PLUS: UNITED STATES MILITARY SECTION

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EXCEPTIONAL PARENT
MAGAZINE
NOVEMBER 2020
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IN THIS ISSUE:

SAVE MONEY *without* LOSING FINANCIAL HELP

AND:

SPECIAL NEEDS PLANNING PROCESS

AN EP EXCLUSIVE:

FINANCIAL LITERACY *for* STUDENTS WITH DISABILITIES

HEARTSIGHT:

MY JOURNEY *to* FINANCIAL COMPETENCY

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ALSO INSIDE:

BEING A NEURODIVERSE ADVOCATE

AMERICAN ACADEMY OF DEVELOPMENTAL MEDICINE & DENTISTRY
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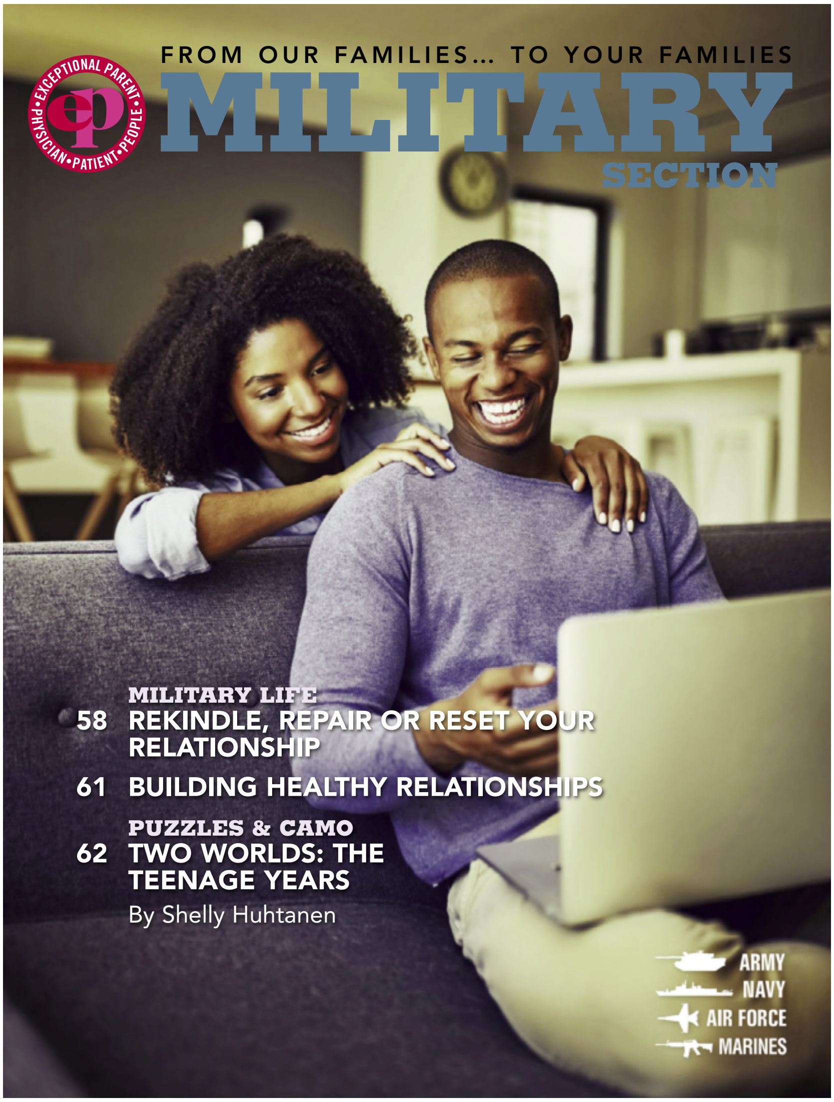

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Information and Support for the Special Needs Community

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

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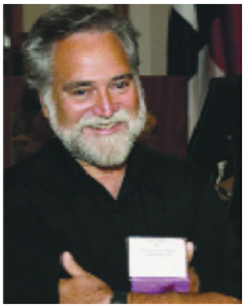
Reflections on My History of Swearing

The third memorable event that found me "swearing" was orchestrated with my left hand on a Bible and my right hand raised in the air. It was on the recent occasion of being "sworn in" as a member of the National Council on Disability. I received both a Presidential nomination and appointment to this august body. It was both humbling and an honor.

Over the course of my 70-plus years of living I probably have sweared (or is it sworn?) thousands of times. But it is noteworthy that there are three incidents that have been significant, memorable and life changing.

First let me distinguish between "swearing" and "swearing".



To most of us "swearing" relates to rude or offensive language that someone uses, especially when they are angry. We know how frequently curse words, "four-letter" words, vulgarity, profanity and "cuss" words find their way into our daily communications.

Perhaps my earliest experience with swearing, or at least that which had a consequence was when I was about nine years old. I discovered that my dog Sparky has stained the carpet and it was my duty (no pun intended) to clean the mess. I declared to my mother that "Sparky shit again on the carpet." My mother was smart enough to wait until I cleaned the carpet to intervene. I can vividly recall her taking me into the bathroom and grabbing the Ivory soap bar on the sink and threatened to "wash my mouth out with soap," a popular antidote for having a "dirty" mouth. This apparently was a very popular "interactive" behavioral modification practiced in the 1940's and 1950's. It was evidence-based and, in my case, it worked. I never cursed again (at least not in close proximity to my mother's hearing range). Sparky was never able to be house-broken and I was told he was placed on a farm in upstate New York and was last seen happily chasing after chickens and cows – another popular behavior modification tactic from that era.

In addition to my mother not approving of swearing, the Bible also had some harsh words on the subject.

In Proverbs 4:24 we find, "Put away you crooked speech, and put devious talk far from you." And Colossians 3:8, "But now you must put them all away: anger, wrath, malice, slander, and obscene talk from your mouth." There is, however, some insight into when the appropriate use of swearing might be supported. Ephesians 4:29 offers a pass, "Let no corrupting talk come out of your mouths, but only such as is good for building up, as fits the occasion, that it may

SWORN TO SERVE: Dr. Rader received a Presidential appointment to the National Council on Disability, which translates the needs and rights of people with disabilities into action that improves their lives.

PHOTOS BY DENNIS WILKES

give grace to those who hear." Looking back, I appreciate the fact that even if I knew that quote by heart, the Sparky incident was not the time to share it with my mother.

Shakespeare was fluent in the art of swearing. "Thou crusty batch of nature!" (Troilus and Cressida) is still effective; however small the number of people who would appreciate that they have been cursed at. If that doesn't work, there is always the Bard's lengthy, eloquent synonym for "idiot".

A SOLEMN OATH: The swearing in ceremony was conducted by the Honorable Neil Romano, the Chairperson of the National Council on Disability. "I was thrilled to be surrounded by my wife, colleagues, friends, board members, and the folks we serve."

"Why, thou clay brained guts, thou knotty pated fool, thou whoreson obscene greasy tallow catch." Try that when someone takes the same parking spot you had envisioned for yourself.

Swearing has its share of health benefits. Alison Escalante, writing in Science, offers, "About a decade ago, the first evidence surfaced that swearing, or 'the use of taboo language conveying connotative information,' had pain-reducing effects. Past research has demonstrated that repeating a swear word helped people tolerate physical pain. It even helped decrease the social pain of being excluded." The title of her article sums it up best, "Swearing: The Fastest Acting Pain Reliever of Them All."

"Swearing" also relates to making a solemn promise, taking an oath or a vow. It's a pledge to commit to something that you have every intention to continue, maintain and adhere to.

While I can recall reciting both the Cub Scouts, and later Boy Scouts Pledge at the opening of every meeting, and reciting the Pledge of Allegiance (to the flag) every morning in school (from elementary school to high school), it was not until 1983 that reciting a pledge truly got my attention.

When I graduated medical school, I stood alongside my classmates and, in unison, we raised our right hands and announced, "I swear by Apollo Healer, by Asclepius, by Hygeia, by Panacea, and by all the gods and goddesses, making them my witnesses, that I will carry out, according to my ability and judgment, this oath and this indenture."

The Hippocratic Oath, written between the third and fifth century BC, is one of the oldest-binding documents in history. It is embraced by new physicians and it is a sacred oath that declares that they will treat the ill to the best of one's ability, that they will preserve a patient's privacy, and teach the secrets of medicine to the next generation.

The third memorable event that found me "swearing" was orchestrated with my left hand on a Bible and my right hand raised in the air. It was on the recent occasion of being "sworn in" as a member of the National Council on Disability (NCD). I received both a Presidential nomination and appointment to this august body. It was both humbling and an honor. The National Council on Disability makes recommendations to the President and Congress on policies affecting Americans with disabilities. They empower individuals with disabilities, and promote equal opportunity. It is the most admired and respected agency that translates the needs and rights of people with disabilities into action that improves the lives of people with disabilities, their families and the communities they contribute to.

The "swearing" in ceremony was conducted by the Honorable Neil Romano, the Chairperson of the National Council on Disability. The significance of the appointment was elucidated by Lisa Grubb, the Executive Director of the National Council on Disability.

The event was made more significant by being held at The Orange Grove Center in Chattanooga, where for the past twenty-five years, I have had the pleasure, responsibility, and privilege of serving as the Director of the Habilitation Center. Orange Grove has provided the opportunity, support and encouragement for me to go out into the world and beg, borrow, and steal the most innovative and promising programs, initiatives and ideas to benefit individuals with disabilities. I was thrilled to be surrounded by my wife, colleagues, friends, board members, and the folks we serve.

One thing is certain. Whether we have placed our hand on a Bible, raised our right hands, swore to Apollo or to the Constitution of the United States, those of us who wake up each morning in pursuit of ideas to make things better for our family, friends, communities and our inclusive society… we stand side by side, shoulder to shoulder… so help us God. •

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

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ACA REPEAL WOULD CREATE CHAOS FOR THE DISABILITY COMMUNITY

PHOTO TOM MIHALEK/REUTERS

Since the passing of Justice Ruth Bader Ginsburg, President Donald Trump and Senate Majority Leader Mitch McConnell looked to fill her seat with a conservative justice who would side with them in repealing the Affordable Care Act (ACA) in *California v. Texas,* which the court will hear November 10th.

The possible repeal of the ACA comes as the disability community is expected to grow by the greatest number of people in 30 years due to the COVID-19 pandemic. Insurers will likely now consider the more than 7 million people who have been diagnosed with COVID-19 to have a preexisting condition, potentially leaving them unable to obtain or maintain insurance if the ACA is repealed.

Ahead of the hearings to confirm Justice Ginsburg's replacement, a new column from Rebecca Cokley, director of the Disability Justice Initiative at the Center for American Progress, looked at the consequences of repealing the ACA for the 61 million Americans living with a disability, including:

- *Limiting the freedom of people with disabilities to change jobs; without the ACA, disabled people would have no guarantee of insurance in a new job due to rules around preexisting conditions.*
- *Hurting young adults with disabilities, who would no longer be eligible to stay on their parents' plans until the age of 26, possibly leading to a return to institutionalization for some members of the disability community.*
- *Eliminating support for survivors of interpersonal or gender-based violence, many of whom are members of the disability community.*
- *Returning to annual or lifetime caps on coverage. Many disabled people, including disabled children, reached these caps at young ages, putting a huge financial burden on themselves and their families and sometimes leading to institutionalization.*
- *Limiting many disabled people's access to Medicaid.*
- *Erasing the ACA's essential health benefits provisions, which ensure that all Americans are covered for disabilities such as behavioral health issues and chronic health conditions such as diabetes.*

"The ACA is the most important piece of legislation for disabled people since the Americans with Disabilities Act and in some ways even rivals the ADA in importance for our community," said Cokley, "Repealing the ACA would mean a return to the days when many disabled people were unable to afford the medical care they needed, unnecessarily institutionalized, and unable to pursue their careers out of fear of losing insurance. It is particularly cruel that Trump and McConnell are working to repeal the ACA in the middle of a once-in-a-century pandemic. Millions of people are acquiring disabilities for the first time or seeing their disabilities compounded by COVID-19. It's no exaggeration to say that repealing the ACA will lead millions of disabled people to suffer or die."

WHAT'S HAPPENING

DOL CELEBRATES NATIONAL DISABILITY EMPLOYMENT AWARENESS MONTH & ADA ANNIVERSARIES

The U.S. Department of Labor commemorated the 75th National Disability Employment Awareness Month (NDEAM) and passage of the Americans with Disabilities Act with a video celebration on Tuesday, Oct. 20, 2020. NDEAM's 2020 theme was "Increasing Access and Opportunity."

The video event, "Building a Future that Works," included remarks by U.S. Secretary of Labor Eugene Scalia on how emerging technologies are making the American workplace accessible to all. Deputy Assistant Secretary of Labor for the Office of Disability Employment Policy, Jennifer Sheehy, moderated the event, which featured insightful conversations with thought leaders. The event showcased accessibility innovations in development that spanned the fields of communications technology, artificial intelligence, and autonomous vehicles.

Participating panelists included:

- Author Cathy Hackl, "Marketing New Realities: An Introduction to Virtual Reality & Augmented Reality Marketing, Branding, & Communications;"
- Vice President and Chief Internet Evangelist Vint Cerf, Google;
- Disability Policy expert Bobby Silverstein, Powers Pyles Sutter and Verville;
- Postdoctoral researcher Martez Mott Ph.D., Microsoft Research;
- Distinguished Professor Rory Cooper Ph.D., University of Pittsburgh; and
- Autism and neurodiversity legal expert Haley Moss.

The mission of the Department of Labor is to foster, promote and develop the welfare of the wage earners, job seekers and retirees of the United States; improve working conditions; advance opportunities for profitable employment; and assure work-related benefits and rights. This year marks not only the 75th observance of NDEAM, but also the 30th anniversary of the ADA. Both milestones are being commemorated with a range of events and activities centered on the theme "Increasing Access and Opportunity." The official poster commemorating the event appears below.

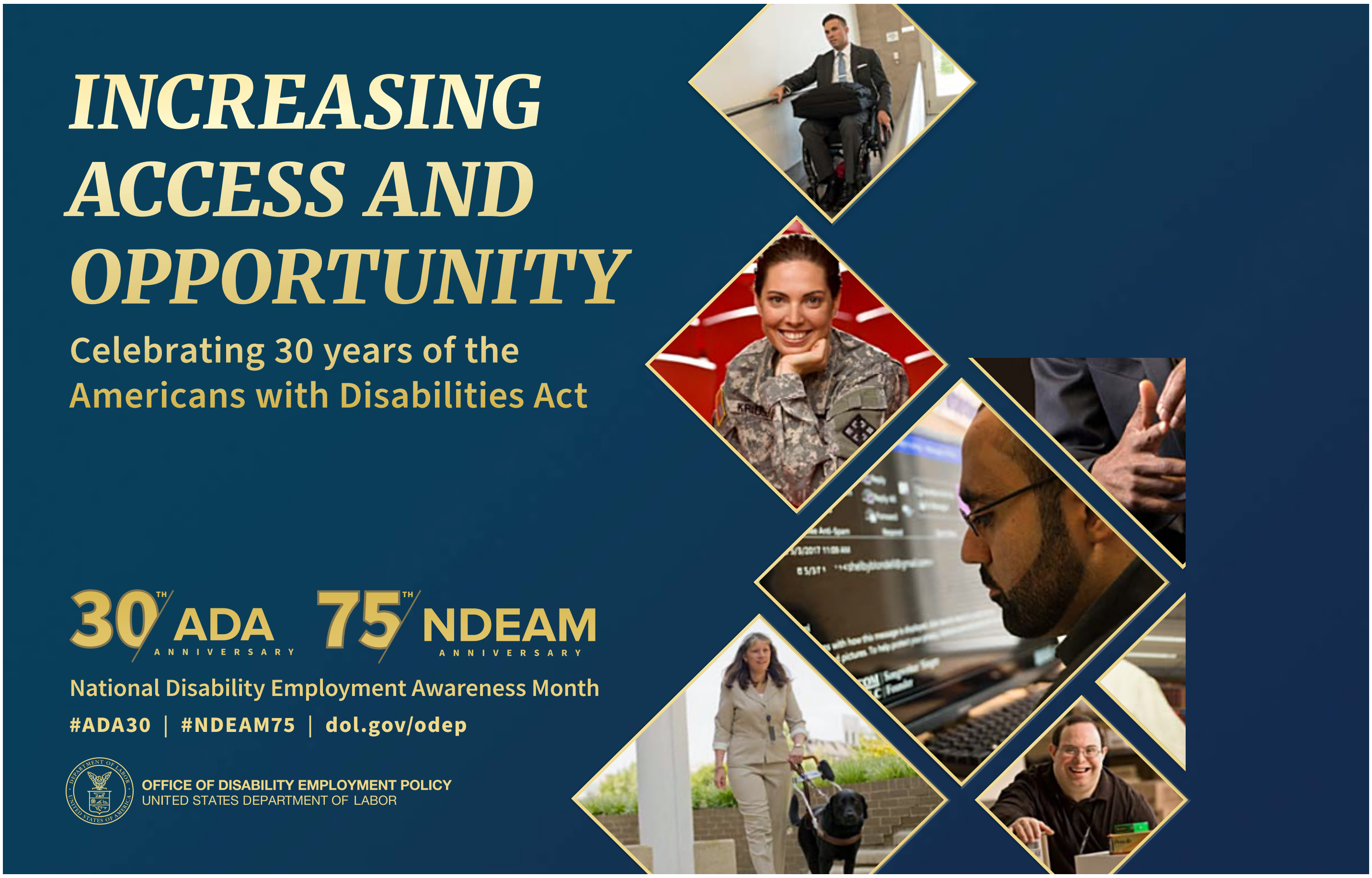

IMAGE COURTESY DOL.GOV

WHAT'S HAPPENING

DANIEL TIGER'S COVID-19 SPECIAL AVAILABLE TO KIDS WITH DISABILITIES

Bridge Multimedia and the Described and Captioned Media Program (DCMP) are excited to announce that the special COVID-19 episode of PBS KIDS' Daniel Tiger's Neighborhood, is now available, on demand at no cost, for children with disabilities through DCMP's Accessible Television Portal.

The timely episode, titled *Daniel Tiger's Neighborhood: Won't You Sing Along with Me? was* audio-described by Bridge Multimedia with funding from OSEP. It joins DCMP's growing library of thousands of free family and classroom programs, augmented with audio description and captioning for viewers with sensory and cognitive impairments. The Accessible Television Portal offers online streaming of TV shows from Litton Entertainment, WNET, Fred Rogers Productions, Nickelodeon, Universal Kids, and others.

When Daniel learns he can't gather with all of his neighbors at the Neighborhood Carnival this year, it leads to lots of big feelings and questions, including what to do when he misses people he loves, how to keep himself and others healthy, and how to find ways to enjoy the extra time at home with his family.

DCMP and the Accessible Television Portal are serving an important need during the COVID-19 crisis, with the sign-up rate tripling in 2020. The Daniel Tiger special, with its Social and Emotional Learning (SEL) aligned audio description, speaks to challenges faced by all children during these times. •

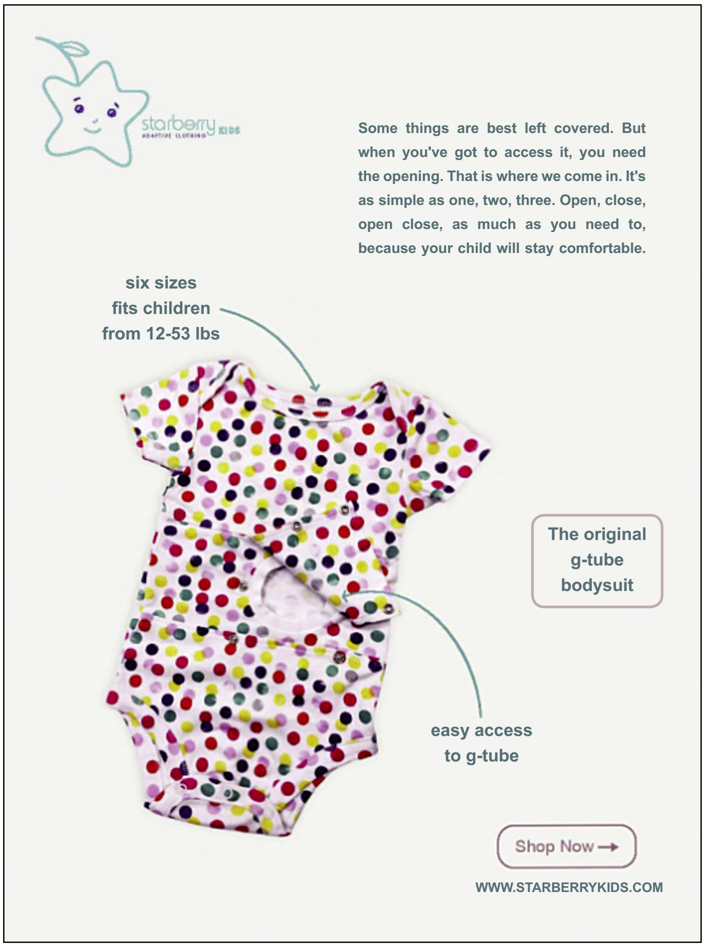

IMAGE COURTESY PBS.ORG

There Really are Differences Between Boys and Girls

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

*According to the National Center for Education Statistics, during the 2017 to 2018 school year, **17 percent of male students** ages, 6 to 21, received special services under the 1975 Individuals With Disabilities Act (IDEA); compared to **9 percent of female students** benefiting from these services.*[1]

The function of IDEA is to ensure that children in public schools with any illness, disorder or condition that can affect learning, should receive support for equal education; this includes youngsters on the autism spectrum, and those who have hearing, speech or language impairment, orthopedic problems, and learning disorders.

*Boys often are thought of as being more likely to have learning disabilities or problems such as attention hyperactivity attention disorder (ADHD) than girls are - **but is this really the case?***

Is this discrepancy substantiated? Do more boys get special education support than girls because they actually *are* greater in number with learning disabilities? Or is it that they're *perceived* by teachers and other education professionals to have more learning disabilities?

"According to Underdog.org, studies have found that based on scientific criteria, there is no gender gap when it comes to education learning problems… notably in attention deficit hyperactivity disorders… **It's just that teachers recommend twice as many boys as girls for learning disorder support.** (emphasis added) [1]

One theory for the difference in referral rates is that boys who are frustrated and struggle academically are more likely to act out. They may be hyperactive, impulsive, or disruptive in class, while girls typically display less obvious signs of their academic frustrations. For instance, girls who appear inattentive are more likely to be viewed by teachers as simply not interested in the subject matter. We also know that boys with ADHD are usually more **hyperactive, impulsive** and aggressive than **girls with ADHD**. That behavior makes them stand out.

In other words, boys with learning disabilities are more *notice-*

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.

READY TO LEARN: Understanding neurological and anatomical factors which predispose boys to learning disabilities is the essential initial step in preparing parents, teachers and the youngster to develop programs to ensure the child’s proper development.

able than girls with the same conditions. (Note: Many of the tests used to diagnose learning disabilities were designed and standardized for boys.) [1,2] That’s why it’s so important to closely observe your child’s behaviors and take notes. If you have concerns, you can **request a free school evaluation** at any time. (sic) [2]

> ***“Because males’ eyes are hardwired to see and function through movement, they tend to learn more while doing so. Secondly, because of how their hearing is wired, males hear less well than females.”*** [2]
>
> *“Approximately 50% of the student population is female, and 50% is male…Yet the majority of students in special education tend to be male, and 85% of educators in America are female… Since the majority of educators are female, and since females do much of the identification, is there an issue there?”* [3]

With the advent of more sophisticated brain research, we are learning there are big differences in how males and females process their respective realities.

- *When a female has an emotional experience, that information is flooded throughout the brain in a matter of minutes. The initial reaction of a female is to cry and talk. When a male brain has an emotional experience, it is initially processed in one region of the brain and, in some studies, averages approximately five hours for that emotional information to permeate the brain. He typically wants to be left alone and to be silent.*
- *In school, if a male gets into a fight and has a female teacher or administrator, the first thing that is demanded of him is to “tell me what happened.” When he sits there and says nothing, he is often accused of being “recalcitrant, uncooperative, and defiant.” Furthermore, when males get emotionally stressed, the natural tendency is for them to “shut down.” So, simply put, they appear uncooperative.*
- *Additionally, males tend to prefer physical aggression, while females often prefer relational, verbal aggression (“he said, she said, they said…”).* [3]

What happens in the early grades (K-3) is that, because of these differences, the male student often gets behind in skill development (e.g. decoding/comprehension, letter/number understandings, vocabulary acquisition, behavioral issues, etc.). By third grade, the gap is often so large that he has difficulty functioning in the mainstream. So we identify him for special education.[3]

MORE ABOUT DIFFERENCES

“Something is awry in the way our culture handles the education needs of boys and girls. A smart 11-year-old boy gets low grades in school, fidgets and drifts off in class, and doesn’t do his homework. A girl in middle school only uses the computer to instant-message her friends; when it comes to mastering more essential computer skills, she defers to the boys in the class.” [4]

New brain imaging technologies confirm that genetically templated brain patterning by gender plays a far larger role than we realized. “**Research into gender and education reveals a mismatch between many of our boys' and girls' learning brains and the institutions empowered to teach our children.”**[4] For example:

The Minds of Girls

- *Girls have, in general, stronger neural connectors in their tem-*

poral brain lobes than boys. These connectors lead to more sensually- detailed memory storage, better listening skills, and better discrimination among the various tones of voice. This leads to greater use of detail in writing assignments.

- *The memory storage area in the brain is larger in girls than in boys, increasing her learning advantage, especially in the language arts.*
- *Girls' prefrontal cortex is generally more active than boys' and develops at earlier ages. They tend to make fewer impulsive decisions than boys do.*
- *Girls generally use more areas of their brains for verbal and emotive functioning. Boys tend to use more areas of the brain for spatial and mechanical functioning.*

These female brain qualities are the tip of the iceberg, yet they can help teachers and parents understand why girls generally outperform boys in reading and writing from early childhood throughout life. Other neurologic variations lessen the inclination to the physical-spatial functions. Although some girls excel in these areas, more males than females gravitate toward physics, industrial engineering, and architecture. [4]

The Minds of Boys

- *Boys' brains have more areas dedicated to spatial-mechanical functioning, using, on average, half the brain space that females use for verbal-emotive functioning. Most boys will experience language and feelings differently than girls do.*
- *As a result of varying body chemicals (e.g. serotonin and oxytocin) boys are more likely to be physically impulsive.*
- *Boys' brains, are structured to compartmentalize learning. Thus, girls tend to multitask better than boys do, with fewer attention span problems and greater ability to make quick transitions between lessons.*
- *It is predominantly boys who drift off without completing assignments, who stop taking notes and fall asleep during a lecture. The more words a teacher uses, the more likely boys are to "zone out."*

The reality in the United States schools:

- *"Boys earn 70 percent of Ds and Fs and fewer than half of the As.*
- *Boys account for two-thirds of learning disability diagnoses.*
- *Boys represent 90 percent of discipline referrals.*
- *Boys dominate such brain-related learning disorders as ADD/ADHD, with millions now medicated in schools.*
- *80 percent of high school dropouts are male.*
- *Males make up fewer than 40 percent of college students.*

"These statistics hold true around the world." (emphasis added) [4]

THERE REALLY ARE DIFFERENCES

It is not just a bunch of boys misbehaving! There are neurological and anatomical factors which predispose boys to learning disabilities and/or problems such as attention hyperactivity attention disorder (ADHD). Understanding these factors is the essential initial step in preparing parents, teachers and the youngster to develop programs to ensure the child's proper development. •

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DSPs - we see you. We see the tireless work you do. We see how much you care for people with ID/ DD – and we thank you. We, **the American Academy of Developmental Medicine & Dentistry and NADSP, our partners in collaborative ID/DD healthcare, appreciate YOU.**

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NATIONAL MPS SOCIETY

BY LESLIE URDANETA

"'Don't Google this.' That's what they told us. I'm a nurse, so I knew when they said that – well, I knew I shouldn't look it up. My husband did, though. We were in shock. We couldn't process anything."

Titus Barrett-Weber was diagnosed with mucopolysaccharidosis type I (MPS I) before he left the hospital. Born in Kentucky in 2019, Titus was screened for MPS I at birth. After a short NICU stay, he was discharged and carried to an office down the hall, where his parents met with a geneticist and received the news that newborn screening detected the rare genetic disorder.

MPS diseases are lysosomal storage disorders, conditions where the body lacks a specific enzyme to break down cellular waste. This waste accumulates as storage within cells and causes progressive damage to the body. There are seven different types of MPS, some with subtypes within those, and all fall within a spectrum of severity from attenuated to severe. MPS diseases are considered progressive and degenerative as more buildup occurs. Without treatment, many individuals face significant symptoms and a shortened lifespan.

"Titus was the second baby to be diagnosed with MPS I in Kentucky. He has Hurler syndrome, the most severe form," shares his mother, Charlotte. "Only two babies diagnosed so far with newborn screening in our state may not seem like too many, but to be that parent that gets a diagnosis so early, it's a huge deal. Titus was

PHOTO COURTESY MPSSOCIETY.ORG

STRENGTH IN NUMBERS: National MPS Society members gather during a recent 5K Run.The National MPS Society organizes dozens of family centered events each year to raise awareness and help cure, support and advocate for MPS and ML.

nine days old when we got the news. Longer times to diagnosis mean increases in symptoms and additional risks associated with treatment options. Titus started treatment before physical symptoms even started to show up.

Today, Titus is a rambunctious 18-month-old with a bright smile who loves the water, dogs, and playing in the dirt. He just returned from a recent trip with a new passion for sand and running on the beach. Titus received a life-saving hematopoietic stem cell transplant at three months of age to halt the impact of MPS I on his body and brain. Living in a small town in rural Kentucky, local doctors had never met anyone with MPS, making the road to diagnosis one that takes several years for many families. Newborn screening created a different path for Titus.

The National MPS Society (https://mpssociety.org) exists to cure, support, and advocate for MPS and mucolipidosis (ML). Individuals with these diagnoses and their families connect with the Society for the most up-to-date information on research, to access resources and family support, and to engage in advocacy efforts. The Pathways program offers direct, targeted support for families throughout the first year of diagnosis, including a face-to-face visit to assist in establishing services and long-term care, provide information and education about treatment options, and ensure connection into the community. Other programs provide support for medical travel expenses, durable medical equipment not covered by insurance, educational and conference scholarships, and for items needed throughout the journey.

> **"The National MPS Society exists to cure, support, and advocate for MPS and mucolipidosis. Individuals with these diagnoses and their families connect with the Society for the most up-to-date information on research, to access resources and family support, and to engage in advocacy efforts."**

In 1998, two-year-old Zach Stockin sat in a waiting room for an appointment for evaluation of a hernia and chronic ear infections. As a doctor passed through, he saw Zach and recognized symptoms consistent with MPS. Testing confirmed a diagnosis of MPS II, Hunter syndrome, in the toddler. His sister, Kristin, reflects on her memories of that time: "The doctors told my mother things about Zach that were awful. There were no cures, not even anything for treatment, and he already had so many symptoms. They said they could do things to help some of the symptoms, but I can't even say the things that they told us about MPS. It was so bad."

Kristin was Zach's best friend: "We were obsessed with each other, and so close. I remember how much he loved simple little things, which brought him so much joy. His favorite thing was to go to the store and use money, which he called 'buy,' to get groceries and other small items. Zach played t-ball and loved animals." As he got older, the impacts of MPS II became more evident in both his brain and body. He developed more physical symptoms and talked less and less.

When Zach was ten years old, enzyme replacement therapy (ERT) was approved and made the standard of care for treatment for MPS II. Kristin recalls changes when he started treatment, as some of the buildup from the cellular waste began to decrease: he felt better overall, little bumps on his skin ("pebbling") from deposits smoothed out, and he did not get sick as often. Though ERT could not undo the damage done to his body by MPS II, it slowed progression for several years before his body started to decline and he passed away. Zach packed a full life into 19 years, visiting theme parks, going backstage to meet Batman, helping with attendance at school, and making friends everywhere he went.

Most types of MPS follow autosomal recessive inheritance patterns, meaning both parents are carriers of genetic mutations that combine for an individual to have MPS. However, MPS II is X-linked and only the mother is a carrier. Males have a 50/50 chance of having a diagnosis of MPS II, and females have a 50/50 chance of being a carrier of the mutation for MPS II.

Kristin found out about her pregnancy and was faced with an additional challenge: she had never been tested to see if she was a carrier for MPS II. “I didn’t know if I was a carrier, and I didn’t want to know,” she shares. “It was too hard to think about. When I got pregnant, it was only then I learned I carried the same gene that caused Zach’s diagnosis. I had an ultrasound that showed I was pregnant with a boy and learned halfway through the pregnancy that he would have MPS II as well.”

> **“Screening is just beginning for one syndrome type, MPS I, in some states. Early diagnosis will save lives.”**

Prenatal diagnosis allowed Kristin several months’ time to develop an action plan before her son’s birth. She began receiving additional prenatal care, now with added conversations about her son and his immediate needs. She set up appointments with medical providers who cared for Zach, now preparing to care for her own son. Things were different this time, almost 20 years after her brother’s diagnosis.

Charlie was born with options. Before him were choices for ERT, clinical trials, and other treatments. At a few weeks of age, Charlie started ERT and received a hematopoietic stem cell transplant, similar to Titus. “The age of diagnosis, before birth, opened up a lot of avenues that people don’t have. That is the big thing. The reason people get diagnosed with MPS is because things are going wrong. For Charlie, nothing was going wrong yet. He had no symptoms because treatment started so early,” says Kristin. “It’s the burden of *choice*. I feel blessed having that burden because my brother had no choice.”

Charlie is almost two years old and his transplant was successful. His body now produces the enzyme that both he and his Uncle Zach were missing. Like his uncle, he loves school; he attends a specialized, inclusive daycare program that provides supplemental therapies to ensure he stays on track and continues to advance academically and socially. He loves to play with his dad and goes swimming any time he can, and Kristin uses his story to advocate for newborn and prenatal screening options, increasing access to information for family planning and carrier testing, and states: “our decision led to us being informed. I want that for others.”

ABOUT THE NATIONAL MPS SOCIETY:

The National MPS Society is a non-profit organization dedicated to acting as a support group for families affected by mucopolysaccharidoses (MPS), mucolipidoses (ML) and other related disorders; increasing professional and public awareness; and raising funds to further research into such disorders. Established in 1974, the National MPS Society promotes patient advocacy, provides referrals to genetic counseling and other services, and has established regional contact families to assist new families and conduct local support meetings. Visit mpssociety.org

A life-threatening diagnosis is wrought with emotions, and parents often share they experience a flood of grief, pain, trauma, anticipation, and fear. Others describe a sense of relief. Newborn screening has been available for some diseases since the 1960s; the concept is not new. Screening is just beginning for one syndrome type, MPS I, in some states. Early diagnosis will save lives. Whether diagnosis leads to early access for established therapies and treatment options, or allows families to consider potentially groundbreaking clinical trials, and early detection is crucial.

Parents and caregivers shared these sentiments: “It was hard, but it was a relief to get a diagnosis. Finally, doctors started to listen to me when I said something was wrong. We went through several months where providers told me they were ordering tests to appease me, and that I was overreacting,” said Amber Mongan, mother of Maura, who has MPS I. Erica McKenzie, mother of Reagan, diagnosed with MPS IIIA, shared her thoughts: “I think, ‘if only’ we could have had newborn screening for MPS! The outcome would not have changed for my daughter as there is not an established and approved form of treatment yet, but we could have gotten on top of things more quickly and known what we were facing. It would have helped us to manage her symptoms.” Caroline Marie Fidalgo’s son, Alex Olivier, was almost two years old when he was diagnosed with MPS I: “He now has psychological, emotional, physical, and social after-effects from his 8 months of hospitalization, of all the medical appointments, treatments, and everything else, and the isolation caused by the complications he experienced after requiring three transplants before having success. People complain about the isolation caused by the COVID-19 pandemic; isolation has been our way of life for 4 years now. I think that with newborn screening, things would have gone better because they would have been taken care of more quickly.”

Across the United States, babies are tested at birth for a variety of conditions. Newborn screening varies from state to state, with an increasing number of conditions being considered. The Recommended Uniform Screening Panel (RUSP) (**www.hrsa.gov/advisory-committees/heritable-disorders/rusp/index.html**) provides federal guidelines for conditions for screening, and patient advocacy groups can nominate a condition for RUSP consideration. A RUSP nomination includes data supporting FDA-approved therapy (such as enzyme replacement therapy) and pilot studies to quantify and qualify the considerations to screen newborns. Adding conditions to the RUSP is an arduous process, requiring extensive documentation, medical support, family testimony, and advocacy efforts. The National MPS Society successfully presented MPS I to the RUSP in 2016 and earlier this year, submitted the nomination for MPS II. Currently, 20 states screen for MPS I.

The “burden of choice” Kristin Stockin describes having for her son is one of hope for those with MPS across the country. Choices imply options and a sense of control amid a seemingly impossible diagnosis. Answers in days immediately after birth, before many symptoms emerge, change the landscape for a baby and family. At the National MPS Society, as we seek to find cures for MPS and ML, we continue to provide direct, comprehensive support and education, and advocate for the entire community. •

ABOUT THE AUTHOR:

Leslie Urdaneta is a licensed clinical social worker and the Family Program Director for the National MPS Society. She lives in North Carolina with her husband, daughter, and a small flock of birds. She seeks to fulfill the mission of the Society to cure, support, and advocate for MPS and ML by providing direct assistance and connection with services and overseeing family support programs, working closely with families throughout every aspect of their journey.

CHRISTINA LLANES MABALOT

My Personal Journey to Financial Competency

We can financially prepare for our child's future, as well as unexpected crises. Determine to educate yourself and gain the financial skills from here on. You need to plan for the best and be prepared for the worst.

Today, there's a crisis that's real and tangible. Economic deficiencies, to say the least, are one of the significant setbacks from lockdowns. I am no financial expert, but I've been flat-broke several times and have bounced back. I'd like to offer some advice if your finances have caught a virus.

KEEP YOUR HEAD ON YOUR SHOULDERS

A financial crisis can drive you crazy. You can make the most unsound decisions and worsen your problem when emotionally unwell. It doesn't help to quit and sink into depression, squander your remaining money, or forget about your predicament. The best way to handle it is to get a grip of your senses, face the situation, weigh your options, and work out a logical plan.

AMAZING CAPABILITIES: Attitude is everything. When dealing with any crisis, a positive attitude will keep you pushing. Be sure to have backup plans, just in case some don't work. Never lose heart. Your focus and priority should be on successfully getting out of the rut.

It seemed like yesterday when I heard myself say, "I hate math, so I'll never manage finances." As a woman with low vision, college graduation signified my freedom from all numbers-related activities. I had gone through unimaginable ordeals just to pass math courses, and dealing with numbers again in any way would conjure horrible images for throwback-Thursdays. But when I set up a school, the lawyer obligated me to keep track of finances. I pitched all my valid and convincing excuses, e.g., "I'm blind, a woman, and hopeless in math." The man responded, cut and dry, "you manage either finances or failure."

He was right. Not knowing much about something isn't an excuse for not learning. Could the lack of knowledge in parenting stop me from being a mother? No way! So, I rewired my brain to like dealing with money.

Unlike Trigonometry, math that I'll never use, financial management is a life skill that will build one's future to live more comfortably. The truth is, my disability drains my pocketbook, and I had no stable source of income. And yet, I was burdened with the expenses of a speech software, growing cab fares (which equal a monthly vehicle payment), eye medications, and salaries for a sighted guide or reader. No school would hire me, so I determined to set up my own. The promise of monthly wages hung in the balance. I needed to get my ducks in line, and the biggest involved finances.

Embracing much-needed change goes beyond knowing you need to do something different, like stopping a bad habit, relationship, or attitude. I think most of us are aware of what we need to do to improve our lives. But, we do what we know is right when fear from impending consequences invades our hearts. One stops smoking of one's fear of dying from lung cancer. I manage my finances because I dread becoming a worthless bum. Change gets real when a crisis becomes palpable and emotional. So, I took up my cross and followed my legal advisor. And boy, was I thankful I started relatively young.

Financial competency is essential for a growing family. Who would have thought we'd be blessed with a visually-impaired child? When Jem came into our lives, I was well into my second entrepreneurial venture, so I had enough sense to double up on our finances. I got scarred by how my mother had always lectured my only sighted brother to be industrious. He was warned that in the future, he'd be caring for all his siblings – four in total. Dumping the financial burden on my only sighted brother set him up for failure. Who wouldn't be overwhelmed with such a responsibility? Parents, never assume that your children without disabilities will take on the responsibility of caring for their sibling(s) with special needs. Also, don't be misled into thinking that the government will automatically sustain your child. They need to be poor, with assets under $2,000 to be subsidized. We can't passively accept that deal.

Society doesn't realize the hidden costs of families and individuals living with disabilities. Medical care tops the list of exorbitant expenses. While medications improve functionality, their cost will kill you. Most insurances don't cover the full amount needed for personal assistance, durable medical equipment, and that Uber ride to the doctor's office. Housing, transportation, utilities, and even food, just about every necessity for living, entail extra expenses for special needs people. I feel like, the more "included" we are in society, the more expensive life becomes. **https://theconversation.com/the-hidden-extra-costs-of-living-with-a-disability-78001**

Because of these financial constraints, we are left with two options. We either try to earn more, or gain the financial skills that will help us manage our money. The latter sounds easier.

WHAT TO DO : FOUR STEPS TO BECOMING FINANCIALLY COMPETENT

1. CREATE A BUDGET

Since it is the only way you can manage your money on a daily basis, budgeting is the rock upon which finances are built. You'd know exactly where your money is going, and you can streamline your expenditures. In case you're hard up with bills, budgeting might even help you cover all your monthly expenses. If you don't have a budget, you're long overdue for creating one.

The first commandment of budgeting is: do not live beyond your means. If breaking this law were punishable by death, no adult would be alive in America. Most of us have spent money we don't have to buy stuff we don't need, using the very tempting credit card. Are you guilty of this crime? Examine your statements for the past three months. Make an inventory of purchases that you can live without – that 16th purse, that 11th watch, those ginormous cups of coffee with the mermaid, and so on. Add them all up. Then, ask yourself, "How much do I make in a month?" Be accountable and turn from your splurging ways!

Budgeting is planning on how to spend your money wisely. It is our guide to reaching a financial end. For our community, our goal is, after paying essentials, leftover money should go towards saving the future of our children with special needs. Sum up necessary expenses, such as housing, vehicles, insurances, utilities, groceries, and additional costs for your child's unique requirements. Hopefully there will be an amount left over from your monthly net income to be put aside for our purpose.

The safer way to save is to set aside at least 10% of your household income every month, before anything else. Since the goal is to gradually increase what you can set aside for your child's future, we might as well call our spending plan "tighten your belt." Let's think like a millionaire whose mindset is on acquiring more savings for investments, and stop acting wealthy for the moment. Follow your budget like you're tailgating a vehicle that will lead you to a pot of gold.

To make budgeting enjoyable, look up some apps that will help at: **https://blog.disabilitycanhappen.org/top-budgeting-apps-available**

2. DEATH TO DEBT

I'm talking about the debt we've accumulated from luxuries, not from basic needs. Luxuries include clothes, travel, toys, eating out, and stuff we don't really need and can't return. Materialism has blinded us to equate happiness with owning stuff. Indeed, we've acquired more goods and, in the process, have disabled our financial potential.

When our family moved to America, we were fascinated by how many credit cards an individual can have. We were in the land of the free; free to shop anytime, free to buy every whim and fancy, and free to feel miserable about growing debt. Several months later, the engineering firm my husband worked for filed for bankruptcy. I realized then that I could actually keep quiet for days when in shock. On the day of reckoning, my husband and I did the math. How much did we owe on our credit cards and how much did we need to pay monthly? The

DETERMINE TO GET OUT OF THE CRISIS

Attitude is everything. When dealing with any crisis, a positive attitude will keep you pushing. Be sure to have backup plans, just in case some don't work. Never lose heart. You can wait out most crises and bounce back on your feet. Your focus and priority should be on successfully getting out of the rut.

PLAN NOW

We can financially prepare for our child's future, as well as unexpected crises. Determine to educate yourself and gain the financial skills from here on. You need to plan for the best and be prepared for the worst. Initially, you may feel overwhelmed and apprehensive about making sacrifices, but that's better than being regretful tomorrow.

Before migrating to America, our family enjoyed a comfortable life. My husband and I had built an apartment building. After bank loan payments, collection from rentals would be a reliable source of income. It would sustain us during retirement and provide for our children, especially Jem, when we're gone. Simultaneously, we had a prosperous massage livelihood. We got the concessions in the big hotels, and we provided a living for several masseurs with visual impairment.

I delivered consultancy services on the side, and my husband, an engineer, contracted projects. We had life insurances, college education plans for our kids, and other investments. We were technically set up for the future, except for one thing. We were concerned that Jem might not maintain her residual vision. At that time, the Philippines didn't have the medical technology and resources for her visual condition. One day, my brother in America advised that we consult his family ophthalmologist. He was a glaucoma specialist in New York who was an expert in aniridia. We made the tough decision to leave everything behind, pack up, and start over in America. Most of our friends and relatives thought we'd gone mad, but our hearts were set on Jem's

long and short of it is, if you don't know offhand how much you owe, and if more than 30% of your take-home salary goes to paying credit card debts, you're in the red.

We worked contractual, even taking on odd jobs to pay our bills and debt. We labored nights and weekends until we got a job. Since then, we vowed to pay off our credit cards and use them only for essential things. We charged this crisis to experience.

The first rule in liquidating debts is to stop adding to it. When you're tempted to buy a luxury item, imagine you're feeding a fire-breathing dragon that burns up your earnings and your ability to build your child's future.

Know exactly how much your debt is costing you each month. Imagine that same amount of money going to savings that could eventually be turned into a special needs trust. Stamp that figure in your mind as your goal to keep you gung-ho in tackling your debt. Figure out a plan for paying it off. You can set a doable target amount each month and monitor it. I always allot more to pay off the credit card with the highest interest rate. Schedule all your payments on the same date monthly so you won't forget. Put away the cards you've paid off, but never close your account or your credit score will slump. As one preacher said, there is life after debt.

3. SAVE

With a budget in place, and as you pay down your debt, you'll have more to save. As a family with special needs, we've learned to expect the unexpected, like sudden medical bills, or necessary assistive technology on top of possible major car or home repair, even job loss. Experience taught me to always maintain an emergency fund. I'll never forget the time when Jem was closest to losing her vision due to her rocket-high eye pressure. Her ophthalmologist prescribed eye drops that cost more than liquid gold. It was a do or die decision to save her vision and our emergency fund saved the day. It kept us from using plastic money and incurring debt. A good target for an emergency fund would be at least three months' worth of expenses.

Make sure you're not leaving money on the table. Research, network, or get nosy about benefits your child might be missing out on. Money saved is money earned and "free" is always in our budget.

4. TURN SAVINGS INTO INVESTMENTS FOR YOUR CHILD'S FUTURE

Envision your child's future. Since you know your child best, you would have an idea of his life as an adult. Would he have a college degree and possibly get employed?

Or would he be dependent on programs? What about living arrangements? Such questions could guide you in setting a long-term savings goal for money to put into a special needs trust or other investments that suit your needs. Factor in your child's current cost of living. Estimate the value of this amount 10 to 15 years from today, considering the rate of inflation. Take an inventory of your estates, like 401-K, real estate properties, and other assets or valuables. If your estate has enough to cover your child's future cost, you're lucky. Otherwise, determine the difference between the value of what you currently own from future expenses for your child. Set the amount as your long-term savings goal for building a special needs trust. In my opinion, the best way to fund a special needs trust is through life insurances.

education, employment, success, and happiness. Set your sights on your child's tomorrow. Draw a vision board to motivate you to invest in his or her future every day.

GOOD NEWS!

Wait! Don't quit reading. I have some good news for you. Financial planning for your child's future isn't limited only to controlling money from your grave. Your children can actually have an account that they can enjoy while you're alive.

Help your child to Achieve a Better Life Experience by creating an ABLE account. The beneficiary of an ABLE account is the owner, the person with a disability. Contributions to the account are not taxed and can be made by the owner, family, special needs trust, or any person. The beauty of the ABLE account is that the beneficiary may have more than $2,000 without losing eligibility for public benefits. The account owner can withdraw money at any time for qualified disability expenses. En-ABLE your child today. Learn more at: **www.ablenrc.org/what-is-able/what-are-able-acounts**

HELP IS AVAILABLE

Don't be overwhelmed by all this money talk! You don't have to do it alone. Consult your family and community. Better yet, seek a certified financial planner and make sure the expert is a chartered Special Needs Consultant. Review the credentials of financial planners very carefully before contracting one. You can also check out financial planning systems like:

- **https://enablesnp.com/free-special-needs-planning-system**
- **https://kidshealth.org/en/parents/needs-planning.html**

Should you decide to improve financial competency during these uncertain times, you will gain a lasting benefit from the pandemic. As Benjamin Franklin once said, "An investment in knowledge pays the best interest." Don't let your finances be another pandemic casualty. •

HEARTSIGHT

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

COVID 19
CORONAVIRUS DISEASE

STOP THE SPREAD OF GERMS

Help prevent the spread of respiratory diseases like COVID-19.


Avoid close contact with people who are sick.


Cover your cough or sneeze with a tissue, then throw the tissue in the trash.


Avoid touching your eyes, nose, and mouth.

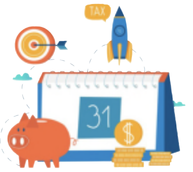

Clean and disinfect frequently touched objects and surfaces.


Stay home when you are sick, except to get medical care.


Wash your hands often with soap and water for at least 20 seconds.

CDC

For more information: www.cdc.gov/COVID19



FINANCIAL PLANNING

THE SPECIAL NEEDS PLANNING PROCESS

BY ALEXANDRA BAIG, MBA, CFP®

Since it reopened, post-COVID restrictions firmly in place, Chicago's Museum of Science and Industry is where my family and I have spent quite a few Sunday afternoons. What I like most about this museum is that it does not just show my children "cool stuff." It shows them what it takes in creativity, daring and hard work to make cool stuff a reality. My children come away understanding the process, not just appreciating the results.

As a parent considering the future life of your son or daughter with a disability, you may have been inspired by shows like *The Specials* (www.the-specials.com) or *Born this Way* (www.youtube.com/watch?v=T_ygHNI8wcg) that show young adults with disabilities living full, independent, and complex lives with support from their families, friends and professionals. You appreciate these results, but the real questions you want to ask are, "How did they get here? What did it take?" These are the questions that I help families answer when we go through the process of creating a comprehensive future financial plan for the family member with a disability. These are the steps we take.

DEFINING THE VISION

People with disabilities do not have "special needs". They have the same needs as everyone else, but they may require additional support to meet those needs. The first step in creating a financial plan for your family member with a disability is developing a vision for that person's future life. If your family member is old enough to participate, then they should be a defining voice in developing the vision. This vision for the future should describe the following aspects of life:

- **Residence.** Where would your family member like to live? In a single-family home with a yard? In a townhome or condominium community with amenities like a clubhouse, pool, or exercise room? Would your family member prefer to live alone, or with roommates, or does he or she expect to have a romantic partner or get married? Does your family member need housing that allows pets? Does your family member prefer a downtown location or a suburb? Is it important to your family member to be in a quiet area? An area with a lot or parks and green spaces?
- **Employment.** Does your family member want and expect to work? Part-time or full-time? One job or more? Paid, or as a volunteer? In what type of occupation? Will your family member require support? Initial support that fades away, or ongoing support through their whole working life?
- **Recreation and exercise.** What does your family member do for fun? Do they need to be near the "Y" or a certain health club? Near a bicycle trail or a hiking or running path? Does your family member need access to a park district with tennis courts or a pool? Do they want easy access to movie or live theater, shopping, museums, the zoo, or other local attractions? Do they have friends in the current neighborhood and need to stay close to them?
- **Community.** Where does your family member find their place of belonging? Is faith community important? Recreational

team sports? Clubs or activity leagues? Do they need to live on campus or close to work to participate in after-hours activities?

- **Transportation.** Does your family member walk or bicycle to their activities? Do they need to be near public transportation or in an area readily served by rideshare drivers?

FORECASTING COST

Once we have described all the components of your family member's desired life, we research and assign a monthly or annual cost to each one. We look at the cumulative expenses your family member will have this year, next year, and every year for the rest of his/her life. We stop and start costs as your family member goes through successive life changes. For example, in young adulthood, your family member may spend more on continuing education, travel, and recreational activities with friends. As your family member gets older, they may need to spend more on medical treatment.

IDENTIFYING RESOURCES

Once we know how much your family member will need to spend each year to maintain their chosen lifestyle, we match that against the income streams your family member will have. If your family member is expected to work, we calculate hours and expected hourly wages or salary and consider money directed towards retirement or other savings. We consider whether the person may take on more hours and/or move into a higher-paying position as their experience and tenure increase. And of course, we consider that, like the rest of us, the person with a disability will need to retire from work at some point.

Social Security benefits are a cornerstone of financial stability for many people with disabilities. We examine the eligibility criteria for Supplemental Security Income (SSI), Social Security Disability Insurance (SSDI) that your family member may earn on their own work record, and the so-called "Childhood Disability Benefits" ("CDB") or "Disabled Adult Child" ("DAC") benefits that your family member may qualify for on the work record of their parents if the member's disability started before age 22. Many people with disabilities will become eligible for more than one of these benefits, sometimes simultaneously, and some people will eventually move through all of them.

People with disabilities who receive SSDI on their own work records or a CDB/DAC benefit will become eligible for Medicare after 24 months. Medicare can cover a range of health care costs, particularly when paired with Medicaid. In addition, if your family member will need a personal care attendant or direct support worker to provide daily living or employment supports, Medicaid may cover much of those cost through Medicaid waiver-funded programs.

A person with a disability may also be eligible for low-income housing subsidies, utilities assistance, local property tax exemptions, and the Supplemental Nutritional Assistance Program (SNAP, formerly known as food stamps). The financial plan looks at how to maximize these benefits over the person's lifetime.

FILLING THE GAP

A person's work income plus Social Security and other government benefit streams will a portion of their expenses. Unless the person is able to work full-time for a living wage and still qualify for a Medicaid waiver program that pays all necessary support costs, there is almost always a gap in the plan between the total annual expenses and the cash inflow to cover them. At this point, we consider the amount of assets the person will need to draw upon over the course of their lifetime to fill that gap. These assets may be owned by the person her/himself in the form of retirement or investment accounts. Of course, it is important to understand how owning such accounts may limit the person's eligibility for the very government benefits that could contribute to income and to consider assets such as ABLE accounts, which are not considered in an eligibility determination. If the family member with a disability has received an inheritance or a settlement of significant size, it may be necessary to create and fund a first-party special needs trust to permit the person to set aside those funds for supplemental needs while accessing government benefits to cover primary needs.

Parents, grandparents and others may also want to fund a third-party special needs trust, which can provide supplemental support to the family member with a disability without disrupting their benefits. An essential part of the comprehensive planning process is determining the least risky and most cost effective, tax efficient way to fund such a trust.

KEEPING CURRENT

The final step of the planning process is iterative. Sometime into the plan, the person with a disability may find a better job. Alternatively, they may be laid off. The person may want to move or take on a new activity. They may have found a romantic partner or different roommates or decided that they want to live alone. The person's health may have improved or worsened compared to the expectations we set at the beginning of the process. For the plan to be both realistic and effective, it must be updated as the life of the person with a disability changes bringing corresponding changes in their income and expense and as the outside environment changes, causing changes in the value of assets and the rules governing their ownership in relation to government benefits.

The goal of a comprehensive financial plan for your family member with a disability is to make sure that has the financial resources needed to support the life they want AND that those resources are secure and dependable even when life takes the inevitable twists and turns away from your initial expectations. Understanding the process is the first step towards making it work.

The goal of a comprehensive financial plan for your family member with a disability is to make sure that has the financial resources needed to support the life they want AND that those resources are secure and dependable even when life takes the inevitable twists and turns away from your initial expectations. Understanding the process is the first step towards making it work.•

ABOUT THE AUTHOR:

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

FINANCIAL PLANNING

ARE YOU ON TRACK WITH SPECIAL NEEDS FINANCIAL PLANNING?

PLANNERS HELP YOU FOCUS ON THE LONG-TERM WHILE RECOMMENDING STRATEGIES FOR TODAY

BY ROB WRUBEL, CFP®

Puzzles. Symphonies. Synchronized swim events. The car you drive. What do these have in common? They are made up of many pieces, each of them requiring mastery, that blend to form something beautiful and coherent.

Financial planning fits into this category. I know, you're thinking, "Financial planning and a puzzle are completely different. One finishes with an interesting picture, the other with a bunch of hard-to-understand computations on paper." And while it's true a puzzle has much to do with art and financial planning with numbers, the process of each is taking parts of a whole,

THE WAY FORWARD: Getting out debt, building reserves and investing for the future take time, and the more you can connect intellectually, emotionally and financially to the future, the easier it is to stay on track.

and organizing them in such a way to bring clarity, coherence and contentment.

Financial planning is a complex process designed to help determine a person's financial goals and needs and develop strategies to achieve them. Tax, legal, risk management, investments and retirement accounts all need to blend to support our goals. Special needs planning has an additional layer to consider – government benefits.

The biggest question I get from people is, "Am I on track?" Financial planning will give you that answer.

Often, "financial planning" happens by accident. We accumulate the pieces of our financial and legal lives without it being coordinated. It happens like this:

- *Someone told me to sign up for the 401k and now, I have one.*
- *My mom told me to get a will when I first married – 15 years ago. It's in a box from the last time I moved, maybe in the basement… or garage… or got recycled.*
- *I heard about special needs trusts and think I need to have one but don't know why.*

It's easy to accumulate financial products – mutual funds, stocks, employer plans, insurances and bank accounts. It's harder to know if they are working for you to help you know whether you are on track to achieve financial security, retire comfortably, pay for college, and achieve your other life goals. Done right, your financial and legal tools support the life you want to live, reduce the stress you feel about an uncertain future, and work to move you towards feelings of security and optimism.

Financial planners start by talking to you about your goals and why they are important to you. They focus on what you want to do with your life and then build a plan to help have the money to pay for what you want and need. Along the way, good planners talk about your experiences, the financial messages you carry around, the roadblocks in your path and the happiness you will feel by hitting certain milestones.

Plans include a list of your goals and timelines for when you need funds. Do you want to retire at 55, 60 or 65? The choice will impact how much you need to save now, what rate of return you need to achieve and impact how you pay for healthcare before Medicare kicks in.

In special needs planning, we highlight certain ages and events for the family member with a disability. Most people apply for Supplemental Security Income (SSI) at 18. School transition programs end at age 21 and we need to think of what happens at that time. The planner generally won't have a list of community organizations; he or she will help you understand that you might have additional expenses to pay for at that time, like transportation, career training, or continued education and recommend account types and strategies to save and invest.

Do you expect your family member with a disability to live independently? If so, you need to accumulate resources to pay for assistance, buy a condo or have other expenses as a result.

Planners help you focus on the long-term while recommending strategies for today. Getting out debt, building reserves and investing for the future take time, and the more you can connect intellectually, emotionally and financially to the future, the easier it is to stay on track.

Make sure to interview a few different people to understand their backgrounds, education, way of working and compensation when hiring a planner. There are a variety of ways to go.

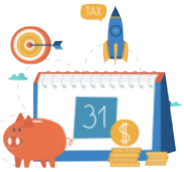
We measure financial success with numbers. The size of our retirement and bank accounts. The amount of debt outstanding. Those figures give us tangible data to help us understand if we are making progress.

True success in financial planning comes when you are comfortable knowing you're headed in the right direction financially. That you're on track.

Planners take complex systems – investing, tax, estate, benefits – and blend them into a format designed to meet the needs of individuals and their families. It can be a personal, rewarding experience for you to meet with a planner, giving you both financial and peace-of-mind benefits. •

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.

FINANCIAL  PLANNING

HOW TO SAVE MONEY *without* LOSING FINANCIAL ASSISTANCE

BY MEGAN PRESTON

People everywhere struggle with personal finance and people with disabilities are no exception. Creating a plan for yourself is a complicated process made even more complex when you factor in the unique expenses and assistance programs for individuals with disabilities. Families want to provide the best care for their loved ones, but they do not want to pay more than necessary for that care. Finding a balance between various disability assistance and benefit programs and your own personal finances can be a real challenge.

Individuals with disabilities can only own a limited amount of assets without risking losing their eligibility for "means tested" benefit programs. This limit greatly impacts an individual's ability to pay all their expenses and improve their standard of living. Paying for anything outside the usual expenses can be stressful and overwhelming if not impossible. It goes without mentioning that living with a disability can result in extraordinary costs that can stretch your resources, but when you are limited on how much you can have saved to cover these costs, you can feel like you're out of options.

One option to be able to save more for these extra needs is an ABLE account. ABLE accounts came about as a result of The Stephen Beck Jr. "Achieving a Better Life Experience" (ABLE) Act that became law on December 19th, 2014. They allow states to sponsor programs that offer the opportunity to invest and save on a tax-favored basis without jeopardizing their eligibility for government disability-related benefits. An attorney specializing in special needs would be able to best advise on how an ABLE account would affect these benefits. An individual with a disability is the account owner and beneficiary of the account. Any of the following references to the account owner or the beneficiary should be considered the same person.

ABLE accounts are opened under a state-specific 529A ABLE program. It is not necessary to use the program set up by the state you live in. You can use a different state's plan as long as the other state's plan accepts out-of-state residents. A state can choose to use its own investment program, another state's program, or an entity such as a financial company. There should be various investment strategies to choose from within each program, and each strategy should be carefully considered. The maximum number of times you can change the investments in an ABLE account is twice per year. Performance and fees are two important things to consider as they directly affect the account balance. You should also consider what investments and investment allocations would help to meet the beneficiary's needs and risk tolerance. The programs differ from state to state, so doing research ahead of time is very important.

An ABLE account is an investment account that is tax-deferred, meaning the investments aren't taxed while they are in the ABLE account, similar to an IRA. This greatly helps the account grow over time as interest and dividends are not taxed and can be reinvested. While the contributions to an ABLE account are not tax deductible, any withdrawals taken from the account are tax-free as long as they

GETTING THE JOB DONE: ABLE accounts are a unique tool only available to some. It gives the opportunity to save and invest money in a tax-deferred account that offers tax-free withdrawals for qualified disability-related expenses, and it generally is disregarded when it comes to many "means tested" programs that some individuals with disabilities rely on.

are used to pay for the beneficiary's qualified disability related expenses. These expenses are broadly defined in Internal Revenue Code Section 529A(e)(5) as:

> *"Any expenses relating to the eligible individual's blindness or disability… including the following expenses: education, housing, transportation, employment training and support, assistive technology and personal support services, health, prevention and wellness, financial management and administrative services, legal fees, expenses for oversight and monitoring, funeral and burial expenses, and other expenses, which are approved by the Secretary under regulations and consistent with the purposes of this section."*

Any distributions of investment earnings that are not used for the beneficiary's qualified disability related expenses are subject to income tax and a 10% penalty tax. The ability to take tax-free distributions for the beneficiary's qualified disability expenses is one advantage of ABLE accounts.

Another advantage of ABLE accounts is that they are generally disregarded in the calculation for determining eligibility for Federal "means tested" programs such as Supplemental Security Income (SSI), Medicaid, or public supports such as Supplemental Nutrition Assistance Program (SNAP) and Temporary Assistance for Needy Families (TANF). One important exception to this is that distributions from the ABLE account that are used to pay for the beneficiary's housing expenses will be counted as income when applying for SSI. Another is that if the account has at least $100,000 or more, the beneficiary's SSI benefits would be suspended, but the beneficiary would not be considered to be disqualified from receiving SSI. This is important for those who are eligible for Medicaid because they also qualify for SSI since, even though the SSI benefits would be suspended, Medicaid benefits could continue.

"An ABLE account beneficiary must meet the SSAs definition of being fully disabled. This means the individual must suffer from a mental or physical impairment that prevents him or her from engaging in any substantial gainful employment."

RESTRICTIONS

As this type of account has several advantages designed to benefit those with disabilities, it has restrictions on who can qualify to use such an account. First, the beneficiary must be blind or meet the Social Security Administration's definition of being fully disabled. This means the individual must suffer from a mental or physical impairment that prevents him or her from engaging in any substantial gainful employment and the impairment must have lasted for at least five months and is expected to last for at least 12 months, or result in death.

Second, while the beneficiary can be any age when the account is created, he or she must have been blind or disabled before age 26. Once the account is created, it can remain open for the life of that individual, even if he or she ceases to be disabled. In the case that the beneficiary is no longer disabled, the distributions from the account would be used for things other than qualified expenses and thus may be taxable and subject to a penalty. Alternatively, the ABLE account could be moved to a sibling or step-sibling of the original beneficiary, as long as the new beneficiary also meets the qualifications to be an ABLE account owner.

> *"While ABLE accounts do not solve every issue when it comes to the personal finances of individuals with disabilities, they are a tool for planning for the future and helping beneficiaries improve their lives."*

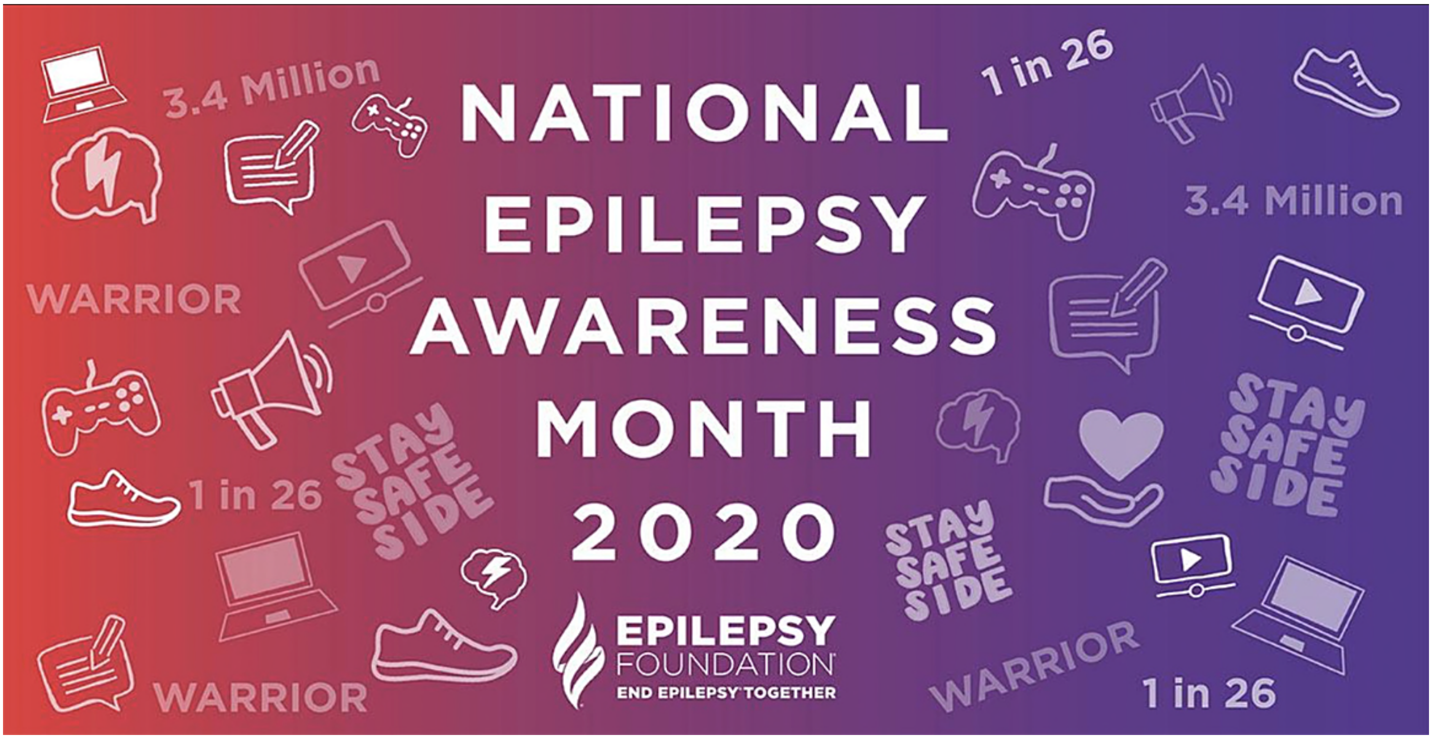
While the individual who has a disability would be the account owner as well as the beneficiary, a family member or other third party can help manage the account, if necessary, since many individuals with disabilities are capable of making their own financial decisions. Anyone – parents, grandparents, siblings, friends and even the beneficiary – can contribute to ABLE accounts, although there is a limit of one ABLE account per eligible person. This can be a benefit for those who prefer to keep track of fewer accounts. The total that can be contributed to an individual's ABLE account from all donors is equal to the annual exclusion in that year, e.g., $15,000 in 2020, or the sponsoring state's 529 plan limit if it is less. This limit does not apply to ABLE account rollovers that go from one sibling to another, as mentioned before. The contributions made to an ABLE account are not tax deductible and so they are treated as gifts to the beneficiary, and the donor's annual exclusion amount (also $15,000 per donor/done in 2020) can be used to offset gift tax consequences. Please consult your tax advisor or tax specialist to discuss the tax implications of utilizing ABLE accounts. Each state also has a limit on how much money can be saved in an ABLE account however and that limit ranges from $235,000 to $529,000. You should always check on the applicable limits when researching ABLE programs that are available to you.

ABLE accounts are a unique tool only available to some. It gives the opportunity to save and invest money in a tax-deferred account that offers tax-free withdrawals for qualified disability-related expenses, and it generally is disregarded when it comes to many "means tested" programs that some individuals with disabilities rely on.

While ABLE accounts do not solve every issue when it comes to the personal finances of individuals with disabilities, they are a tool for planning for the future and helping beneficiaries improve their lives. For those who would like to learn more about ABLE accounts please visit the ABLE National Resource Center at **www.ablenrc.org** •

ABOUT THE AUTHOR:

Megan Preston is a Financial Advisor at Robert W. Baird & Co. in La Crosse, Wisconsin. She helps clients develop customized strategies to meet their personal and familial goals. Baird does not offer tax or legal advice. Megan lives in La Crosse, Wisconsin. She can be reached at MPreston@rwbaird.com.



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

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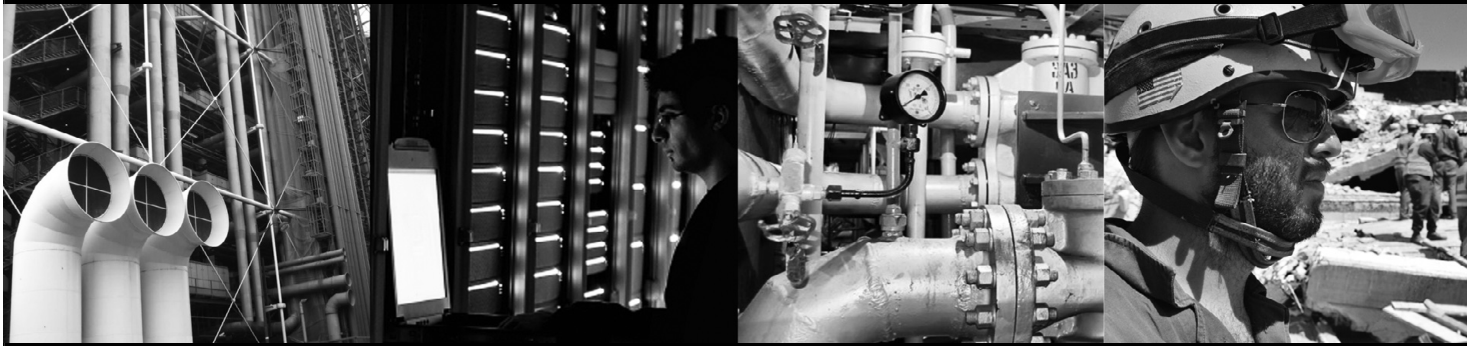

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SPECIAL NEEDS TRUSTS: ONE SIZE DOES NOT FIT ALL

BY RICHARD I. MILLER

Special Needs Trusts enable funds to be set aside for individuals with a disability without disqualifying a beneficiary from government benefits such as SSI and Medicaid. To qualify for SSI and Medicaid, an individual's resources cannot exceed $2,000. A properly designed Special Needs Trust will supplement public benefits without jeopardizing eligibility, because the transferred assets will not be treated as an available resource of the individual for government benefit purposes.

TRUST WORTHY: It is advisable to consult with an experienced professional before you establish or fund a trust to ensure your objectives are achieved and the financial security of the individual with a disability is preserved.

Special Needs Trusts enable funds to be set aside for individuals with a disability without disqualifying a beneficiary from government benefits such as SSI and Medicaid. To qualify for SSI and Medicaid, an individual's resources cannot exceed $2,000. A properly designed Special Needs Trust will supplement public benefits without jeopardizing eligibility, because the transferred assets will not be treated as an available resource of the individual for government benefit purposes.

The term Special Needs Trust is often used generically and interchangeably when considering the preservation of assets for an individual with a disability who is receiving government benefits. It is important to understand, however, that there are two types of Special Needs Trusts that have different rules and consequences. Recognizing the difference between these instruments is critical prior to establishing and funding the trust.

THIRD-PARTY TRUST (Supplemental Needs Trust)

Third-Party Trusts are established with funds originating from someone other than the individual with a disability. In general, these funds are received by way of inheritance or gift from a family member.

SELF-SETTLED TRUST

Self-Settled Trusts are established with the funds of the individual with a disability. These funds are usually derived from a personal injury award, custodial account or the individual's own assets which were accumulated prior to disability.

Both types of trusts allow assets to be preserved for individual with a disability without disqualifying him or her from SSI or Medicaid. There are significant differences, however, in the way the trusts are funded, administered and distributed.

Most notably, a self-settled trust requires a payback provision – i.e. any funds remaining in the trust upon the death of the beneficiary must first be used to reimburse the State for benefits expended on behalf of the beneficiary. In addition, the Trustee must file an annual accounting with the State detailing how the funds are used. The nature of the disbursements can be questioned by the State, since every dollar spent during the beneficiary's life means there is less available to reimburse the State upon the beneficiary's death. A self-settled trust must only contain assets of the individual with a disability; be for the sole benefit of the individual with a disability; and established prior to the individual with a disability turning age 65.

A third-party trust has none of these restrictions. Any funds remaining in a third-party trust can be distributed as directed by the individual who establishes the trust. Likewise, there is no accountability to the State as to how the funds are disbursed during the lifetime of the beneficiary since no State payback is mandated. The Trust can also be established irrespective of the beneficiary's age.

The advantages of a third-party trust make this the preferred option, if possible. Avoidable mistakes, however, often result in assets passing directly to the individual with a disability, leaving the self-settled trust as the only option. For example, parents unintentionally leave inheritances to their child with a disability, through their will or inadvertently designate the child as a beneficiary of a retirement account, life insurance policy or annuity. It is also common for family members to establish UTMA or custodial accounts for minors with a disability, not realizing these assets vest with the child when he or she turns 18 or 21, thereby disqualifying the child from benefits. Once assets pass to the child, a self-settled trust may be the only recourse to salvage the situation. For this reason, it is critical to engage in proactive estate planning, so assets are distributed directly to a third-party trust.

In addition, it is important to consider who should be appointed as Trustee of a Special Needs Trust. The Trustee must be prepared to accept the responsibility of administering the Trust and understand the impact on the beneficiary's government benefits. For instance, distributions from a Special Needs Trust could unintentionally reduce SSI payments if made directly to the beneficiary or used to pay for food or shelter.

Navigating the complexities of special needs trusts and the maze of government benefits can be confusing and overwhelming, even for the most sophisticated parties. Before you establish or fund a trust, it is advisable to consult with an experienced professional to ensure your objectives are achieved and the financial security of the individual with a disability is preserved.•

ABOUT THE AUTHOR:

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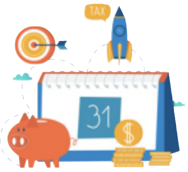


FINANCIAL PLANNING

INDEPENDENCE

FINANCIAL LITERACY FOR STUDENTS WITH DISABILITIES

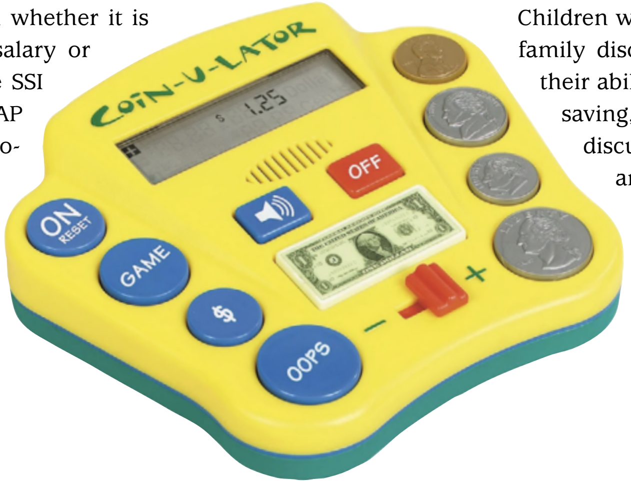
BY LAUREN AGORATUS, M.A.

Financial literacy is key for students with disabilities to develop independence. Four key issues to address are defining financial literacy skills, the importance of starting early, the family's role, and how assistive technology (AT) can help with independence in transitioning to adult life.

WHAT ARE FINANCIAL LITERACY SKILLS?

Students with disabilities need to understand the concepts of earning, budgeting, and borrowing. For earning, they need to understand their pay and benefits. Students will learn to make the most of what they bring in whether it is earned income such as wages and salary or unearned income from programs like SSI (supplemental security income), SNAP (supplemental nutrition assistance program, aka food stamps), etc.

Regarding saving and budgeting, students with disabilities need to have an understanding of what saving is and how to invest money. Budgeting is the most important tool for controlling finances. Students need to plan for spending and saving and spending less than they make. Some ideas for budgeting include making a separate line for saving in the budget, putting away $1 a day, saving in a jar, etc. While spending, students with disabilities need to understand the value of an item they want to purchase. They also need to know the various ways to pay such as cash, check, debit/credit, or electronically. Automatic deductions for rent, utilities, phone etc. may be helpful. Students should also know how to get good value for something by comparing prices.



ON THE MONEY: Students can learn about money with this interactive coin-counting calculator. The Coin-U-Lator can count money, teach the value of different coins, determine how much money is needed to make a purchase, and more.

For borrowing, students with disabilities need an understanding how to borrow and the pros and cons of loans and credit cards. They need to realize if they don't have enough money, they can pay later but sometimes this comes with interest so they end up paying even more. Families can use supported decision-making to help with this (see Resources).

IMPORTANCE OF STARTING FINANCIAL LITERACY INSTRUCTION EARLY

Developing financial capability is an important part of transition. The U.S. Treasury defines this as the ability "to manage financial resources effectively" and this applies to everyone, including students with disabilities. Lessons in school must be age appropriate and should be individualized by the goals and objectives in the IEP (Individualized Education Program) during transition

WHAT IS THE FAMILY'S ROLE?

Children with disabilities should be involved in family discussions on finances to the best of their ability. Families can talk about earning, saving, and borrowing. Another important discussion is how to protect your money and identity, such as using a bank account for a paycheck. Families can also discuss benefits such as SSI to help students understand supports available to them if needed.

HOW ASSISTIVE TECHNOLOGY CAN AID IN INDEPENDENCE IN ADULT LIFE

It is important to note that the need for Assistive Technology (AT), including AT that can help with financial literacy, must be considered in the IEP/504 process. Per IDEA (Individuals with Disabilities Education Act), AT is used to "increase, maintain, or improve functional capabilities". There are two considerations regarding AT in the educational process: the actual devices and services, and training in their use.

Financial literacy is one of the key components necessary for successful transition of students with disabilities to adult life. Specific concepts in developing these skills include earnings (both earned and unearned income), saving and budgeting, and understanding borrowing. This must be started early by both families and schools. Assistive technology tools can help facilitate this process. Everyone, but especially students with special needs, can benefit from developing financial literacy skills.

Note: This article is based on SPAN's (SPAN Parent Advocacy Network) Developing Independence webinar series; Special thanks to Dawn Monaco of SPAN for her help.•

ABOUT THE AUTHOR:

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

MAKING CENTS : MONEY SKILLS AND BUDGETING RESOURCES

MONEY SKILLS: BASICS

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COUNTING BILLS AND COINS APP
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CALCULATOR APP
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Financial Literacy for Students with Disabilities
Annotated Bibliography
www.transitionta.org/sites/default/files/Annotated_Bibliography_Financial_Literacy_KClark.pdf

SPAN
Parent Advocacy Network

SPAN
SPAN webinar
www.youtube.com/watch?v=EzV77vBehCc&feature=youtu.be

BOOK EXCERPT

HONEST MEDICINE:

Effective, Time-Tested, Inexpensive Treatments for Life-Threatening Diseases

Introduction: *The following is a chapter from Julia Schopick's bestselling book,* HONEST MEDICINE: Effective, Time-Tested, Inexpensive Treatments for Life-Threatening Diseases. *This chapter was written by Jim Abrahams, Hollywood writer/director of several iconic movies, the most famous of which is* **Airplane!** *In 1993, something not-so-funny happened to Jim and his family, when one-year-old Charlie developed epilepsy. This is Jim's story. It has been updated, and is being published in two parts in this magazine: Part 1 in November, and Part 2, in December.)*

CHAPTER 7

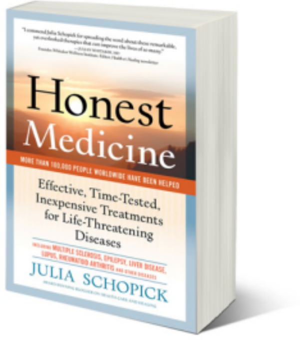
JIM ABRAHAMS: CHARLIE'S DAD, DIRECTOR OF THE CHARLIE FOUNDATION

Dr. Rumack: Captain, how soon can we land?
Captain Oveur: I can't tell.
Dr. Rumack: You can tell me, I'm a doctor.

When my partners and I wrote that line for our 1980 movie *Airplane!,* I had no idea of the reality we were tapping into. Fifteen years later I found out.

"IMPRESSION: It is my impression that Charlie has a mixed seizure disorder, most likely a variation of Lennox-Gastaut syndrome. Parents are fully aware of the ramifications of this diagnosis. Although there are many traditional combinations and permutations of drugs that could be used here, I agree with the current approach. It is my understanding that the next drug to be tried is a combination of Felbamate and Tegretol with which I have no problem. I would also consider the combination of Felbamate with Valproate with perhaps a benzodiazepine. In addition one wonders if the Felbamate could be pushed to an even higher dose than it is now, since we really do not know what the maximum dose of Felbamate is in young children. Another possibility is high dose Valproate monotherapy. One other alternative therapy which I have mentioned to the family, but only reluctantly because of the high incidence of side effects is high dose ACTH. The problem is that while high dose ACTH may be effective in stopping the seizures, they almost always recur as the dose is tapered. This makes one wonder if the risk-benefit ratio justifies the use of this somewhat dangerous mode of therapy. Finally, I think that if all pharmacological or therapeutic modalities fail, I would seriously consider a corpus callosotomy [an irreversible operation that severs the two halves of the brain] on this child. A corpus callosotomy would not be curative of all the seizure types, but may help the most troublesome part of his seizure complex, i.e. the drops."

– Written by Charlie's fourth pediatric neurologist, October 1993, two months before he became seizure- and drug-free on the Ketogenic Diet.



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**
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For those of us who have had children with difficult-to-control epilepsy, it is quite literally impossible to put the feelings into words. Sadness, frustration, agony, helplessness, anger, pain, despair. These words, even when bunched together, fall short. It's not just the seizures, or the drug side effects, or the failed surgeries. It's standing by and watching your child slip away – watching the lights go out – one day, one hour, one minute at a time.

That's how it was with my son, Charlie. His first seizure was on his first birthday, March 11, 1993. Over the following months he tried every available anticonvulsant drug medication. The seizures got worse. Dozens, frequently as many as a hundred per day. Brain surgery didn't work either.

For me, the hardest part of Charlie's seizures was seeing his eyes. One minute they were bright, clear, smiley. A split second later they were dull, unfocused. . .dead. Then they'd roll back. It was like watching him die. The rest of the seizure, whether it was a quick drop or his body stiffening and shaking with a high piercing noise, was terrifying and heartbreaking. But, for some reason, what has stuck with me the most were his eyes. No matter how many times we saw them, it never got easier for Nancy and me.

We were deep into the drug regimens when our neurologist told us the best chance to stop the seizures would be a surgery to drain fluid from Charlie's left ventricle. Turns out that seizures don't emanate from the ventricles of the brain, but we trusted him and his credentials. Charlie weighed about eighteen pounds on the day of the surgery. They promised Nancy he'd be asleep when they took him into surgery. But he was wide awake and crying when she had to hand him over. We were told the "procedure" was relatively simple, painless, and would last less than an hour. Three excruciating hours later, someone came up to the waiting room and told us that Charlie was having a bad reaction to the morphine, and that we needed to wait a little longer.

"Morphine?!" we asked. "For what?"

"Pain."

"How much pain?"

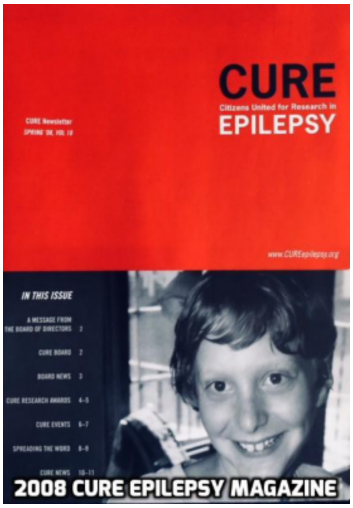
"It's hard to tell. He was uncomfortable."

"What was the bad reaction?"

"Hives."

When we finally were allowed to see him in the recovery room he was all red and swollen. Two days later, his seizures returned.

Charlie saw four pediatric neurologists in three cities. Over nine months, the seizures that had begun so subtly mounted in severity and frequency into the thousands. The seemingly endless drugs and drug cocktails altered his personality, development, appetite, sleep, complexion and bowels. We watched helplessly as he began to fade away. The fourth neurologist, quoted above, basically told us his epilepsy was incurable – that Charlie could expect a life of continued seizures and "progressive retardation." Nancy and I had to pull the car over on the way home because we could not see through our tears. We lost hope.



2008 CURE EPILEPSY MAGAZINE

1994 SEIZURE FREE CHARLIE

BUILDING IT: The Charlie Foundation had a clear idea of what we wanted to accomplish, but there was no road map. We tried a two-pronged approach, focusing on both public and medical awareness.

Then, in an effort to figure out how Charlie and his brother and sister and Nancy and I were going to get through the rest of his life with such a bleak prognosis, I went to the UCLA medical library (those were pre-Internet days) to do some reading. This was not in an effort to find a cure – after all, we had taken Charlie to many of the leading experts in the country, and they had all concurred about treatment options: Medications and surgery were the only alternatives.

I went to the library to figure out how Charlie and our family were going to cope with what we were told lay ahead of us.

Neither science nor research come naturally to me, but here is a sampling of the medical information I found – reports and studies about the Ketogenic Diet – on that one day in the medical library at UCLA in the fall of 1993. What confused me the most was that for years – even generations – the Ketogenic Diet had been consistently reported as helping a majority of the thousands of children who had tried it. Yet, though they all knew about the diet, not one of Charlie's doctors had even mentioned it to us.

> *"Thirty seven patients with essential epilepsy have been treated for periods of from three to thirty months by means of a ketogenic diet. Twelve have improved and nineteen have been free from attacks since institution of this treatment. Three patients remained free from convulsions for three to eight months and were not heard from again."*
>
> – *New England Journal of Medicine,*
> M. G. Peterman, MD, Mayo Clinic,
> April 4, 1925.

* *

> *"Of thirty patients treated with the ketogenic diet, 26.6 percent have remained free from attacks for long periods and have resumed an unrestricted diet."*
>
> –"Epilepsy in Childhood – Results with the Ketogenic Diet,"
> Lawson Wilkins, MD,
> *The Journal of Pediatrics,* January through June, 1937.

* *

> *"Results of treatment with ketogenic diet in 530 cooperative patients: No known attacks 5 to 36 years: 162 (30.6%); Improvement: 128 (24.1%); Failure 206 [38.9%]."*
>
> – *Convulsive Disorders in Children – With Reference to Treatment with Ketogenic Diet,*
> Dr. Haddow M. Keith, Mayo Clinic, 1963.

* *

> *"As of 1958, we had treated 426 children with the ketogenic diet. Seizures were controlled in 52%; in an additional 27% there was marked improvement; 21% did not respond to treatment. Since 1958 we have treated an additional 575 patients with the ketogenic diet regimen and the results relative to seizure control were essentially the same as those reported previously."*
>
> – *Comprehensive Management of Epilepsy in Infancy, Childhood and Adolescence,*
> Samuel Livingston, Johns Hopkins, 1972.

* *

> *"Before using the ketogenic diet, 80% of the patients had multiple seizure types and 88% were treated with multiple antiepileptic drugs; these children were among our most intractable patients. Thirty-eight percent of these children had a decrease in seizure frequency of at least 50% and 29% had virtually complete seizure control."*
>
> – *Efficacy of the Ketogenic Diet for Intractable Seizure Disorders: Review of 58 Cases,* Kinsman, Vining, Quaskey,
> Mellitis, Freeman, Johns Hopkins, 1992.

Astonishingly, the above-quoted 1992 article had been published in *Epilepsia,* the premiere medical epilepsy journal, just a year before Charlie got sick. It was hot off the presses. Different doctors, from different hospitals, in different decades used the identical therapy on a similar patient population and came up with nearly identical results. And no one told us. How could that possibly be?

When I broached the subject to Charlie's primary neurologist and mentioned the Ketogenic Diet and another possibility we were considering – an herbalist we had heard about who worked out of a strip mall in Houston, Texas – he said, "Flip a coin, I don't believe either will work." For the final time, we took his advice. We flipped

PHOTOS PROVIDED BY JIM ABRAHAMS

the coin. It said to go to Texas. We did, and Charlie's seizures continued.

At last I called Dr. John Freeman from Johns Hopkins, one of the authors of the 1992 article, and co-author of the book, *Seizures and Epilepsy in Childhood: A Parent's Guide.* He suggested we bring Charlie to Hopkins. We did and Charlie was started on the diet. He went from having dozens, frequently as many as one hundred seizures a day, to zero within forty-eight hours. He was off his four anti-convulsant medicines within a month. Five years later he was weaned off the diet and has remained seizure- and drug-free while eating a regular diet to this day. Charlie is now a pre-school teacher in West Los Angeles, has played the piano for eighteen years, and is also a boxer. He has never had another seizure. The Ketogenic Diet *cured* his epilepsy.

What makes Charlie's story unusual is not that his seizures were difficult to control, or that the medications had bad side effects and failed to help. There is a world epilepsy population of over 60 million people and most of those people start having their seizures as children. Yet only a tiny fraction of 1% of the parents whose children would benefit from a Ketogenic Diet therapy ever hear about it. Let that sink in. How many children worldwide have suffered unnecessarily because their parents were uninformed or misinformed about the diet since 1925? What is the collateral damage? It's a human tragedy of incalculable proportions.

What does make Charlie's story unusual was that he eventually got to the Ketogenic Diet. Though it had been a first-line therapy for children with intractable epilepsy in the 1930s and '40s and '50s in America, it began to fall into disuse when anti-convulsant medications came along. By the time we took Charlie to Hopkins in 1993, the diet was on the verge of extinction. Hopkins had one of two or three Ketogenic Diet programs in the world, and they were only initiating a handful of children every year.

Later, when we asked Charlie's neurologists why they hadn't told us about the diet, these were their top three answers:

1) *"The Ketogenic Diet is a high-fat diet and therefore may have health consequences."*
2) *"The Ketogenic Diet is too difficult."*
3) *"There is no science behind the diet."*

1) Health consequences? The demonization of fat by the cardiology community and the American Heart Association has long been exposed and debunked: https://youtu.be/GsoidXRiHQw. As the quote that begins this chapter indicates, Charlie's doctors were considering several extremely dangerous treatment options: yet more drugs and drug combinations in higher doses, with terrible side effects; ACTH, a brutal, multi-thousand dollar per day injected hormone therapy; and cutting his brain in half, i.e. a corpus callosotomy. This surgery is irreversible and precludes any possibility of a normal life—or even seizure freedom. The safest, most effective option for Charlie—the Ketogenic Diet—wasn't even discussed.
2) Too difficult? Shouldn't that be the family's decision? Is the standard of care really that a practitioner can decide what therapy is "too difficult" for a critically sick child's parents to undertake? Certainly the diet was challenging, but it was a walk on the beach compared to the trauma Charlie and my family had just experienced. Nancy and I assumed a system of informed joint decision making between physician and patient. We were wrong.
3) No science? I find this the most insidious of all the arguments. When we were told there was no scientific understanding of the mechanisms of the Ketogenic Diet, we assumed there were scientific explanations of how the drugs worked. Wrong! There is no science behind any of the drugs or drug combinations Charlie had been prescribed – unless you want to include rodents, cats, and rabbits. It is illegal to scientifically study medications in children younger than four. Plus there is no scientific understanding of the interactions of endless drug combinations on people of any age. As Dr. Freeman from Johns Hopkins said, "Treating epilepsy in people with drug resistant seizures is 80% art and 20% science." To arbitrarily represent that medications are science, and to use that misrepresentation as an argument against the Ketogenic Diet, is a cruel double standard. In fact, statistically, after the failure of two medications, the diet has a far greater chance of success than any medication or combination of medications.

I found myself in an extraordinary position. I had experienced the horror of Charlie's childhood epilepsy. I had stumbled across a dying medical therapy that could benefit most and cure many – but that somehow, unfathomably, did not fit the model and constraints of modern Western Medicine. And I knew that Charlie was but one of millions of children who were in the same position. So, Nancy and I started the Charlie Foundation in order to elevate awareness: www.charliefoundation.org.

At its inception in 1994, The Charlie Foundation certainly had a clear idea of what we wanted to accomplish, but there was no road map. So we adopted a sort of "if you build it, they will come" attitude. We decided to try a two-pronged approach, focusing on both public and medical awareness.

Knowing the incredible power of parent- and patient-driven movements, as well as the desperation of parents who walked in our shoes, we first dedicated ourselves to a campaign of public awareness. My background in the movie industry proved valuable here. We produced a 45-minute video hosted by our friend Meryl Streep, entitled "An Introduction to the Ketogenic Diet." The video is now online, and millions have seen it (https://youtu.be/2_8D1hH7mzo). As a result, Charlie's story was picked up by the media. Charlie and the Ketogenic Diet were featured in *People Magazine, Dateline NBC* (on three occasions), *Entertainment Tonight*, *USA Today, The Wall Street Journal, Newsweek,* and countless other periodicals. We were reaching the public.•

[Editor's Note: The rest of Jim and Charlie's story will appear in the December issue of this publication.]

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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www.bantec.store/products/bantec-disinfecting-kit

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HELPING YOU COMBAT COVID-19
BANTEC SANITIZING

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BEING A NEURODIVERSE ADVOCATE

BY JULIA FUTO

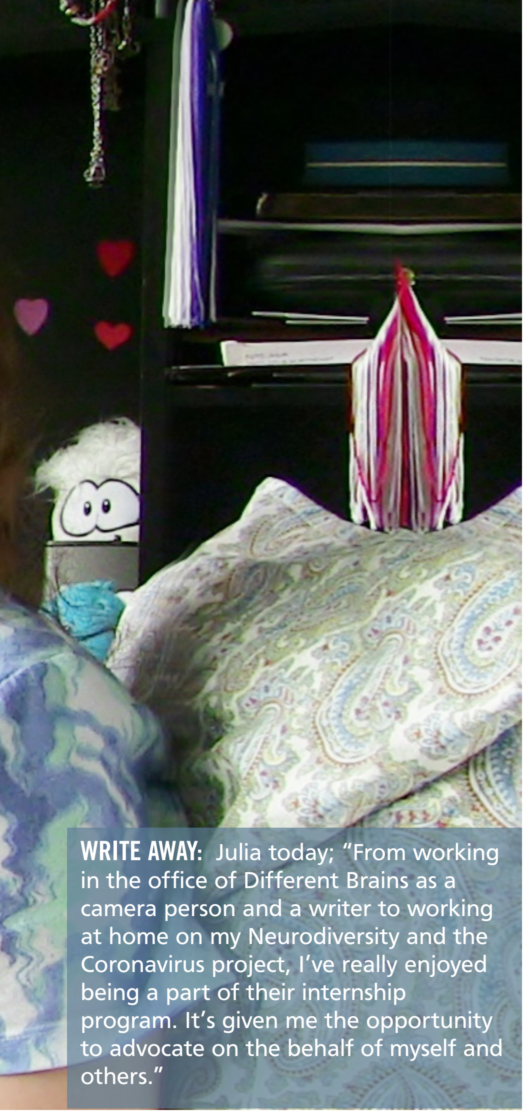
It's important for someone who is neurodivergent to be able to know how to stand up for themselves, but so is knowing how to help them when they need it the most. This is for the educators, employers, co-workers, caregivers, parents, friends, and family members out there.

The word "advocate" can be defined in many ways. An advocate can be a person who publicly supports a particular cause or policy, defends or maintains a cause, or promotes the interests of some kind of group. A self-advocate, on the other hand, is someone who represents themselves or their views and interests. They strive to help others with the same views and interests as their own. Advocacy is crucial, but how does one become a good self-advocate? The best way for me to explain this would be through my own personal experiences and how they helped me become the person I am today.

My journey began the day I was born. Although my mom's pregnancy with me was uneventful, I was extracted with a pump because I was in distress. My shoulder was stuck, the cord was wrapped around my shoulder and neck, and there was a true knot in my umbilical cord. We also learned my umbilical cord was connected to the placenta abnormally (velamentous cord insertion). I was born blue with Apgar scores of 5/8. My first blood test results came back atypical for 18 of the 31 results. I also had jaundice and went home with a light for three weeks. My mom's delivery nurse called me a "miracle baby" and told my mom I was born for a reason.

I was my parents' first child. My mother's family lived in New York, and we lived in Florida. My mom, having no experience with babies, thought I was a "high need baby" as was described in her "What to Expect the First Year" book, so she followed the directions and attended to my needs, not knowing what a "regular need baby" was like. Her mom was an elementary school teacher and she noticed things about me that were different before I was one

PHOTOS PROVIDED BY HAROLD S. REITMAN, M.D AND JULIA FUTO



WRITE AWAY: Julia today; "From working in the office of Different Brains as a camera person and a writer to working at home on my Neurodiversity and the Coronavirus project, I've really enjoyed being a part of their internship program. It's given me the opportunity to advocate on the behalf of myself and others."

year old. My grandmother enlisted my aunt to help. My aunt is a speech pathologist in an elementary school. My aunt arranged a developmental screening for me when I was three years old, which recommended further evaluations.

To compound problems, my eyes started to cross, and after months of alternate eye patching with no success, I had double strabismus eye surgery a few months after my fourth birthday. My depth perception has always been impaired because my eyes don't converge. I failed every school eye test, so I get notes from the eye doctor's office after testing one eye at a time to pass. Besides being uncoordinated, the lack of depth perception made me trip over curbs and walk over the ends of playground equipment. I frequently injured myself by accident.

In kindergarten, I underwent a professional evaluation by a respected neurologist at the Dan Marino Center. I was diagnosed with encephalopathy, which is a fancy way of saying, "brain damage", and developmental coordination disorder (DCD), also called "dyspraxia". DCD is both a physical and developmental disorder that impacts the ability to learn motor skills and coordination, things many people take for granted. DCD can also impact learning ability. For me, it affected my coordination, balance, motor skills, knowing where my body was in space, and because it's a developmental delay, I was always behind in everything. I also started physical and occupational therapy.

I struggled a lot in kindergarten. Little things were constant challenges, like keeping my pencil from rolling off my desk. I was given a desk in kindergarten that had a sloped top instead of a flat surface, which didn't fit with the flat-table groups the rest of the kids had. I also had assistance from a classroom aide at my desk, and as a result, I didn't sit in the circle to learn the teacher's lesson or instructions. I didn't sit with my peers, so I was isolated. I stood out, not in a good way. As a little kid with disabilities, I didn't know how to advocate for myself, or even that I needed to.

> The beginning of high school was tough! I didn't belong there, so it was time for a change, and I'm glad I did because it led to a breakthrough.

As part of the Exceptional Student Education process, I was evaluated by the school at the end of kindergarten to determine my "placement" and to develop an Individual Education Plan (IEP). A school psychologist evaluated me for my first-ever IEP during recess, where she observed me sitting by myself under the playground slide. I actually sat there on purpose because the playground was set up within an interior courtyard. All the kids played dodgeball and the balls would, for me, unpredictably ricochet off the walls throughout recess. I wasn't able to judge how to stay out of the way, so the balls frequently hit me. The other kids laughed when I got hit. I liked neither the pain nor embarrassment of recess, and felt safe under the playground equipment since the balls couldn't hit me there. The school psychologist never bothered to ask me why I hid under the playground equipment, and I would have told her it felt safe. In her report, the psychologist declared my behavior as anti-social, and I was diagnosed with autism. My school IEP placement labels were autism and OHI (Other Health Impaired), to include the DCD.

When I was eight, I had a language evaluation, which resulted in a vestibular (balance) evaluation, and additional therapy to integrate my primitive reflexes. I was in third grade with retained primitive reflexes. This was very unusual because primitive reflexes are supposed to be gone at three to four months of age. I spent an entire summer, five days a week, with physical and occupational therapists trying to integrate them, but to this day, I still have some, and they cause me to always feel on edge. I was also diagnosed with nonverbal learning disorder.

When I was ten years old, my mom enrolled me in a type of Japanese martial arts called "aikido", which helped me in so many ways. Not only was I learning martial arts, I became stronger physically, mentally, and emotionally. The people at Aikido accepted me unconditionally, which significantly improved my development, social skills, confidence, and self-esteem.

The beginning of high school was tough! I was enrolled in a technical high school for my first two years and the pace was too quick for me. I also felt very lonely. I didn't belong there, so it was time for a change, and I'm glad I did because it led to a breakthrough.

I transferred to my home high school my junior year, and one of the classes I had to take was journalism. My journalism teacher took notice of me early on—not because I was "different", but because of my writing skills, work ethic, interest in photography and videography, and because I got things done on time. Instead of making me stand out in a bad way, he saw my strengths and helped me enhance them. He saw potential in me and went out of his way to help me succeed, which is something no teacher had ever done for me before.

The next year, he became my yearbook teacher and gave me the role of copy editor. However, I wasn't limited to that one job. I attended school events as a camera person and had to go interview people, which was the first time I did "extra-curricular" activities at school. My ESE facilitator noticed my involvement in school and asked me to give an informative speech on my overall ESE experience to a group of Caribbean school officials visiting our school to learn about exceptional student programs. I had never done anything like this before, so I had no idea how it would go, but it went so well, I ended up giving a few more speeches before I graduated—one of which was at a faculty meeting. This was huge because no student in my school had ever attended a faculty meeting to be a guest speaker and teach the teachers something. I also gave a speech about kindness at the Senior Class Award banquet, and received a standing ovation. My ESE facilitator and yearbook teacher helped transform me from being a nobody into a somebody with a strong voice.

AGES AND STAGES: *(clockwise from top left)* "As a baby, I had an elongated head since I had to be pulled out with a vacuum. My family likes to joke around about the shape of my head, and they think it looked like a tic tac;" "Here I am at nine years old. I spent this summer doing physical and occupational therapy every day to integrate my primitive reflexes. My dog, Ting Ting, made me very happy; "My kindergarten school picture. My face has a few scratches on it because I am clumsy. This is also about one year after my double eye surgery, and my eyes are still a little crossed."

At aikido, I learned I was powerful, but I didn't know how powerful I was until I got up in front of a large group of people, shared my life story with them, and offered them advice on how to help someone who is neurodiverse. It was a beautiful stage of my life that I will never forget and will always cherish. This is how I became an advocate; now it's time for me to share with you the lessons I've learned and how to be a self-advocate.

The first step for me was self-acceptance. If you have difficulties accepting who you are as a person, you may be left with low self-esteem and try to be someone you're not, which makes functioning in life even harder. At first, having a diagnosis can be scary, and then you may deal with the thoughts of "something is wrong with me," but know you are more than your label(s). Just because you are a little different, it doesn't mean you are incapable of accomplishing anything. In fact, neurodiverse people are often extremely gifted in areas that the neurotypical population would find unfathomable.

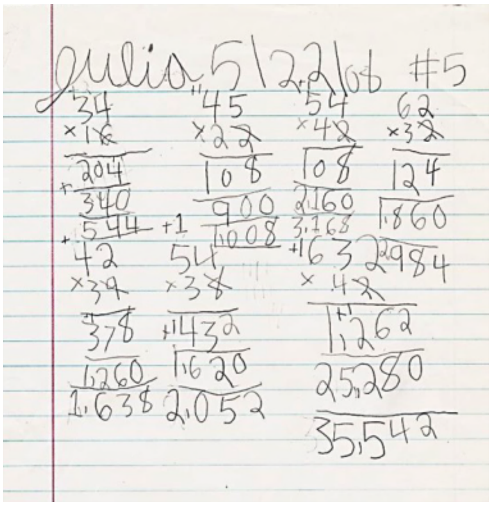
Upon recognizing you do have strengths and knowing what they are, you can be a force to be reckoned with! Because I'm a little slower than average, I have been told by many I have the patience of a saint. I've used this patience to not be judgmental of others, which, in one case, was even lifesaving to one of my friends who had depression and considered suicide. I listened to all of her problems and let her know I was there for her. She felt accepted, and that's all she needed. I then learned my patience was helpful to others. When you hone your skills and find something you're passionate about, the rest is a walk in the park. This is where you want to start, because you'll then be able to find your voice.

Upon having a passion about something and finding your voice, you'll have what you need to start an advocacy role. To find your voice, it's important to have confidence in yourself and be able to set boundaries with yourself, others, and organizations. If you aren't getting the help you need, but you also don't stand up for yourself, you may never get the help. Sometimes, you'll need to be the one to take initiative to help yourself or others, and when you do, it feels very rewarding. Sometimes, we need help finding our voices, and that's where having connections to the right people helps.

Several people and groups have helped me develop into the advocate I am in different ways, but I had to ask for help first. Although it can be difficult to ask for help, there's no shame in doing so. By asking for help, you are advocating for yourself. These people and groups would ideally have your best interest in mind, and like my ESE facilitator and journalism teacher, they'd have the ability to see the best in you and help you bring out your strengths.

Finding a platform helps too. I enjoyed giving speeches in high school so much, I didn't want it to end upon graduating, and I was in luck. One of my aikido teachers introduced me to an internship program at DifferentBrains.org, a non-profit organization that helps the neurodiverse population become advocates through journalism. She knew one of the board members, who knew the founder, and forwarded me an email detailing their internship program. I'm so glad I joined, because through Different Brains, I've met people from many different walks of life and of various professions.

Introducing interns to professionals in different fields is part of what they do there. At Different Brains, I've created various blogs ranging from my own experiences with DCD, to making an entire coronavirus and neurodiversity project, where I give other neurodivergent interns the opportunity to tell their stories as well as offer advice to people having a hard time dealing with COVID-19. Different Brains interns are provided with one-on-one attention and they have the ability to work with, and learn from other self-advocates. I've gotten more support from Different Brains than I've gotten from almost any other agency and I get to do what I love, so finding this platform was a win-win situation for me.



Julia 5\22\06 #5

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54 ×42 108 2,160 3,168

62 ×32 124 1,860 1,984

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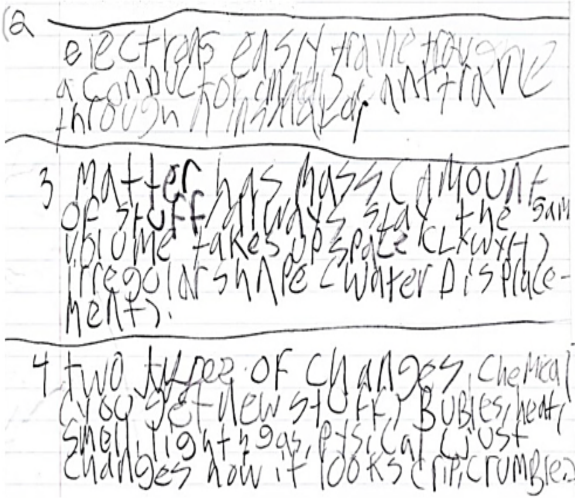
632 ×42 1,262 25,280 35,542



2 electrons easy travle through a conductor [illegible] cant travle through a insulator

3 matter has mass (amount of stuff) always stay the sam volume takes up space (L×W×H) irregoolar shape (water displacements).

4 two types of changes chemical (you get new stuff) bubles, heat, smell, light, gas, pysical (just changes how it looks (rip, crumble)

DEVELOPING DISCIPLINE: *(clockwise from top left)* "Trying to do assignments and homework as a little kid was tough. I couldn't even read my own handwriting so studying for tests from my own notes was impossible!;" "I started aikido as a ten-year-old. I attended their spring camp as a trial and I liked it so much, I came back for their summer program. Here, I am helping a kid younger than me practice falling by gently pushing him down to the floor.

It's important for someone who is neurodivergent to be able to know how to stand up for themselves, but so is knowing how to help them when they need it the most. This is for the educators, employers, co-workers, caregivers, parents, friends, and family members out there. Here are some of the things people have done for me that have worked and may be able to help you help someone who is neurodiverse.

Spend time to get to know us on a personal level. You never know what has happened to us behind closed doors, what struggles we've been through, and how our experiences further affect how we behave; ask questions like why they might be sitting under a slide at recess, the answers might surprise you. By getting to know us and not stereotyping us, you are earning our trust and we can start opening up to you. You may also be able to find our strengths and help us work on them.

Communicate amongst each other about our progress. It takes a village to raise a single person, but how can the village help if they're not communicating with each other and don't know how we're doing? Communication with someone who is neurodiverse through encouragement, positive reinforcement, confidence building, and in my case, candy corn (I would do anything at school for a piece of candy corn), can be the teamwork that makes the dream work! Also, we need to be around people we do well with, as being with mismatched teachers can cause us a lot of damage, and exacerbate our delays. Patience with us is key, as it may take us a little longer to learn or comprehend something, but it is well worth it in the end.

In the words of Francis of Assisi, "Start by doing what's necessary; then do what's possible; and suddenly, you are doing the impossible." In life, we all face adversity, but we become stronger and better human beings as a result of it. This rings true especially for the life of an advocate and someone that is neurodiverse. Light shines the brightest during the darkest of times, and during these times, we begin to discover who we truly are as well as the power we have. Our biggest weaknesses can oftentimes be our greatest strengths. •

ABOUT THE AUTHOR:

Julia Futo is neurodiverse, an intern at Different Brains, a college student, and martial artist whose purpose is helping people find their voices. She enjoys reading, writing, art, music, Zumba, and helping others.

OUR BEST SELVES

BY KIMBERLEE RUTAN MCCAFFERTY

The reality hit me from the email I received from Justin's case manager yesterday. It included a letter introducing herself to the "newbies" in our town who are sending their children to Justin's private autism school for the first time, and a reminder to the "oldies" that fortunately she would be sticking around again this year. I almost missed it as my eyes quickly went to the meat of the message to make sure she wasn't being replaced, but eventually they returned to the top; under "student name" the words "grade 12" were prominently placed.

Grade 12. It is Justin's senior year.

When I was carrying him, this really isn't how I thought it would go.

> "I don't believe it's okay to be so distraught with grieving seventeen years later that I can't help him be his best self, or enjoy him for who he is."

Of course six months ago, I didn't think we'd be embroiled in a world pandemic that would last six months and have no forseeable ending, so maybe my powers of prediction aren't that strong. I will tell you, however, that I never thought the child I was carrying would be spending his senior year in an autism school, not contemplating prom, nor SAT prep, nor driving.

Perhaps I don't mourn the latter quite so much.

There are people in the community who would berate me for mourning these things almost two decades after his birth, perhaps lamenting that I don't accept and revel in him as he is. Frankly, I say that is ridiculous. We are so connected, this child of mine who made me a mom. It's okay to be sad he won't have those choices, because for me, it's really about the lack of those choices, to love, to learn in college, and to drive to his girlfriend's house. It is okay to wish he had these options.

I don't believe it's okay to be so distraught with grieving seventeen years later that I can't help him be his best self, or enjoy him for who he is. And I've worked really hard over the years to get to that place.

I have shelved those losses, but I admit I haven't shelved them all. I will never be at peace with the fact that I must likely won't be here his whole life to love and shelter him, to keep him safe. Will he have a brother and cousins to help him carry out that sacred task? Absolutely. Will it ever be enough to give me peace of mind? Absolutely not.

That ache, that worry and concern, will never fade for me.

I have found over the course of living with autism and all its adventures for seventeen years that probably some of the biggest factors in having a safe, happy, and productive autism family are being able to admit fears and concerns, accept your child's strengths and limitations, and taking small steps constantly to solicit their best selves. If you can do those things while simultaneously being kind to yourself as you work through the myriad of challenges you will face as a family, you have a much better chance at a safe and happy family.

And at the end of the day, that is what I always wish for.•

ABOUT THE AUTHOR:

Kimberlee Rutan McCafferty, mother to two sons on the autism spectrum and an Autism Family Partner at the Children's Hospital of Philadelphia (CHOP). Kim is also the author of a blog at autismmommytherapist.wordpress.com. Kim's book *Raising Autism: Surviving the Early Years* is on sale on Amazon here.

PHOTO COURTESY KIMBERLEE RUTAN MCCAFFERTY

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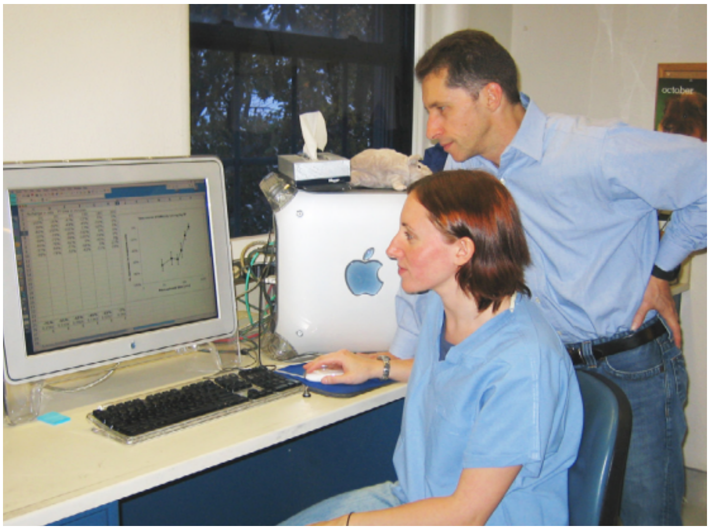

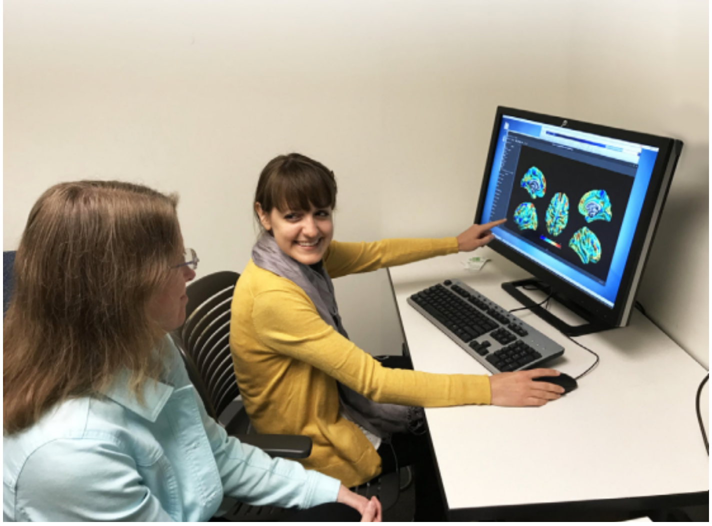

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CHANGE THE GOOD, THE BAD AND THE INEVITABLE

BY PATTI WADE

Right at the beginning, I want to assert that the following is an opinion piece, my opinion. I have worked in the field of Intellectual and Developmental Disabilities (IDD) for a bit over 25 years. I have seen a lot of change, some welcome and some not. I suspect I will see a good bit more.

One of the first things that comes to my mind when I think of change, is **TECHNOLOGY.** Technology is always changing, and it seems to be changing at a faster than ever pace. Technology can be a God-send or a nightmare when it comes to being a person with IDD or trying to help support someone. There are countless options today for devices that can help a person be more independent, which is certainly a good thing. However, learning to use them can be frustrating and make a person feel even more helpless and in need of assistance.

By all accounts, I do not have an intellectual disability, nor am I experiencing cognitive impairment or memory loss (yet). Still, I struggle to even marginally keep up with all of the technological changes whizzing by me. If you are the same, find a tech-savvy friend and don't be ashamed to ask for help. Several of my friends with IDD are better at modern day tech than I, especially those who have grown up with it. They delight in being able to teach me, and I try to return the favor in other areas. These are changes that are here to stay, like it or not, so we should all embrace them and help each other out. This is an area where younger family members and staff often excel, and they can be an untapped resource when you're considering a new device or want to learn about what's out there. Let them shine and welcome the future.

Along with the changes in technology there are also **SOCIETAL CHANGES.** Social change comes about, often due to changes in our cultural beliefs and values. This may be the culture of the country or of an agency. No longer do we, as a society, believe that it is acceptable to shuttle disabled people to institutions or keep them apart from the general community. They are increasingly gaining acceptance as valued members of the community and finally being seen as people with the same hopes, dreams and rights as all people should have. That said, well meaning people often advocate that all people with IDD be "out in the community", whether they want to be or not. I think what most people want are *options* and not to have change forced upon them. New ways do not always have to replace the old, but rather should offer another option for people to choose from. Sometimes, change is good but too fast, and people adapt at different rates. The change should be up to the person who will most be affected. Yes, they should have the option of working. Yes, they should be able to live anywhere in the community they like. Yes, they have rights, just like the rest of us, but that should include the right to decline an opportunity, or at least wait until they are the ones who decide to make the change.

> “I have learned to change my attitude about what is possible, but I also have learned to temper some aspirations with a touch of reality and not expect too much, too soon. Let each person develop at their own rate and celebrate them as they are.”

COVID-19 has brought a screeching halt to the rush to get everyone out into the community. After all the push to be out there, we are now charged with teaching Social Distancing and enforcing stay- home mandates. Some have enjoyed the slower pace, some hate missing work, others are just confused, and their staff and families do not have an answer for when this will this end. I just want to urge all the decision-makers to remember, when this is finally over, some people will be able to immediately return to their previous lives and schedules, but many others will need time to readjust. The pandemic gave us no time in the begining, with everyone struggling to make the needed changes. Let's do a better job on the other end of allowing a gradual change back to “normal,” or whatever the new normal will be.

Finally, there are the changes as we **AGE.** People who have IDD are not exempt from the changes we all face moving from childhood to adulthood, and eventually into old age. People with IDD used to be thought of as perpetual children, and treated accordingly. That is starting to change, and rightfully so. We need to not just care for people, but help them learn to care for themselves, as much as possible. "As much as possible" is a different benchmark for every person, but each individual can achieve some level of independence if we and they believe they can.

Over the 25 + years that I have been working in the field, I have seen countless individuals achieve much more than anyone thought they could. I have learned to change my attitude about what is possible, but I also have learned to temper some aspirations with a touch of reality and not expect too much, too soon. Let each person develop at their own rate and celebrate them as they are. Keep in mind that they will slow down as they grow old. We all will. Some will age sooner than others. Some will develop Alzheimer's or other forms of dementia. Some will stay alert and clear headed until the end. Most will have the ailments of old age, some won't be able to tell you, so we need to watch for the signs of arthritis or decreasing vision and hearing. We need to allow them to slow down when they are ready, not when someone else decides it is appropriate.Watch and listen and you will see the changes and know when they are telling you it is time.

Always be the positive change you want to see in the world. •

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.”

Help Protect Yourself and Others from COVID-19

Practice Social Distancing

Stay 6 feet (2 arm's lengths) from other people.

And Wear a Cloth Face Covering

Be sure it covers your nose and mouth to help protect others.
You could be infected and not have symptoms.

cdc.gov/coronavirus

STRONG MINDS FOR STRANGE TIMES

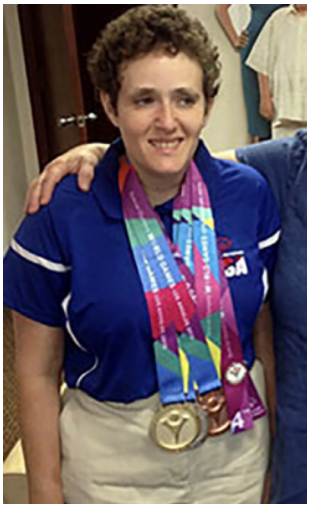
SUBMITTED BY SPECIAL OLYMPICS

Once the COVID-19 pandemic hit, Abby Resnick could no longer participate in competitions, coach floor hockey, and teach drum and tone for people with special needs. She started to look for new activities to do at home.

“I heard about the Special Olympics ‘Strong Minds-fulness’ challenge and wanted to try it. I joined all ten sessions and learned different meditation techniques,” shares Resnick, a Special Olympics athlete from Maryland and three-time Special Olympics World Games 2015 gold winner.

As Resnick knows, it is important to seek opportunities to focus on emotional health now more than ever and practice - or develop - healthy habits. During the time of COVID-19, the number of people reporting mental health concerns is skyrocketing with some sources reporting a threefold increase since pre-pandemic times.

Recognizing the need, Special Olympics hosted ten weeks of free mindfulness sessions for people with intellectual disabilities and their families. Participants could join for one hour each week to learn deep breathing techniques, progressive muscle relaxation, mindful movement, and guided meditation. The Strong Minds Activity Guide was provided to all participants and is designed to develop coping skills, and is available for free on the Special Olympics website. **https://media.specialolympics.org/resources/health/disciplines/strongminds/Strong-Minds-YA-Activity-Cards-08-2020.pdf.**



STRONG MINDFULNESS: Abby Resnick *(above)* and Kayte Barton *(far right)* learned deep breathing techniques, progressive muscle relaxation, mindful movement, and guided meditation during ten weeks of free mindfulness sessions.

“We know that this is a stressful time for everyone, but it may be especially stressful for people with intellectual and developmental disabilities and their caregivers, who can be particularly vulnerable to stress,” shared Dr. Carly McMorris, Strong Minds Clinical Director.

“Mindfulness is a set of skills that can include meditation, being kind to ourselves and others, and paying attention to how our bodies feel. We know from past research that when people practice mindfulness regularly, it can help them to feel calm, significantly reduce stress and improve mental health.”

I learned relaxation techniques and now always try these when I find myself overwhelmed. I would recommend these strategies to others, too. A strong mind is an important part to a happy body,” shares Kayte Barton, a Special Olympics athlete from Minnesota.

Barton was a part of the Special Olympics committee to help develop emotional health programming for Special Olympics athletes across the world in its flagship Special Olympics Healthy Athletes® program. Strong Minds, an emotional health focus, was launched as a Healthy Athletes discipline in 2017. To date, Special Olympics has provided over 2-million free health screenings and trained more than 280,000 health professionals and students to treat people with intellectual disabilities.

Guided by mental health professionals such as social workers, psychologists and psychiatrists, Strong Minds encourages athletes to practice active coping strategies, such as deep breathing, positive thinking, and yoga or stretching, to help deal with stress in competition and everyday life. •

To access emotional wellness and mindfulness resources that Special Olympics developed to support athletes during the Covid-19 pandemic and to promote the health, safety, well-being of the Special Olympics community, visit **www.specialolympics.org/our-work/covid19**

PHOTOS PROVIDED BY RENEE DEASE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the
Healing Power
of Music!
PianoforSpecialNeeds.org

Do I miss performing in concert, composing music, working with the symphonies and playing music with some of the most extraordinarily talented musicians I've known? Yes. The road I chose became one of isolation, following what beckoned me to look closer, and understand more about children with special needs.

THE CHOICE I MADE

BY PATTY CARLSON

This is a story of an unusual set of circumstances that brought me into your life and the lives of so many families with children who need help. The story is not about me, though by necessity, I am writing it. This story is about you and how much you truly mean to me. I began to play the piano when I was twenty one. My goal was to compose and produce music for films. I still recall emphatic lectures from friends and family. "It's not possible, Patty. Everyone knows you would have had to start to learn music at a very young age and have exceptional talent."

I was determined. Listening to music, I thought, it just can't be that hard. I taught myself, memorizing musical phrases in songs, using the piano to find the sequence of tones used to compose the music. I understood music as a mathematical language of structural form and motion, the expression of ideas and feelings through tones. By the time I was thirty, I was composing and producing music for Marty Stouffer's PBS "Wild America" series, ABC Mutual of Omaha films and films broadcast on TBS.

Producing quality music scores is expensive. Budgets were tight. Between film production schedules, I began teaching piano.

My first student was an eleven year old boy. I explained the simplicity of the language of music. I introduced him to the primary tonal "alphabet", the seven basic forms of music vocabulary, multiple choices of hand motions to play the vocabulary across the piano keyboard, and how a simple numeric sequence would influence the emotional content of the music.

Two weeks later he returned playing his first composition. He performed fluently from one end of the piano to the other. An impressive composition, having never played before. Clearly he understood my instruction.

Living in Aspen, Colorado, my reputation as a piano teacher spread rapidly among celebrity community members. ABC news interviewed me about my methods of teaching. I appeared on Turner Broadcasting Systems "Looking Up" show. Hollywood producers wanted to film my lessons. "Play the Piano Overnight" was launched, voted "Best Music Instruction" by *Billboard Magazine*. I appeared in a half hour infomercial which aired internationally for almost three years. I made multiple appearances on Home Shopping Network, multiple appearances on BBC's "Dini Petty Show," the *Home Show,* CBS News, WGN Radio interviews in Chicago. I was performing in concert, and producing film scores at Fantasy Films Recording Studios in Berkeley.

An unanticipated turning point in my career happened quite by accident, or destiny, one might wonder. I was collaborating with Barbi Benton on a song. I was writing the music. She was writing the lyrics. One day she was at my house wanting to know how she could continue working on the project since she had to leave for Los Angeles. I asked her if she had a piano. "Yes" she replied, "but I don't know how to play it." I said, "Sit down and I'll show you how to play the piano." Visibly annoyed, she said "Patty, I only have 20 minutes before I have to go." I said "Sit

KEYS TO PROGRESS: Occasionally, real breakthroughs happen when someone from outside of professional doctrine brings new information to the research.

down. I only need fifteen." Twenty minutes later, she left.

Two days later, my phone started ringing. It was Barbi. "I have to see you. I have to see you again before I leave for L.A." "Barbi," I said looking at the clock, "it's five o'clock in the morning. We had a snow storm last night. You can't get down my driveway." "I don't care!" she said. "I have to see you again before I leave."

Six o'clock in the morning, I watched Barbi Benton and her husband climb over a barbed wire fence across the pasture and hike through knee deep snow on their way to my house. Entering through the front door, Barbi was ecstatic. "You have to hear what I did with what you taught me!".

I wasn't entirely sharing her enthusiasm. Two days ago she couldn't play the piano at all. I started towards the kitchen to make coffee. Barbi walked directly to my piano, sat down and began to play. The moment she started, I literally froze. I could not believe what I was hearing. The music was magnificent, complex, sophisticated, beautiful, an extraordinary composition. It wasn't rational to believe twenty minutes of piano instruction studied over the course of two days could possibly have created that music. There had to be a way to understand how, or why the information I gave Barbi produced that result.

The foundation of knowledge I built my program on had no reasonable comparison to how music was taught in traditional music education. I was granted a US Patent for a unique method of conveying musical information.

Searching for an answer, I concentrated on analyzing what I taught versus conventional music education. The two programs were totally different. The foundation of knowledge I built my program on had no reasonable comparison to how music was taught in traditional music education. I applied for and was granted a US Patent for a unique method of conveying musical information.

I started a "Development Case Study" program seeking to understand how the information I was teaching produced what I suspected was similar to an acquired savant result. Filmed testimonies were abundant from people of multiple ages thrilled with their new found talent. Rapid results achieved in fluent piano performance ability was consistent but hadn't revealed the answer I was looking for, until the day I interviewed Tracy Williams, seven year old Adam's mother.

During a filmed session, Tracy asked if she could talk about something that happened at her son's school. Adam began studying my program while he was in kindergarten. He had been studying once a week from January through the summer. The end of kindergarten, Adam's teacher told Tracy that Adam's handwriting was the absolute worst in his class. He ran all of his lines together. She really needed to work with him to get his handwriting better. Tracy, a working mother, hadn't been able to work with Adam at all. The following school year, the first thing the new teacher told her was Adam's handwriting was beautiful. It was the most beautiful hand writing she'd ever seen, especially for a boy. Tracy was thrilled, and went to tell the teacher from the previous year. He didn't believe her. They went to the office to compare Adam's papers.

He could not believe what he was seeing, how beautiful Adam's handwriting was. Checking other papers, he asked Tracy "Did you see this?" Adam's tests indicated he was reading at a fifth grade, third month level. The only difference in Adam's everyday routine was studying the Numeric Language of Music program with me.

I'd heard of research indicating there was a relationship between the study of a musical instrument and the brain. Taking music lessons in childhood was believed to be a significant predictor of a higher IQ in young adulthood and better high school grades, but Adam had advanced from a first grade reading level to a fifth grade, third month level. What caused his handwriting skills to develop to near perfection?

I'd heard of research indicating there was a relationship between the study of a musical instrument and the brain. Taking music lessons in childhood was believed to be a significant predictor of a higher IQ in young adulthood and better high school grades. What caused Adam's handwriting skills to develop to near perfection?

Documenting academic results in other students studying the program became a priority. Sixteen year old Stephanie advanced from D- to 98% in math. Fifteen year old Jennifer improved from completely failing math to a B. Sixteen year old Megan was failing math, non social, wasn't participating in class at all, had been placed in the Response to Intervention program, without success, and was recommended to be placed on prescription drugs. Desperate for help, the family contacted me. Five weeks after starting the program Megan had 100% in math and joined the basketball team.

Researching neuroscience articles about the relationship between music and the brain, I became hopeful my program had potential to help people suffering from Alzheimer's disease. I tested the program with three individuals residing at a local assisted living center. One resident had advanced Alzheimer's, one had advanced Parkinsons and the third had suffered a disability for over ten years due to a stroke. The resident brain injury specialist monitored the progress of the program over several months time. "I was stunned" she said in a filmed interview. Symptoms reversed in all three cases.

The program I tested at the assisted living center included only the basic components of the Numeric Language of Music. If I documented the exact steps I was using in an instructional manual, would the program produce similar results?

In August of 2019, Martha, our local postmaster, told me her grandson was on the autism spectrum. Did I think the program would help him, she asked. As always, I would only say what the program has done, not what the program can or will do. That being said, so far I don't know what it can't do. I would be inclined to believe that yes, it was very possible.

Martha's youngest grandson Cale, was three years old. He was diagnosed with Childhood Apraxia of Speech. Her oldest grandson, Kaden, was eleven. Kaden was falling far behind in school performing at a third grade level starting fifth grade. I gave Martha the instructional program I had written. The program was easy to use, a simple numeric system of tonal sequences to be played on a piano keyboard.

Martha and the boy's mother, Shannon, taught the boys the tonal sequences I provided in the manual. Kaden was older, and quickly advanced to the Piano Logic program he studied on DVD.

Three months later, I received a letter from Shannon. Cale's speech had improved 70%. His teachers were no longer frustrated as now they could understand his needs. Even a stranger would be able to understand him. Martha said now she could understand everything her grandson was saying. Kaden's reading scores advanced from a 3.4 reading level to a 5.8 reading level. Kaden's math teacher told them he has never seen a student improve in math so quickly, he was so impressed.

"We can't thank you enough" Martha wrote. "You have discovered something AMAZING with the piano and I am so thankful you have and are pursuing it." Only later did I learn there was no known cure for CAS. Most children never overcome it.

Do I miss performing in concert, composing music, working with the symphonies and playing music with some of the most extraordinarily talented musicians I've known? Yes. The road I chose became one of isolation, following what beckoned me to look closer, understand more about the Numeric Language of Music® I was teaching and how the program was reversing previously perceived impossibilities in children on the Autism Spectrum, with children with Special Needs struggling with math and reading and with advanced neurodegenerative diseases including Alzheimer's and Parkinson's disease.

That is why this story is not about me. It's about you. You,your children, and every person's life this program helps are absolutely worth the choice I made.•

ABOUT THE AUTHOR:

Patty Carlson is a predominantly self taught film score composer and producer, recording artist, concert pianist, celebrity music educator and professional lecturer and developer of the Numeric Language of Music program. Learn more at www.pianoforspecialneeds.org

OPENING UP: The D-Termined Program has been used as an effective tool to enhance efforts by the dental team to guide the behavior of children with ASD. Using both the remote and physical dental office setting, the same principles of behavior guidance apply to overcome barriers that the COVID-19 circumstances have presented.

YES! DENTAL APPOINTMENTS CAN BE SUCCESSFUL:

MODIFYING THE D-TERMINED PROGRAM™ OF FAMILIARIZATION & REPETITIVE TASKING TO THE COVID-19 PANDEMIC CIRCUMSTANCES

BY DAVID A. TESINI DMD, MS AND AMY LUEDEMANN-LAZAR, DDS, MS

INTRODUCTION

Yes! Children with special health care needs (CSHCN) have difficulty accessing quality, comprehensive dental care. The barriers of finding trained and willing providers, negotiating hurdles of Medicaid and insurance company coverage, and just plain balancing jobs, family and other activities of daily living, often make this an unsurmountable challenge. COVID-19 has magnified these difficulties and heightened the barriers. The result: many children with special healthcare needs (CSHCN) are being recommended for general anesthesia in the hospital or out-patient setting because it is mistakenly viewed as the easiest and best route during the COVID-19 pandemic. But, with our understanding of how children with autism spectrum disorder (ASD) learn in school and educational settings, dentists can adapt these learning concepts to the dental office and avoid retreating to the use of general anesthesia. COVID-19 has given us this opportunity to innovate and adapt behavior guidance techniques to the digital transformation without the use of sedation or general anesthesia.

One such technique is the D-Termined Program,™ a behavior guidance approach that uses Applied Behavior Analysis (ABA) to prepare children for a dental visit. This encourages desensitization through familiarization without the use of protective stabilization, sedation, or general anesthesia. Modified for the COVID-19 pandemic circumstances, this program is practiced at home and applied in the dental office. With practice, families and dentists can use teledentistry and video communication, in combination with the D-Termined Program, to help children with ASD and other disabilities succeed in the dental office setting.

Virtual conferencing, video communication, and teledentistry are enhancing the traditional models of care delivery. For children with ASD and related disorders, the challenges for successful transition to these methods may be initially difficult, but in the end surprisingly successful. With knowledge of how children with ASD learn, and by understanding their social behavior, dentists can innovate to make routine dental care available to all children with challenging behaviors. *We cannot let the disability eclipse the need for dental care.*

ABA AND DENTAL DESENSITIZATION: A WINNING TEAM

Our fear is that preventive and routine dental care for CSHCN will be postponed until dental office protocols become more familiar for both patients and staff. Children are seen "waiting for an opening" for their "turn" for a general anesthesia appointment. There is a growing concern, if behavior guidance approaches, and utilizing teledentistry and innovation are not quickly integrated into dental offices, special care dentistry could be set back by decades.

Applied Behavior Analysis (ABA) therapy utilizes learning theories to modify behavior, most specifically social behaviors. This therapy has been shown effective for children with ASD, by creating new behaviors, refining already acquired behaviors or skills, and decreasing disruptive behaviors. This therapy uses communication, repetition, and reward as cornerstones in behavior shaping. The D-Termined Program of familiarization and repetitive tasking is based on these principles.

A study at Tufts Dental School in Boston (AlHumaid et al 2016) showed that the D-Termined Program can reduce the need for general anesthesia. This involved frequent office visits of desensitization which is not practical in the present COVID-19 circumstances. Fortunately, learning mechanisms of ABA that are central to the D-Termined Program are adaptable to remote learning and teledentistry. This gives us an opportunity to innovate our past behavior guidance approaches by integrating video communication and video conferencing (VC).

IMPROVING OUR UNDERSTANDING OF THE "AUTISM PERSPECTIVE"

When we lecture, we always point out that "it is more about understanding behavior than managing behavior." As parents and dentists, we work hard to understand the "autism perspective". It is a call for us to "get into *their* world." Impairment in social interaction, communication skills and sensory processing disorders can combine with anxiety and dyspraxia to create difficulty for dentists to design behavior guidance approaches. The COVID-19 crisis has magnified this challenge. Some behaviors become rooted and repetitive, so emphasis needs to be directed to recognize these behaviors before they form. Communication between the patient, parent, caregiver, therapist, and dental provider will help us to manage these concerns.

Parents have successfully used ABA procedures through home-based learning formats and telehealth (Lindgren et al., 2016). Telehealth as a service delivery mechanism depends on parent participation and dentist training with dependable follow through. These models of training are then integrated into the D-Termined Program. The first visits, typically the most important in any training process, are followed by component tasks that are then delegated with instruction for parent and child to do "between visit homework."

WHAT IS THE D-TERMINED PROGRAM OF FAMILIARIZATION AND REPETITIVE TASKING?

The D-Termined Program of Familiarization and Repetitive Tasking uses desensitization through repetitive tasking in a structured learning sequence (Tesini DA, 2014). As in ABA theory, this method systematically applies the principles of behavior analysis in order to identify the variables that improve social behavior It uses visual icons and verbal cues *(see figure 1)*.

FIGURE 1: Icons for story book, positional modeling photo card and iconic counting framework

Repetition and familiarization form the basis of this non-pharmacological behavior guidance approach. **Three *repetition factors*** are the keys to success.

1. *"Look at me"* for eye contact
2. *"Put your feet out straight and hands on your tummy"* for positional modeling (Figure 1)
3. *Use of a counting framework "1.2.3.4.5.6…." verbal or visual* (counting charts)

As the patient learns the use of these repetitive commands, the dental provider can now simply follow the **five *major principles*** of the D -Termined Program:

1) **Divide** the Skill (Tasking chart figure 4)
2) **Demonstrate** the Skill
3) **Drill** the Skill
4) **Delegate** the Repetition
5) **Delight** the Learner.

We are fortunate that both training videos and supplemental support materials are available on the internet. Videos provide a great resource for orientation of the parents and training of dental staff: **(https://specializedcare.com/collections/educational-products/products/d-termined-program-for-patients-with-autism)**

BUT HOW DO WE MODIFY THE D-TERMINED PROGRAM FOR COVID-19 PANDEMIC CIRCUMSTANCES?

Modifications of the D-Termined Program, utilizing teledentistry combined with traditional office visits may at first be met with trepidation by the dental team. Drs. Lindgren and Wacker from the University of Iowa reported in 2016 that ABA telehealth can in fact, be used effectively to successfully communicate and teach skills of behavior guidance. It succeeds because parents of children with ASD already understand these challenges and are already making necessary adjustments with school, recreation, and other gap activities for their child.

The five basic principles of the D-Termined Program are modified and integrated between a virtual and physical world. A precedent videoconference consult with parents is important to define

IMAGES COURTESY DAVID A TESINI DMD, MS

the objectives and timeline and introduction with patient. Include a picture of you with the patient, if seen previously in the office. Be aware that the training for parents and patient is time sensitive in periodicity and must be planned within the context of other ADL (Activities of Daily Living). The initial teledentistry appointment can be used to introduce exaggerated PPE and infection controll guidelines so it will not interfere with developing behavior guidance protocols The number of visits dedicated to learning the repetitions of "feet out straight, hands on tummy and counting framework" through videoconferencing will vary from patient to patient *(see figure 2)*.

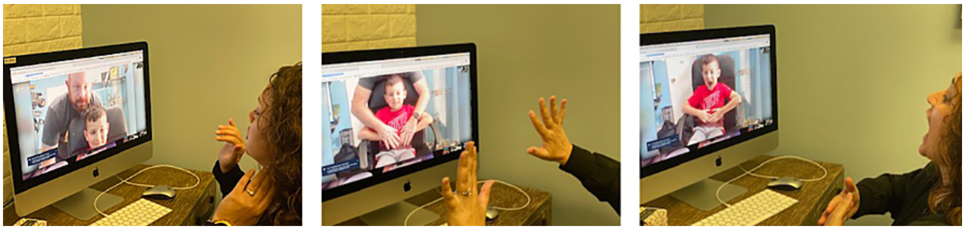


FIGURE 2: Teledentistry and video communication training tailored to patient centered D-Termined Program training.

After the telehealth training visits, based on patient progress, the decision on when to schedule the first physical office setting appointment can then be made. This will vary from patient to patient and is always subject to modification. An initial approach for continuity in the training would be to schedule four telehealth, two in-office and a final telehealth appointment, with defined objectives for each visit.

Teledentistry 1: Parents Consult VC: Narrated 'Preview Video', Communication (The picture book, "Look at me", "Positional modeling" and a "Counting Framework"

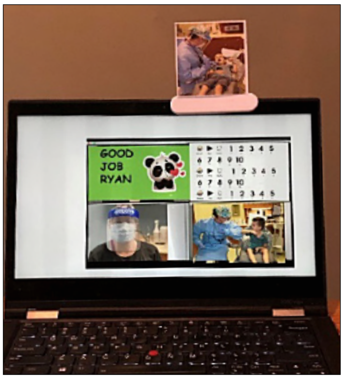
Teledentistry 2: Patient Centered VC: Introduce PPE, Picture Book, Communication. "Look at me", "Positional modeling" and a "Counting Framework".

Teledentistry 3: : Patient Centered VC: Tasking Chart in Progressive tasks

Teledentistry 4: Patient Centered VC: Repetition as necessary

Physical Office 5: Patient in-office Visit #1: Tasking Chart

Physical Office 6: Patient in-office Visit #2: Tasking Chart to Prophy and Fluoride



FIGURES 3 & 4: There are opportunities to enhance the video-audio communication experience with advancing knowledge of the use of video conferencing applications (apps) and computer attachments for visual support directly to the computer screen; Adjunctive Visual icons. Power Point "share screen" with photo clip attached to top of the patient's computer screen.

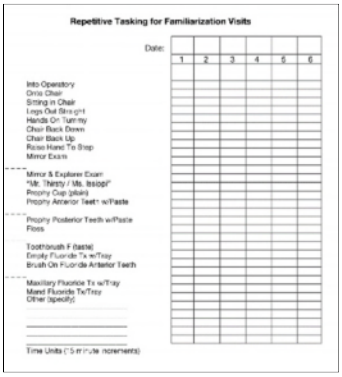
Again, the repetition of directions and requests that form the cornerstone of the D-Termined training, (i.e., "feet out straight", "hands on your tummy" and using the counting framework) are readily adapted and critical to virtual training with audio and screen-time technology. There are opportunities to enhance the video-audio communication experience with advancing knowledge of the use of video conferencing applications (apps) and computer attachments for visual support directly to the computer screen *(see figure 3)*. Teledentistry visits can include lessons prepared in power point and using "shared screen" on the VC application. Innovation can include the use of videos, in-meeting chat and recording content.

Between visits and training with the parent, classroom teacher, and/or behavioral therapist become critical to the patient by learning through continuity and repetitive tasking; *"eye contact … feet out straight… counting framework".* Ordering and structuring of video conferencing and in-office visits can be reviewed and modified with all participants and agreed upon as the program progresses. The tasking sheet will serve as a guide to planning these visits *(see figure 5)*.

Training of the dental office staff is important for the long-term success of the D-Termined Program. The dentist must *"delegate the repetition"* in order for this program to be successfully integrated into the dental office. Parents can involve dentists, teachers, and therapists to assure that their child has access to this program. Accolades for all on social media must not be underestimated as a wonderful motivator.

THE BOTTOM LINE IS TO GET THE WORD OUT

The D-Termined Program has been used as an effective tool to enhance efforts by the dental team to guide the behavior of children with ASD. Using both the remote and physical dental office setting, the same principles of behavior guidance apply to overcome barriers that the COVID-19 circumstances have presented. Innovation and planning at first may seem overwhelming, but with a structured approach and between-visit parental and caregiver training, the methods used in ABA learning can be adapted to providing dental care to children with special healthcare needs. Each office can customize the benefits of telehealth to their patient needs. Both parents and the dental team must be determined to succeed.•



Repetitive Tasking for Familiarization Visits

Date:
1 2 3 4 5 6

Into Operatory
Onto Chair
Sitting in Chair
Legs Out Straight
Hands On Tummy
Chair Back Down
Chair Back Up
Raise Hand To Stop
Mirror Exam

Mirror & Explorer Exam
"Mr. Thirsty / Ms. Isolite"
Prophy Cup (plain)
Prophy Anterior Teeth w/Paste

Prophy Posterior Teeth w/Paste
Floss

Toothbrush F (taste)
Empty Fluoride Tx w/Tray
Brush On Fluoride Anterior Teeth

Maxillary Fluoride Tx w/Tray
Mand Fluoride Tx/Tray
Other (specify)

Time Units (15 minute increments)

FIGURE 5: Generic Tasking Chart; Hash lines are used to set landmarks for each in-office visit.

Acknowledgements: The Nancy Laurie Marks Foundation Brookline MA. funded the original instructional videos, which have been used for training parents, dentists, and staff since 2004.

Suzy Yankowitz, RDH and parent, for her help and advice with video communication.

The videos are distributed by Specialized Care Corporation Hampton, NH. ((800) 722-7375) and are available to preview through their website https://vimeo.com/443140616

ABOUT THE AUTHOR:

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Dr. Amy Luedemann-Lazar is a board-certified pediatric dentist. She earned a DDS degree from the University of Texas and a master's degree from the University of Washington in Seattle. She worked at Seattle Children's Hospital and taught at the University of Washington, serving on the craniofacial team and working extensively with children who had special health care needs. She believes in giving back and helping those in need and has been on numerous medical/dental mission trips around the world.

MANAGING WAIT TIME FOR CHILDREN WITH SPECIAL NEEDS

BY MARILYN HOYSON, PH.D AND ANDREA MORRIS, M.ED

Waiting can be difficult for anyone, particularly for children with special needs, as times spent waiting could lead to challenging behaviors in your child. Learning how to wait is a valuable skill to learn, as some estimates say human beings spend about six months of their lives waiting in line!

The grocery store checkout, doctor's office, traffic tie-ups – all are situations where waiting may be necessary, and therefore potentially problematic for your child. Here are some tips for successfully managing wait times to navigate through them with your child.

First, mindset is key: remember that waiting is a skill to be learned. While it requires some planning on your part, as well as making sure that you have appropriate supports for your child, the learning that will occur as your child masters the skill of waiting will benefit your child later. Not only will this help your child transition better between activities, it will also help them to understand delayed gratification. Your child will also sharpen awareness of expectation, time, anticipation, patience and trust as you share this experience.

SET EXPECTATIONS

Acknowledge that unstructured time can lead to anxiety in your child, and when a child feels anxious, he or she may exhibit challenging behaviors. Knowing this will help you to plan ahead for situations in which waiting is likely to occur.

As a first step, anticipate the wait and find out what may be involved, particularly if you aren't familiar with this setting. If possible, check in where you'll be going to see if they are running on schedule. Schedules can get behind up as the day progresses, so a quick call to their office provides that information before you get on your way. If this is a new setting, ask about the waiting area and what's available within it. This will also help you know what kind of supplies to take along, such as antibacterial wipes, hand sanitizer and the like. Moreover, if there are items or toys with which you prefer your child not engage, knowing their presence ahead of time will help you gear up.

Next, prepare your child in terms he or she can understand for the wait by telling them why you'll be waiting and what to expect during the wait. This will help ease anxieties. For example, "today we're going to get the tires changed on mommy's car. We'll be waiting, and while they change the tire, we can watch them change the tires if you want! I'll be with you while we wait for the car to be done." Other information such as, "there will be

KEEP YOUR WORD: Remember that if you say you'll do something later with your child, be sure to keep that promise. It's important to reinforce your child's successful waiting by ensuring that he or she receive what you promised. This also builds trust with your child.

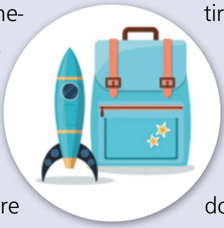
THE WAITING IS THE HARDEST PART : TIPS FOR MANAGING WAIT TIMES

TIME CONCEPTS

Avoid describing time in terms that your child might not understand such as, "it won't be long," "we'll only be there a little while," or specific times such as minutes or hours. These are abstract terms and difficult concepts to understand, and to them – any wait is going to seem like a long time! Instead, you could enjoy an activity together and have a timer in the background, such as an egg timer or visual timer. This might help your child see how time is "flying by" while you are engaged doing something together.

ANTICIPATION

In anticipation of the activity with a wait time, prepare a "wait bag" or "fidget bin" that you can fill with your child's favorite items, activities or toys. Ideally, these should be favored items such as a special book or toy, preferably something your child doesn't get to play with frequently. The possibility of playing with these "exclusive items" will give your child extra motivation for future events and visits! Let your child select an item when you arrive and begin waiting, and play with it while waiting. Be sure to have them return it to the "wait bag" or "fidget bin" for the next time, so the item remains novel to them. You can even have something small and edible in a baggie that you can have ready, if necessary.



MODEL PATIENCE

Be sure to be a good model for patient waiting! Your child is looking to you for cues, so when you are waiting for something with them, resist the temptation to pull out your phone (this is hard, I know!). It's also a good idea to limit technology for your child during wait times. Remember, the instant feedback a child receives from games and other electronic devices isn't going to help them to develop the skills to wait! Playing games together, naming items in the area of a certain color, or that begin with a certain letter are all fun!

TRUST

It's ok to say you'll do something later after the wait time, such as "we'll be able to go the park after they finish changing mommy's tires." You can clarify this verbal information by using a simple visual support, such as a quick hand-drawn sketch that shows your child what happens first (tires changed) and then what happens next (visit the park). If your child is a reader, you can write down the order in which things will happen and review it with him or her. You can also refer your child back to this visual if he or she starts to get antsy. But remember that if you say you'll do something, be sure to keep that promise. It's important to reinforce your child's successful waiting by ensuring that he or she receive what you promised to them. This also builds trust with your child.

SOCIAL STORIES AS A TOOL

If the wait time will be something extended, or something on an ongoing basis, such as regular appointments for something, you might want to consider using a social story to prepare for the wait time.

Social stories, also known as behavior stories, are individualized short stories that illustrate a social situation your child may encounter. Social stories are used to teach skill development through the use of sequential information about everyday events that your child might find to be challenging or confusing. The primary goal of a social story is to reduce and prevent further anxiety.

An example of a social story in our tire scenario could be:

"When we go to the auto repair shop, I will have to wait with mommy while they change the tires; The auto repair shop will be filled with new smells and sounds; I might not like it; That is okay with everyone; I can take my "wait bag" and play with my toys while mommy and I wait for the new tires; When the new tires are on the car, mommy and I can go to the park."

You can see a variety of samples social stories, and download them for your use here: **www.thewatsoninstitute.org/resources/behavior-stories** The Watson Institute makes these free resources available for families, educators and caregivers.

a fish tank," or "they'll have a Lego® table" is helpful – if known, and can help you prepare for the environment you'll encounter.

If you think it will be a long wait, it may not be best to include your child. Try to plan so that you have a sitter. Instead, it may be helpful to include your child in shorter waits to that he slowly becomes accustomed to waiting and he is ready for a longer wait.

After the wait time, be sure to praise your child for the skills they demonstrated. Helping them to connect the experience to learning, and understanding their accomplishment are important!

Lastly, remember that calm environments encourage patience. Your child senses when you are anxious or frantic, so try to exercise mindfulness as much as you can. By carefully planning the visit, you'll be taking control and setting expectations where you can, reducing your anxiety and positively affecting your child in the process!

As a final note, as you think about the experience, consider what worked and what didn't so that you can consider changes for the next opportunity you and your child have to practice patient waiting. Nice work – you've got this!•

ABOUT THE AUTHOR:

Marilyn Hoyson, Ph.D., has worked in the Special Education field for more than 40 years and has been employed at the Watson Institute since 1995. Dr. Hoyson is currently the Chief Operating Officer at the Watson Institute, overseeing all of the Watson Institute's programs. Dr. Hoyson earned her Ph.D. and M.Ed. in special Education at the University of Pittsburgh and earned her B.S. in Special Education at California University of PA.

Andrea Morris, M.Ed. Andrea ("Andee") has worked in the field of Special Education for over 20 years. Ms. Morris has a Masters of Education from the University of Pittsburgh, as well as a Master's in Public Health Certification. In her current role as an Educational Consultant with the Watson Institute, she provides training and consultation to educational and direct care teams serving individuals with disabilities in a variety of educational and care settings. Her areas of expertise include: autism and related disorders, inclusive practices, positive behavior support, naturalistic and structured teaching strategies. She has authored several journal articles and is a skilled presenter.

INTRODUCING THE ALL-NEW
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EP's Innovative New Digital Strategy

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

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

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

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

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

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

FROM OUR FAMILIES... TO YOUR FAMILIES

MILITARY
SECTION

MILITARY LIFE

PUZZLES & CAMO

By Shelly Huhtanen

ARMY
NAVY
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MARINES

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Coronavirus.org

Artwork by Shepard Fairey | Amplifier.org


Carmen McGinnis
I AM A VETERAN AND THIS IS MY VICTORY.

BUILDING HEALTHY RELATIONSHIPS

Make your most important relationships even stronger. This new specialty consultation from Military OneSource helps you deepen relationships with family, friends and others through an education-based consultation.

Building Healthy Relationships offers coaching sessions, practical tools, resources and problem-solving techniques. This consultation is designed to be flexible and personable, and is available to you by phone or video.

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This consultation offers a variety of tracks that are customized to different relationship dynamics. Your consultant will help you identify the track or tracks that are right for you. The personalized coaching sessions, educational tools, resources and empowering skills will help you be at your best. Building Healthy Relationships consultation tracks are designed so that you can do them from the comfort of your home.

- **Building Healthy Relationships with Your Significant Other.** This track focuses on providing educational resources, guidance on common issues couples can face being a part of the military culture and tools to support strong relationships. Consultations can include both or one partner.
- **Healthy Parent-Child Connections.** This track allows the parent to work with a consultant to identify relationship goals, with parents receiving education and resources to enhance these vital relationships. It is also possible for children to attend sessions with their parent as appropriate.
- **Communication Refreshers.** Communication can be one of the most important parts of a healthy relationship. This track offers individuals or couples educational webinars, inventories and services to improve the way they communicate with one another. This is an excellent path for those seeking to enhance communication with a spouse, colleague or family member.
- **Staying Connected While Away.** Part of military life can come with deployment and separations due to military duty. With this track, a consultant can assist service members or adult loved ones with identifying goals and resources to assist with emotional coping and keeping connected with that family member during these times.
- **Reconnecting After Deployment.** When service members return from deployment, a major shift can occur for the entire family. This track is tailored to the unique period of reintegration by assisting service members and/or family members with identifying goals and providing materials that can ease stress and shape resiliency.
- **Blended Family.** Couples may encounter new family dynamics when partners have children from previous relationships. This track focuses on co-parenting as a way to build a solid leadership unit for the military family, accounting for unique experiences and dynamics. This is an excellent path for those couples who are trying to introduce civilian children to military life.
- **MilSpouse Toolkit.** From education on military culture to navigating resources, this track is beneficial for new spouses who may be experiencing a disconnect from their family and need to identify a support system in their new community. This track focuses resources to assist new and current military spouses with adjustment to the military lifestyle, developing coping skills and resources for resiliency.

If one or more individuals do not speak English, your consultant can facilitate a three-way call for simultaneous language interpretation.

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PUZZLES & CAMO SHELLY HUHTANEN

Two Worlds: The Teenage Years

Raising two boys, one that is typical and one with special needs, can still feel like I'm living in two worlds. These two worlds can be very different, but somehow, there is a space where they connect, a space where there are similarities.

There are many differences in raising a typical child and a child with special needs, but lately I've noticed the similarities. I've written in the past about my feelings of whiplash, and felt as if I'm not living in one world, but two worlds. With my typical son, I'm interacting with parents who also have typical children and our discussions consist of school sports, sleep-overs, balancing computer time with homework, or who is dating whom. Three hours later, I'm talking with an RBT (Registered Behavior Technician) about our son with special needs, expanding his food repertoire, vocal stereotypy, or the decision that he is officially considered "non-diploma track" that will influence the rest of his academic journey. There are so many differences, and as we travel into the teenage years with both of our boys, this trend continues.

Our typical son, Hayden, is now 16 years old and a junior in high school. Keeping grades up and practicing for the SAT and ACT exams are the topic of discussion. Where does he want to go to college? Does he want to apply to colleges far away from us? If so, how will I cope with my inability to reach him if he needs us? He is now in the process of learning how to drive and will soon take driver's education classes. The thought of our son driving on the highway with heavy traffic gives me an ulcer, but I know it will need to happen someday. Dragging him into the kitchen to show him how to scramble his own eggs in the morning, or luring him into the laundry room to ensure he knows how to properly sort his laundry are daily occurenses in our house. Will our son be ready to leave the nest confidently enough to be on his own? We ask this question to ourselves every day.

Our other son, Broden, is 14 years old and his list of skills to become more independent are very different. Walking by sprinklers has always been an issue, because he does not like the way the water leaves the sprinkler head. This aversion to sprinklers bleeds into taking a shower. Our goal for him is to eventually be able to take a shower himself. Every morning, I jump in the shower with a sports bra and gym shorts on and work with him to desensitize the feeling of being in the shower. Progress has been slow, but steady. A few months ago, it was difficult for him to hold his hand under the water with water coming from the shower head. Now, we have worked our way into the shower with the showerhead in my hand while I wash his hair. This is great progress, and I'm hopeful that someday, I'll be able to slowly fade myself out of the shower and provide him his own space to shower himself that he surely needs.

QUALITY TIME: "One minute I'm talking to Hayden about getting his driver's license and that he needs to study some more for the SAT, the next minute he's laying his head on my chest asking me to play with his hair because he wants some "mom time."

Independence is key for Broden, just like Hayden, but it looks different. As Hayden is learning how to scramble his eggs and cook other meals, Broden is learning how to program the air fryer so he can cook his own chicken nuggets or hot dogs. While Hayden has his list of chores around the

house, we have made sure to give Broden his own too. Broden is now responsible for going to the mailbox to get the mail. Both of our boys are working towards independence, but it looks a little different.

Broden will most likely not be going to college like Hayden, but we still talk about what he could be doing next in his life. Even though he is severely autistic, he still has a future. The difference is that it will be Broden's future, but a future that is not any less significant than Hayden's.

Even though there has been a focus on our boys building independence, I have still been very selfish in keeping those moments that remind us that they will always be my boys and I will always be their mom. After I work with Broden in the shower, I will wrap Broden in a long-hooded towel that his Nana made him. He will curl up into a ball in his towel on my lap. Sometimes I will sing to him, and there are days when I will just hum. The other day, he put his hand on my chest, looked up at me and said, "I love you." I have small windows of time when Broden will let me into his world and this is one of them. I don't know when I'll be able to let that time go. It means too much to me.

> "I have small windows of time when Broden will let me into his world. I don't know when I'll be able to let that time go. It means too much to me."

With Hayden, I have those moments too. One minute I'm talking to him about getting his driver's license and that he needs to study some more for the SAT, the next minute he's laying his head on my chest asking me to play with his hair because he wants some "mom time". If he seems to be doubting himself, I'll remind him that I wanted to be his mom so bad 16 years ago, and I still do. Similar to Broden, I don't think I'll ever tell Hayden he can't have "mom time" because that time is just as important to me as it is to him.

Raising two boys, one that is typical and one with special needs, can still feel like I'm living in two worlds. These two worlds can be very different, but somehow, there is a space where they connect, a space where there are similarities. With both of my boys, there will be moments where I connect with them at their level when we are both reminded that I will always be their mom and they will always be my boys. Both boys are growing more independent each day. •

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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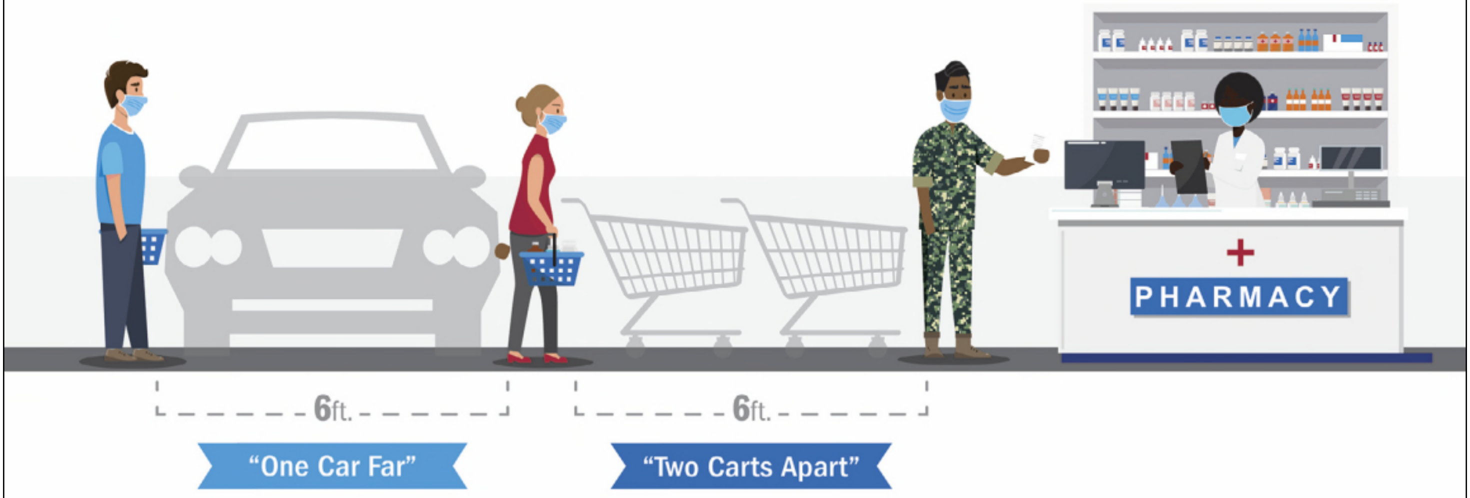
Coronavirus Disease 2019

COVID-19

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

How Do You Practice Social Distancing?

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



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