dan took a grand total of 20 minutes before they cold-turkey dropped the discussion, embraced their uniquely created daughter and embarked on their beautiful and wonderful journey toward the Lucky Fin Project.

Molly and Dan founded the Lucky Fin Project in 2010. As published in their Mission Statement: “The mission of the Lucky Fin Project is to celebrate, educate, support and unite families and individuals with limb differences.” The name of the organization was born out of the Walt Disney movie Finding Nemo whose main character, a clownfish named Nemo happened to be born with a foreshortened fin, which he referred to as his “lucky fin”. Despite the “fin disparity” (Symbrachy-fin-dactaly maybe?), the courageous fish defies all odds in the expanse of the ferocious ocean and achieves far more than his protective father would ever imagine. Not unlike the extraordinary community of the Lucky Fin Project.

ABOUT THE LUCKY FIN PROJECT

The Lucky Fin Project is a 501(c)(3) nonprofit organization that exists to raise awareness and celebrate children and individuals born with symbrachydactyly or other limb differences. The Lucky Fin Project creates a support network for parents across the U.S. and around the world. It links parents to medical information and resources, provides education on limb differences and hosts events and financially support efforts for children attend specialized camps, obtain prosthetics, and to fund other organizations within the limb different community. Contact CEO/Founder Molly Stapelman at mollysryan@yahoo.com or visit www.luckyfinproject.org Email: luckyfinproject@yahoo.com

But what about the obvious disability, you ask. Mention the D-word around Lucky-Finners and you’ll get an earful. They don’t pity themselves, consider themselves to have a disability, or to have “special needs.” Ironically, they will all celebrate the “special gift” they have received in acquiring their limb disparity. Ask Lucky Finner Angel Giuffria, an award-winning actress and writer. Oh, she also was born without a left forearm. Having roles in *The Hunger Games, FBI: Most Wanted* and *Goliath* to name a few, she considers her limb disparity the physical attribute which inspired her to excel and defy the odds. As an invaluable byproduct, she drew attention to the limb disparity community which caused Hollywood to recognize this diversely unique community in acting, the arts, and music.

Tell Nick Newell, also a member of the Lucky Fin community, that he has a disability and he'll kick your butt. Literally. Nick is a renowned professional mixed martial arts fighter. He has an impressive resume, including multiple victories in the XFC or Extreme Fighting Championships. He won’t mention the fact that he was born without a left hand, but I will. He also doesn’t consider his achievements exceptional. He simply considers it a normal outcome for anyone who works hard. The college educated fighter will explain that he was never on a mission to exploit his limb discrepancy in any way. Rather, he says, “I was on a mission to be the very best version of myself I could be, and anything else that I got out of that was just a bonus.’

So, they sing, they dance, they act, they fight professionally, they play baseball, and even play the violin. What they don’t do is engage in self-pity. Their general attitude is one of confidence, basking in the knowledge that they are natural problem-solvers. They’ll be the first to tell you that they get more out of life than you do.

“I praise you because I am fearfully and wonderfully made; your works are wonderful, I know that full well.” That was King David in his Psalm of praise to his Creator. Whether or not he had a limb disparity or not nobody can be sure. But, what is certain is the fact that each and every member of the Lucky Fin community lives with the sublime truth that they are wonderfully created.

In his dramatic monologue poem Andrea Del Sarto, English poet Robert Browning writes, “Ah, but a man’s reach should exceed his grasp, Or what's a heaven for?”

Yes, a Lucky Finner can grasp anything that is within their vicinity, but, more than that, they will tell you that they also have the unique ability to reach for the stars.•

ABOUT THE AUTHOR:

Dr. Carl Lange is a board-certified surgeon and emergency medicine physician.
He shares his perspectives on being diagnosed with multiple sclerosis and how it has influenced his understanding of patients with special needs, including his own.

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FACIAL EQUITY AND THE LEGACY OF JAMES PARTRIDGE

BY JOHHNY PAYNE

In 2008, the tunnels of the London Underground transportation system were dotted with posters of young people with facial disfigurements.

"Are you only comfortable looking here?" one poster read, directing the viewer to the typical-looking hairline of a girl with a disfigured face. These carefully placed introductions to the young people in the displays were a thoughtful attempt to humanize the experience of disfigurement.

Much has been done in the past 30 years to bring light to the not-often-mentioned social disability experienced by those with facial disfigurements, or "distinguished faces", as author and activist James Partridge describes.

James himself was the victim of a car fire when he was a young man, which left him with a significantly disfigured face. He writes in the latest of his two books, "We (normals).... believe the person with the stigma (me) is not quite human. On this assumption, we exercise varieties of discrimination, through which we effectively, if often unthinkingly, reduce his life chances. We construct stigma theory, and ideology to explain his inferiority and account for the danger he represents… ".

THE FACE OF DISTINCTION: "I live with my very distinctive face with pride." James Partridge died in August.

James passed this past August and leaves behind a legacy of advocacy, framework of empowerment, and insight into the human experience for those experiencing the social stigma of facial disfigurement. James also has to his credit the founding of two charities, Changing Faces and Face Equality International. He has given the past 28 years of his life to campaigning for the equal value of people with "distinguished faces" and for "face equality", a term that he himself coined. He holds an honorary Doctorate, numerous awards, and has been credited with influencing the passing of the American with Disabilities Act and similar legislation in Britain.

In an interview with *EP*, long-time friend Cheryl Gartley notes an event she attended with James later in his career. "Knowing that we were both to meet at the event, James saw me first. He came directly up to me, confidently introduced himself, and kissed me on both cheeks, as is the British tradition. He did not let others' potential perception of him set the stage for his interactions. He decided how he wanted other people to feel about him, and he helped them to feel that way by the way he interacted with them. James was fond of saying, "I live with my very distinctive face with pride."

PHOTO COURTESY CHRIS GEORGE/THE GUARDIAN

COMFORT ZONE: *(Above)* Changing Faces campaigns work toward a society free from prejudice and discrimination and one that respects difference; *(Right)* James Partridge holds a copy of his new book published in June 2020; he called it "a memoir, a manual, a manifesto."

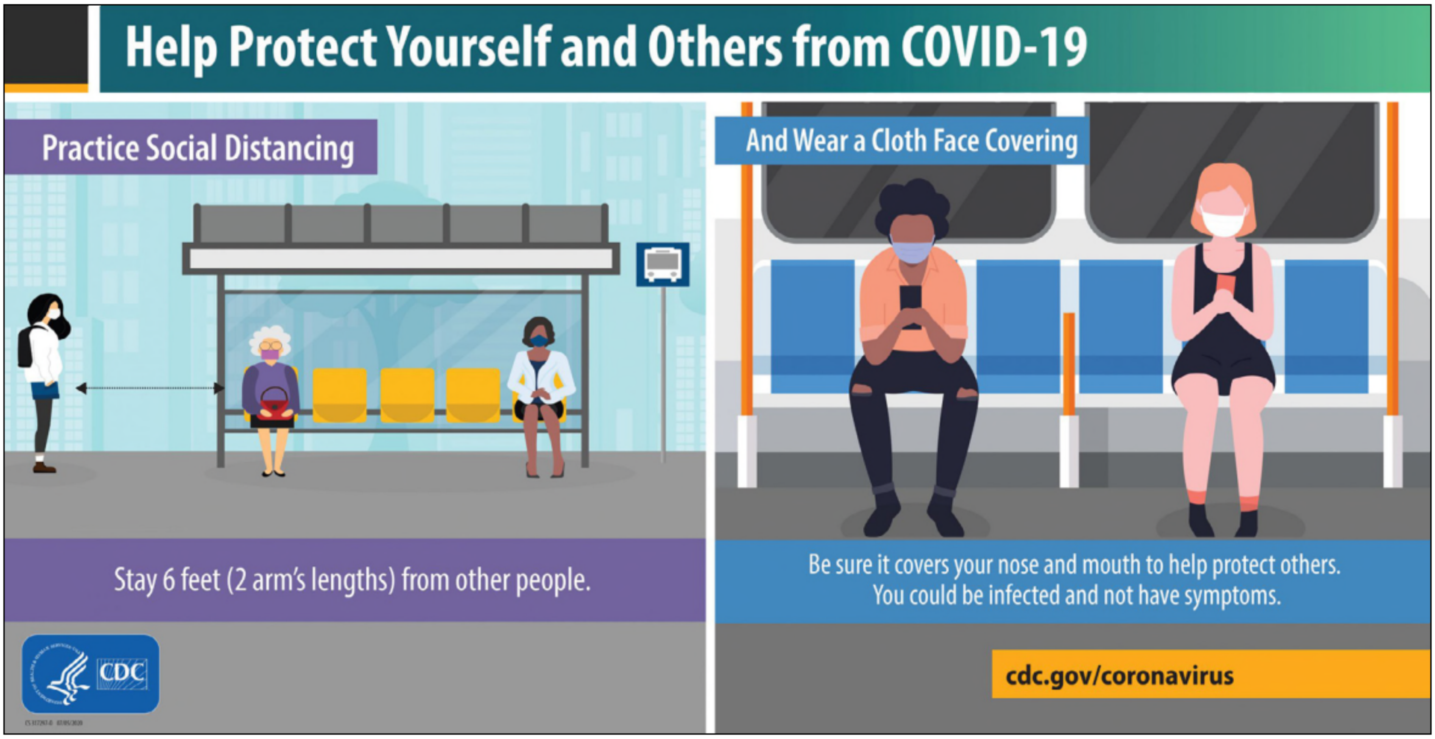
James' second book, *Face It: Facial Disfigurement and My Fight for Face Equality* serves as a biography of his life experience and of his work, but also as a guide to those people and organizations who would desire to learn from his success with advocacy.

His work on this book is incredibly thoughtful, human, and hopeful. It is an eye-opening walk through the stigmatizing experience of being disfigured. It is also an approachable education into our own biases and practices which perpetuate broken systems of value for our neighboring humans.

James sums up the heart of his work in his final book: "Every human face should carry the same value, because each and every one is fascinating and beautifully made and is owned by a person worthy of equal respect. We all need face equality now. Let's make it happen." •

ABOUT THE AUTHOR:

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



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CHOOSE ACTION OVER DISTRACTION

BY ROB WRUBEL, CFP®

The sprint to the end of the year started when we turned back our clocks in November, and it accelerates as we hit Thanksgiving and eat, drink, see family, and open presents before the big celebration on New Year's Eve. Once that first day of the new year date comes, we sit with a sigh, wondering how time moves so quickly.

This year, the noisy and contentious election occupied our brains with too many nights of concern and anxiety pulling us away from the focus we need to plan, enjoy our lives, and take action in areas of our lives we can impact.

It's easy to get distracted from the financial, legal and future planning work we know we need to do. As parents of family members with intellectual and developmental disabilities, we have a lot to do and this COVID-19 year has only increased the pulls on our time, our hearts, and our patience. My daughter attends school virtually and I try to work, prepare lunch, and monitor her ability to follow class all at the same time. Sometimes, it actually works. Other times, it's possible her classroom sees me switching hats from business casual to lunch-chef-Dad t-shirt.

Over the years, I've come to understand that most of what drives success in legal and financial planning has less to do with people having technical knowledge and more to do with their desire and ability to forge ahead even with the crazy, exciting lives we live. I've learned a few techniques that I hope will work for you. You can take steps in all of these before now and the end of the year.

FORGING AHEAD : FIVE STEPS TO TAKE BETWEEN NOW AND THE END OF THE YEAR

1. Find an hour to think

Planning starts at that moment you decide to choose a future different than the life you lead today. Otherwise, it's living from minute to minute or event to event without a strategy or desire to achieve specific goals. Get out your planner or calendar and schedule a block of time to sit, think and write down the dreams you carry around in your head and the goals you have for you and each member of your family. Do this monthly, at least.

2. Engage competent professionals

Not sure where to start? Cannot decide on what planning steps to take? Hire a financial planner or estate attorney to start you down the path. Most likely, you will need both. A planner can help map out a strategy and put an action plan in place to get out of debt, build emergency funds and invest for the future. The attorney will help create estate documents with special needs trust provisions to care for your family upon your passing.

3. Automate savings

Does your company offer a retirement plan? If so, review the percent you contribute to the plan and look to increase it by at least one percent per year until you reach a target level that gets you on track for a comfortable retirement. Do the same with an IRA or Roth IRA if you haven't already. It's crucial to put money away and invest for growth to achieve long-term goals. So many people don't start and lose years of potential growth. Commit to saving before the New Year comes around.

4. Review and reposition regularly

When was the last time you reviewed your investment selections and your financial plan? About the same time that the wheel was invented? Life changes. Investment profiles change. Review your accounts to see if your selections from years ago continue to serve your family.

5. Perfect is the enemy of good

Can't get started? Sometimes, people get overwhelmed and cannot make decisions. Other times, they are afraid of making mistakes. Both happen to everyone, even to those who seem to have it altogether. Almost every mistake can be fixed as you move through life – you can change beneficiaries in your estate plan and move money from one investment to another. Stumble forward and learn as you go.

There's no need to wait for the New Year to roll in to take action. Yes, this time of year is distracting. There are shopping specials from your favorite stores that pop into your email daily and new menu items to prepare.

Enjoy all of that but don't let your pursuit of a good deal or finding a new way to tie a gift bow take you away from the actions needed to create financial freedom. Over time, financial stability and progress towards life goals will bring as much joy as that new sweater. Carve out some time this week to gain momentum going into the new year. •

ABOUT THE AUTHOR:

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

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FAMILY, COMMUNITY AND THE HOLIDAYS

When distance and mobility issues are coupled with learning and developmental differences faced by a grandchild identified with special needs, increasing creative effort and adaptability are necessary for the entire family system.

MERGING MILITARY AND FAMILY THROUGH THE GRANDPARENTING LENS

BY ANGELA SHAW AND REANNA SHAW

Without doubt, military families face challenges and struggles unique to the military life which are not typical to most other families.

In addition to realizing the typical family responsibilities, military service members fulfill obligation to their country requiring a mobile existence beyond that which is customary to civilian families, as well as the extreme real threat of combat.The mobile life of military family is a challenge to grandparenting, but grandparents express tremendous pride in the service to country that their family members provide. Strength, flexibility and resiliency are positive outcomes that we often look toward when successfully transitioning rough terrain. Social connectedness can be hard-won, in the wake of fast-paced and ever-mobile lives. In addition to finding themselves amongst new faces and places every two to four years, grandparents left behind may fade away from the traditional arrangements of the extended family that civilian life naturally provides. Such increased mobility impacts the way grandparents can interact with their military family members, but distance does not have to be the demise of the grandparent-grandchild bond.

The vital connection between grandparents and grandchildren generates potential to strengthen and secure families across generations and into the future. Happiness, security, and family traditions can be some of the positive outcomes of grandparent interaction. A bridge between yesterday and today that has the capacity to propel grandchildren onto their future

PLAYING AND STAYING TOGETHER: Playing and learning go hand in hand. Discovering new games, stories and places together provides opportunities for joy, and a path of lifetime learning.

paths – stocked with wisdoms and perspectives that they can synthesize with tomorrow's promise and discoveries – is realized with such interaction. Grandchildren are the joy, love and purpose that keep them looking toward a bright, happy and relevant life.

As with many transitions in life, a critical variable begins with the natural renegotiation of relationships, in this case, across the extended family system via day-to-day interaction and flexibility. Due to the inherent nature of mobility and distance built into the family life, military grandparents and parents are called to draw upon an innovative and strategic line of thinking in order to construct and maintain close emotional ties across the generations. When distance and mobility issues are coupled with learning and developmental differences faced by a grandchild identified with special needs, increasing creative effort and adaptability are necessary for the entire family system.

Forging deeper connections with grandchildren through an array of today's technologies, such as internet, cell phone and social media, can melt away the miles. Through digital communication tools, grandmas and grandpas can link in and participate in their grandchild's life. Whether tech savvy, a novice to the digital world, or somewhere in-between, grandparents bring strengths, experiences and personality to their quest. A rewarding grandparenting connection can be reimagined and put into action through staying in touch and finding joy in playing together, regardless of the mileage on the odometer.

PORTALS FOR INTERACTION

Many 21st century grandparents have access to a variety of digital devices. Some popular digital tools that can be downloaded on smartphones or computers for video calling, offering a portal for interaction, include Skype, FaceTime or Zoom. Video calling is beneficial for connecting with babies and younger children who are not yet able to chat on the phone. Moreover, older grandkids who use these programs in their day-to-day lives, identify this as an authentic and relevant venue. Grandparents can smile, sing and play with their littles through video calling. Older kids and teens enjoy the interactive platform and delight in teaching grandparents the ins and outs of technology. Through texting, grandparents are offered a dynamic avenue for staying in touch.

Digital applications offer a way to share interests, activities and begin or continue traditions. Good old-fashioned snail mail also builds connections. First and foremost, remaining ever-mindful of developmental readiness and waiting until grandkids are safely able to negotiate an activity or event enhances the experience. Common sense is a helpful guide toward encouraging enjoyment of time together.

The following is offered, to spark the imagination in pursuit of a grandparenthood that provides meaningful connection with grandkids who are part of a military family:

Communication provides the building blocks essential in creating and maintaining positive relationships with grandchildren, whether they take place just around the corner or on a multi-hour flight across the span of an ocean. Through the act of a simple conversation or written expression, grandkids will grow in their ability to understand and navigate their world, as well as effectively express themselves. In addition to acclimating grandkids to a grandparent's voice and learning about one another's perspectives, joys, and challenges, communicating with grandkids can help build vocabulary and language. Remaining mindful of age and developmental aspects while chatting is key. Toddlers and children with language delays may require a little more time for receiving and expressing messages. To support language development and keep things interesting:

- *Use open-ended questions that require more than one word, or a yes or no answer. Visuals, such as pictures or objects, supports receptive language. Incorporating puppets or stuffed animals as talking prompts adds to the fun and playfulness of the conversation.*
- *Model expressive language by expanding upon responses. Provide affirmation and add a detail to bolster vocabulary and expression. For example, after receiving an answer, a grandparent may respond, "You're right, that's a ball. It is a gigantic red ball."*
- *Pretend-play and storytelling are amazing ways to target higher-level language skills. Through pretending, kids experience storytelling and sequencing. Grandparents can ask what is going to happen next or why something happened.*

Playing and learning go hand in hand. Discovering new games, stories and places together provides opportunities for joy, and a path of lifetime learning.

Play actively engages children in the world and builds self-awareness and self-confidence. Play is a great stress reliever and positively influences a child's physical, emotional and cognitive growth through:

1. Gaining physical strength and dexterity.
2. Discovering essential social skills.
3. Building foundational aspects for acquiring math and language-based learning.

When engaging in virtual activities and games, be certain they are developmental and age appropriate. Let the virtual play commence by sharing:

- Yoga stories
- Cooking
- Crafts
- Scavenger hunts
- Read-alouds
- Gardening
- Music

From low-tech to high-tech, grandparents and grandchildren are limited only by their imaginations. Mail-based endeavors in support of virtual encounters, to include postcards, small parcels and photos are vibrant and tangible ways to boost connection.

Connectedness is key to being a part of your grandkids' lives. Sharing family history and stories relevant to heirlooms and pictures creates visual and auditory connection to family and lend deep meaning to memories, traditions and interests:

- *Following extra-curricular and school activity schedules and keeping a calendar of upcoming events can be accomplished through chats with grandkids and their parents. School websites can provide a list of upcoming PTA events or holiday celebrations. Social media often provides opportunities to follow activities.*
- *Keeping up your grandkid's interests provides an abundance of opportunity for connection. Researching and taking virtu-*

RELAXING CHAIR YOGA FOR GRANDPARENTS

Come into your Yoga space. Mindfully approach your chair of choice. Take a moment to inspect your chair, ensuring that it will support your weight while also supporting these dynamic Yoga postures. Seated comfortably, find a space between effort and ease, lengthen your spine (sit tall) and relax shoulders downward away from ears (neck is long). Find your inhale: sipping fresh air in slowly through your nose, fill up your belly with your breath, and notice your front ribcage expand with revitalizing air. Deeply exhale: release all your breath out through your mouth as you take a vocalized sigh. Repeat this cycle of breathing for threerounds before shifting into traditional Yoga belly breathing. Your traditional Yoga belly breathing will welcome air slowly and deeply in through your nose as well as out through your nose. This traditional Yogic way of breathing will continue to focus your breath down into your belly, expanding your front ribcage, and further guiding you into a more relaxed state of being. Moving into this relaxing chair Yoga sequence, continue to practice honing your breath as a complementary element to your Yoga experience.

1. Cat and Cow Flow: 4-8 rounds

Seated on your chair, find your inhale: scooping your chest gently forward and drawing your shoulders gently downward and backward. Feel your heart space expand. When you exhale: while rounding your shoulders, send your belly button gently upward and inward toward your spine (engaging your deep core muscles softly for a moment). Feel the area between your shoulder blades open. Moving through a few rounds of Cat and Cow Flow will help you create more space for your breath as you stretch across your chest and through your upper back. You will also enjoy a dynamic movement along the length of your spine which will help you stretch throughout your core.

2. Shoulder Opening Stretch: 5 full deep breathing cycles

Remain in a comfortable seat, between effort and ease, on your chair. Begin to bring your arms forward of your chest and interlace your fingers. Now flip your palms away from your gaze, round your shoulders, and draw your chin toward your chest. Upon your next deep breath in, you will notice a stretch through your upper back and between your shoulder blades.

3. Heart Opening Stretch: 5 full deep breathing cycles

Move your bottom closer to the front edge of chair. Start to reach arms behind your body, finding the back of chair with your hands. Look forward, take a couple full deep cycles of breathing, and enjoy a nice stretch across your chest.

4. Downward Facing Dog: 5 full deep breathing cycles

Stacking wrists under shoulders (wrists should be a hair wider than shoulders), place your hands down on chair. Lengthen legs behind you and find your Plank position (you will be up on the balls of your feet with your heels lifted toward the sky). Keep lifting up and out of your core to protect lower back. If you feel stable on your chair in your Plank position, then with a slight bend in elbows and in knees, begin to slowly guide hips upward and backward (bend knees enough to lift your tailbone toward the sky and feel a gentle release in your lower back). When you reach Downward Facing Dog, shift weight equally between upper and lower body.

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al tours pave the way for great talks, learning ops, and adventuring.

- *Sharing interests paves the way for future endeavors. Read literature and watch programs that are trending in your grandchild's interest and developmental range.*
- *Creating a family-based social media platform to include grandchildren provides opportunities for family connection across generations.*

An active grandparenting life can add an element of contentment and broaden cognizance. Self-care is a vital component to those who nurture and care for others. Explore opportunities to support relaxation, mindfulness and well-being through Yoga sequences such as the one offered in Spotlight (in this article), or learn a new skill or hobby. In addition to personal fulfillment, providing the priceless treasure of partnership reaps a future holding promise of strengths that will carry grandkids through the joys and challenges of experiencing their best life. •

ABOUT THE AUTHORS:

Angela Shaw is a retired special educator. She synthesizes her diverse education and experience as her publishing focus to provide information to support and encourage families as they navigate the special needs of their children. Shaw's son-in-law is active duty military. She and her husband spend much of their free time adventuring to various PCS locations and enjoying every single possible minute with their son-in-law, daughter, and baby grandson. For Reanna, Yoga has been a constant guide throughout hers and her family's military PCS journey. Reanna graduated from Spira (Breath) Power Yoga, a Washington State Licensed Yoga Career School. Reanna has also earned a 200-hour Yoga Alliance-approved certification. Prenatal and Postnatal Fitness and Yoga Certification from Oh Baby Fitness, an American Council on Exercise-approved program. And a kids (0-4 years) Yoga Certification from Kidding Around Yoga, a Yoga Alliance-approved program.

5. Warrior One: 5 full deep breathing cycles

Come up to standing beside your chair. If you like, hold on to the back of chair with one hand for more support, as Warrior One may challenge your balance. Step one leg back behind you and turn back heel in – then release back heel down on the earth. Take a look at front knee, ensuring that front knee is stacked in alignment with front ankle for safety. Gaze forward, breathe deeply, and enjoy this gentle hip opening stretch while also strengthening your lower body. (Repeat on your opposite side).

6. Forward Fold: 5 full deep breathing cycles

Stand Facing chair. With a slight or generous bend in knees, take a deep exhale, and fold forward. If it feels beneficial to you, possibly brush the top of head lightly down on the seat of chair. Keep lifting up and out of your core and feel the lightness as you protect head and neck from weight-bearing. Drawing most of your weight back into heels (keep knees bent as much as you like) feel a stretch down the back of legs.

7. Warrior Two: 5 full deep breathing cycles

You may want to hold onto the back of your chair with one hand for more support in this pose. From Warrior One, slowly pivot on your back heel, to shift your back toes outward to the side (your back toes will point outward toward the side of your Yoga mat). Look down to check that your front knee is still aligned over your front ankle. Stacking your joints is a good rule of thumb to follow; stacking your joints will keep you safe throughout your Yoga practice. Bring your gaze forward and breath. (Repeat on opposite side).

8. Rabbit Pose: 5 full deep breathing cycles

Continue standing and face chair. Begin to reach arms behind your body, you may find that hands reach each other or you may hold onto a Yoga strap to bridge the gap between hands (a belt, dog leash, or towel can work as a fine Yoga strap). If hands do reach each other, interlace fingers behind lower back. Bend knees as much as needed, take a deep exhale, and fold forward. If it serves you, you have the option of lightly resting the top of head down on the seat of chair. Keep lifting up and out of your core to protect head and neck from bearing any weight. Draw most of your weight back into heels and keep knees bent as much as you like. If you want to feel more sensation, give shoulders a good rinse by drawing hands from lower back upward toward the sky.

9. Seated Pigeon: 8 full deep breathing cycles

Have a seat on chair and cross one leg over the top of other leg. If you would like to deepen this stretch, then bring ankle that is attached to your top leg to rest on top of other leg at thigh. Slow down, breathe deeply, and feel your body relax while opening hips and stretching lower body. (Repeat on opposite side).

10. Chair Straddle with a Shoulder Opening Stretch: 8 full deep breathing cycles

Finishing up in a seated variation – turn to face the back of chair. Legs will straddle the back of chair, giving a nice hip opener at the end of your practice. Get comfortable here. When you're ready, thread one of your arms under chest (palm of hand facing open behind you). Take a few moments to breath and enjoy a gentle stretch between shoulder blades. (Repeat on opposite side).

SHELLY HUHTANEN

One Vote

Jill Escher, the President of National Council on Severe Autism said it best. We need to create a “system for proxy voting that uses the same principles as Conservatorship proceedings.” Adults with autism are “systematically disenfranchised” and stealing their right to vote, including other individuals with severe disabilities, continues to erode the fact that they are people of value in this country.

“Mom, who won? Do we know yet!?” Hayden ran into the living room and jumped into the chair to check out the results of the presidential election. I glanced over, “I don’t think we’re going to know for a while because we are waiting for all the mail-in ballots. It’s amazing that so many people exercised their right to vote this election.” I started to hear Hayden chant, “C’mon Florida!” Confused, I looked over to him curious as to why he’s so interested about this election. He slid over in the chair and told me that in his government class, everyone was given a map and each student needed to predict the winner of each state. Whoever had the best predictions would get a candy bar. I’m still amazed at how motivated my sixteen-year-old can be when a candy bar hangs in the balance.

VOTE OF CONFIDENCE?: Who gets to decide what a person with autism is thinking? Are we only allowed to gauge a person’s expressive language? Why would it be acceptable for a person to deny another person the right to vote? What is their mode of measurement?

The next day after school, I asked Hayden if there were any discussions about the infamous candy bar in government class. With a look of frustration, he shook his head knowing that as the country waits for the results, the candy bar would stay in his teacher’s drawer. As he shuffled his feet out of the kitchen, he looked back, “I can’t wait until it’s my turn to vote. I have friends that just turned eighteen this year and they got to vote.” As his mom, I just had to smile at his excitement about exercising his right to vote. Good for him for understanding what makes our democracy so special.

Then, Broden walked into the room, turned around and ran back upstairs.

“Hayden, do you think Broden should be able to vote even though he has severe autism?” He looked off in deep thought and then answered, “Of course Broden should be able to vote. He’s a U.S. citizen. He can vote when he’s eighteen, can’t he?” Honestly, I hadn’t thought about it before until Hayden expressed his interest in voting in the next election. I told him that I would have to research it because there could be an argument about the severity of his disability. Hayden looked up and said, “Mom, where is the line on who is “smart enough or competent enough” to vote? What’s the difference between a competent individual just marking any candidate without doing their research and someone with a severe disability marking a candidate that they think should win? How is that different?”

After promising him I’d look into it, I realized he made a few good points. Who gets to decide what a person with autism is thinking? Are we only allowed to gauge a person’s expressive language? There are people with autism that are completely nonverbal that have written books. There are people with autism that could be labeled as “mentally incompetent” by one person, but could also be savants. Why would it be acceptable for a person to deny another person the right to vote? What is their mode of measurement?

To my surprise, the answer to my question was harder to answer than I thought. Every state has its own rules. Some are more rigid than others. The issue that seemed to be raised was conservatorship. If conservatorship needs to be in place to ensure a person is cared for, there needs to be an agreement that the person is unable to make decisions on their behalf that affect their health and safety. There are many different types of conservatorships and it would be decided on a case-by-case basis. The more I read, the more I got hooked on the term “mentally incompetent”. Who thinks it’s acceptable to make a slap judgement if the conservatee is mentally incompetent? Also, if someone has been designated as a conservator, one who has the best interests of the conservatee, wouldn't one think that they could assist the conservatee on voting?

One may argue that the vote would be skewed to the view of the conservator who is assisting the conservatee with the vote, but I challenge that argument. If the conservator has the best interest of the person with the disability, wouldn't they choose a candidate that would believe in laws and policies that would most benefit the person with the disability? Is it a perfect scenario? No, it's not, but is it any worse than having a "competent" individual vote without taking any time to research the candidates on the ballot? Who are we to decide how others vote?

Jill Escher, the President of National Council on Severe Autism said it best. We need to create a "system for proxy voting that uses the same principles as Conservatorship proceedings." Adults with autism are "systematically disenfranchised" and stealing their right to vote, including other individuals with severe disabilities, continues to erode the fact that they are people of value in this country.

> "The people should speak for loved ones who may not have a voice. Who should have the ability to decide who is worth a vote?"

In the state of California, this issue has been addressed. In 2016, under SB 589, even though a person is under a conservatorship, they can still vote unless a judge decides otherwise. If the person does not have expressive language, they are able to communicate using devices and any other form to express their interest in voting. The conservator has the ability to challenge the judge's decision by asking a disability rights lawyer for assistance.

Like the state of California, it's up to the people. The people should speak for loved ones who may not have a voice. Who should have the ability to decide who is worth a vote? As a country, it's evident that it shouldn't matter your gender, ethnicity, financial situation, the color of your skin, and it also shouldn't matter if you have a disability. One person, one vote. My son is one vote. •

PUZZLES & CAMO

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

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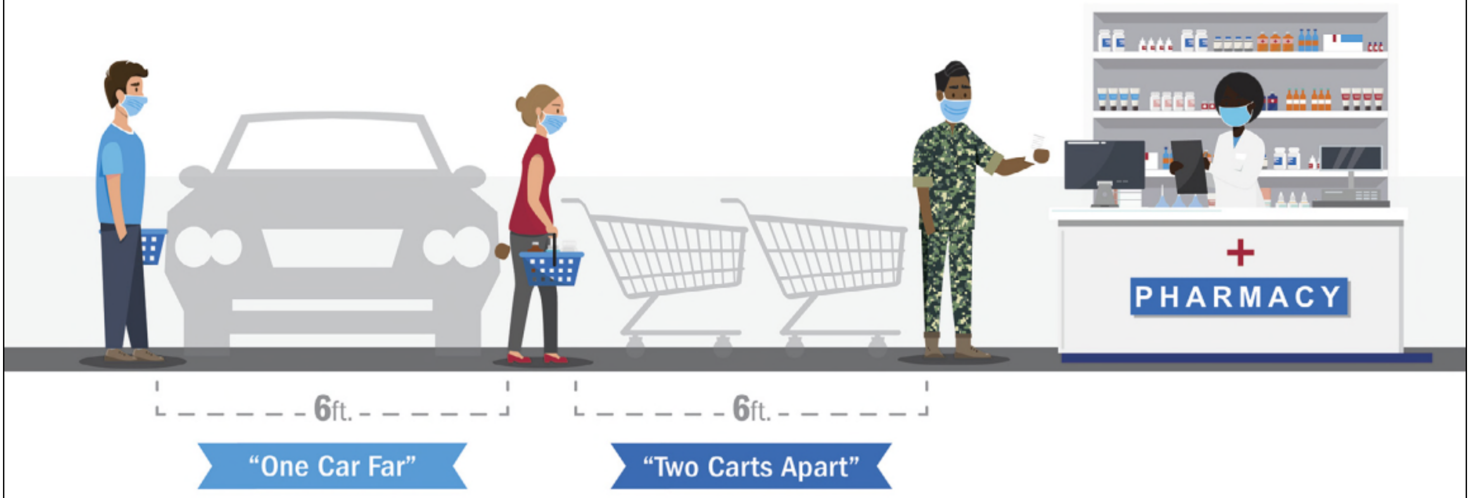

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