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EXCEPTIONAL PARENT  
MAGAZINE

FEBRUARY 2021  
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& NUTRITION  
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PLUS:

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EP's ANNUAL ISSUE:

# DIET & NUTRITION

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FROM OUR FAMILIES... TO YOUR FAMILIES

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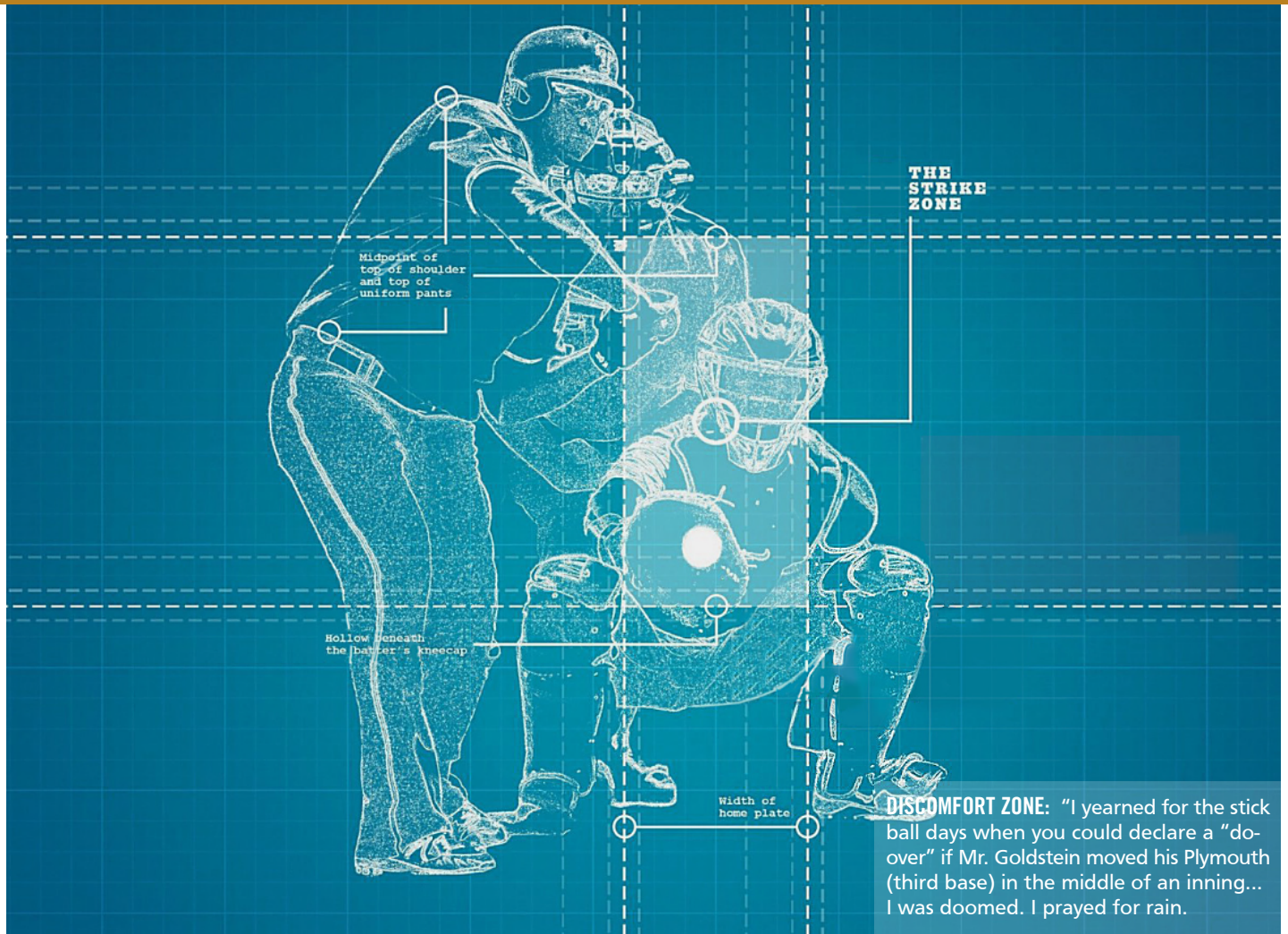
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Note from the Editor-in-chief: EP World, Inc. advocates for the dignity of all citizens with disabilities including the use of "people first language" where possible. We do not normally edit articles and submissions that do not reflect this language,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

— Rick Rader, MD

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# Strike Zone

The readers of *Exceptional Parent Magazine* are used to catching fast balls that are thrown “somewhere there.”

I thought I got away with murder.

When I was about seven years old, I gave in to peer pressure and joined the Little League. I had aspirations of becoming a polo player, but my parents said their Oldsmobile was not going to stay outside so that I could keep a horse in the garage. So, baseball it was.

Baseball was not my thing. I was getting all I needed in the run, throw and hit culture by playing stickball. We didn’t use gloves, we used a pink rubber ball instead of a hard ball, and we used broom sticks with tape on the handle instead of bats. The parked cars and the round iron sewer cov-

ers were used to demarcate boundaries. It checked off all the boxes.

I went along with my close friends to the Little League, each of us with a bulging back pocket of Topps baseball cards and a pink rubber band.

Tryouts were grueling. We had to run the bases, play the outfield, take batting practice, duck from badly thrown balls, and demonstrate how to slide into bases. This was starting to feel like root canal, or at least what I had heard about getting root canal treatment from a dentist.

When the coach said he thought I would



be best as the catcher, I thought I got away with murder.

Being a catcher appealed to me. For one thing, you didn’t have to run back and forth to the outfield and you were saved from all eyes being on you as you prayed that the fly

ball to right field would land in your leather glove. You didn’t have to be in the infield where skills, agility and hustle really counted. For me, being the catcher appeared to be nirvana. You got to stay behind home plate, wore almost the same gear as the bomb squad and, from time to time, got to

run up to the pitcher to ask him if he had any spare chewing gum. At times, there also was the adrenaline surge when a runner from third was approaching home plate and there was a desperate attempt to get the ball to the catcher for a tag out. But you conducted yourself in virtual anonymity. Boy was I wrong!

My illusions were shattered when the coach instructed me to “move your glove to the spot before the ball gets there.” It was all downhill after that. The coaching tips seemed more like training for a ninja warrior. “Keep your hands soft, but your arm and wrist firm.”

“Don’t reach for the ball, let it come to you.” “It is easier to reach up for a high pitch than down for a low pitch.” “Use your glove to signal the pitcher where the strike should be.”

I yearned for the stick ball days when you could declare a “do-over” if Mr. Goldstein moved his Plymouth (third base) in the middle of an inning.

The catcher’s world is the strike zone.

According to Major League Official Rules, “the strike zone is a volume of space delimited by vertical planes extending up from the pentagonal boundaries of the home plate and limited at the top and bottom by upper and lower horizontal planes passing through the horizontal lines of the definition above. This volume thus takes the form of a vertical right pentagonal prism located above home plate. A pitch passing outside the front of the defined volume of the strike zone but curving so as to enter this volume farther back (without being hit) is described as a “back-door-strike.”

I was doomed. I prayed for rain.

I can’t image what being a major league catcher must be like. They are described as being the “quarterback of the baseball team.” The majority of major league managers were former catchers.

Then there is the full inventory of how

balls are delivered to home plate. There is the fast ball, the curve ball, the knuckleball, and the screwball. When asked about the best way to catch a knuckleball, one catcher responded, “Wait ‘ill it stops rolling, then go pick it up.” It has been said that a batter (and catcher) can see the stitches on a base-

ball at 80 mph. At 100 mph, that same ball looks like a golf ball. There are pitchers who can throw the ball at 105 mph.

Yogi Berra, everyone’s favorite baseball catcher (who said, “I never said most of the things I said”), summed up playing catcher perfectly, “It’s 90%

mental and the other half is physical.”

The same could be said about parenting a child with special health care needs, or being a Direct Support Professional, or a therapist, or healthcare provider, or advocate. These professionals and parents often have to play the part of BOTH the pitcher and the catcher. The special needs “strike zone” can change from day to day, from administration to administration. Their “strike zone” is more like the strike zone in stick ball than in baseball. In baseball, the strike zone is concrete, stationary, and well defined. In stick ball the strike zone may depend on where home plate is, perhaps it’s a manhole cover, an outline drawn in chalk, three school books on the ground, or simply “somewhere there.”

The readers of Exceptional Parent Magazine are used to catching fast balls that are thrown “somewhere there.”

I was the catcher for the Flatbush Flyers for one season. •

**“Professionals and parents often have to play the part of BOTH the pitcher and the catcher. The special needs ‘strike zone’ can change from day to day, from administration to administration.”**

**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

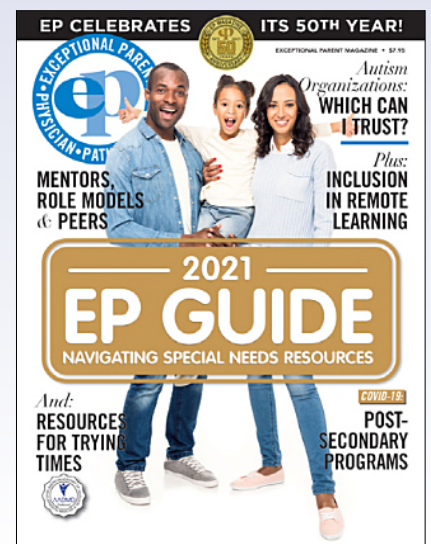


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EP’s 50th year began with the 2021 EP GUIDE to Navigating Special Needs Resources. Visit [epmagazine.com](http://epmagazine.com) and don’t miss an issue!



# WHAT'S HAPPENING

## EXPLORING THE BENEFITS OF THE CHARTERED SPECIAL NEEDS CONSULTANT DESIGNATION

Families caring for a person with special needs face complex and unique financial challenges. They need all the help they can get to prepare for the future.

This is why it is important to work with a financial advisor who has the specialized training necessary to help parents and caregivers plan for immediate and long-term considerations. A Chartered Special Needs Consultant® (ChSNC®) designation indicates that a service provider is equipped to provide you with the strategies and knowledge necessary to help these families thrive. ChSNC® planners are trained to provide assistance in disability law, government benefits, estate planning, income tax issues, special needs trusts, and other financial strategies families and loved ones need.

As the father of a 26-year-old child with a disability, Thomas M. Brinker, Jr., LL.M., CPA is uniquely qualified to lead ChSNC®'s program at the MassMutual Center for Special Needs at The American College of Financial Services. Tom is aware of the complexity of preparing a financial plan to adequately protect a child. Tom explains that ChSNC® training addresses issues unique to families caring for individuals with special needs. His personal connection to this greatly underserved part of the community helps make the ChSNC® curriculum special.

Through the ChSNC® program, professionals will augment their current financial and interpersonal skills with specialized skills focused on helping parents and caregivers plan for immediate and long-term considerations. They will learn to wisely and compassionately guide families through complex financial decisions and public benefit systems so they can gain the peace-of-mind they deserve.

With the ChSNC®, professionals can give their careers a higher purpose and make a real difference in people's lives. The ChSNC® program offered by the American College of Financial Services consist of three training modules.

The course material covers important issues like advocacy, housing, guardianship, income tax planning, Medicaid, Supplemental Social Security Income and Social Security Disability Income qualification issues, aging out and various lifetime planning issues. Creating a plan for a family having a child with special needs requires a more comprehensive lifetime and estate plan than traditional financial planning engagements. The American College program provide this training and awards the participant with the nationally respected ChSNC® certification.

One in five individuals are reported to have a disability. These include: autism, Asperger's, Downs syndrome, and a multitude of physical and/or intellectual disabilities

This is a greatly underserved community. It is a constant challenge to find answers to difficult questions. Major companies have



**PERSONAL CONNECTION:** Thomas M. Brinker, Jr. is Adjunct Professor of Taxation and Special Needs Planning at The American College of Financial Services. He is responsible for teaching and course development in The College's Irwin Graduate School and Huebner School programs, and is director of the MassMutual Center for Special Needs.

limited internal educational programs; typically, one to two days of training as contrasted to the College's comprehensive special needs planning curriculum. The American College's program is the only program that focuses on this very special community and provides the educational resources needed to assist families caring for those with special needs.

This training is beneficial to parents, accountants, financial planners (CFP, CLU and CHFC), social security experts, social workers, educators, attorneys and anyone in the field of human services.

Practices can expand as a result of obtaining the ChSNC® designation. Earning the trust of one family in this community may create the opportunity to serve many other families in the special needs community. This program prepares you for intricacies that most practitioners are not aware of and provides an expertise that traditional financial planners simply do not have.

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Since 1927, The American College of Financial Services has helped professionals realize their career goals through rigorous and practical education in financial services. Our mission is clear – we are committed to benefitting society by delivering the highest quality education to the professionals entrusted with the public's financial well-being. That commitment drives us to a focus on student success, relevant course material, and discovering new solutions for financial security. Learn more at [www.theamericancollege.edu](http://www.theamericancollege.edu)



# WHAT'S HAPPENING

## NO FITNESS EQUIPMENT? NO PROBLEM

If you are ready to jumpstart your 2021, check out the brand-new Special Olympics workouts featuring WWE superstar Drew McIntyre.

Special Olympics and WWE® athletes collaborated to create a workout designed to help get you strong and fit. You will be able to complete a full-body workout using a variety of equipment found in a Unified Fitness Kit that Special Olympics is distributing to students at select Unified Champion Schools® across the United States.



**OLYMPIC RINGS:** Drew McIntyre leads a brand new workout.

It is not a problem if you don't get the kit. Special Olympics made sure that everyone can do these workouts by substituting equipment with things from around the house. For example, you can replace an exercise ball with a small pillow, or use stuffed animals instead of cones.

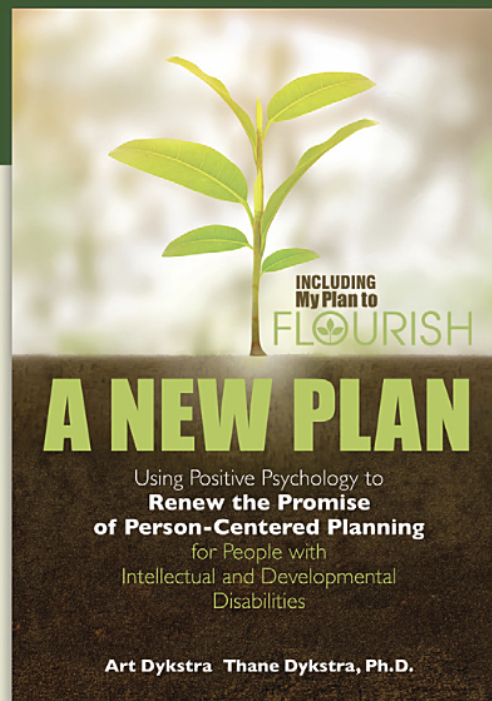
"I love getting creative with my workout routines. I watch YouTube videos for inspiration, and when they call for fitness equipment that I don't own, I substitute it with objects from around the house," shares Elizabeth Price, Special Olympics US Youth Ambassador.

WWE Superstar Drew McIntyre leads this online workout and encourages you to, "Get moving. Stay active. Keep pushing forward. Aim to work out five times each week and balance your training with plenty of

rest and hydration." This online resource joins a host of other downloadable fitness resources and workout ideas. Put on your workout clothes and get ready to sweat! [www.specialolympics.org/class-is-in-session](http://www.specialolympics.org/class-is-in-session). •

## Worried About Your Son or Daughter?

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



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Art Dykstra and  
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*In its most notable and virtuous meaning, person-centered planning is about relationships, caring for each other and helping everyone involved live a better life.*

-Dykstra & Dykstra

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# WHAT'S HAPPENING

## TJ NELLIGAN: LIVE LIKE SEAN

An entrepreneur, advocate, and former Chairman & CEO of the 2014 Special Olympics USA Games, TJ Nelligan is a man of action who has made it his life's mission to benefit others.

Inspired after his son's sudden passing, *Live Like Sean* provides a first-person perspective of seeing the world through the eyes of his son with special needs who taught TJ the world more than it could ever teach him. It took TJ years of climbing the corporate ladder of success to learn that happiness is not a future destination. A life built on the expectation of future rewards makes it difficult to enjoy the journey because the end is never reached.

When TJ began this journey as the parent of a child with special needs, he was filled with anger and disappointment, wondering how he would raise a child with so many issues. TJ never realized how many lessons Sean would ultimately teach him. Sean Nelligan was born with intellectual disabilities that never prevented him from living a full, rich life, or from pro-



**LIVES IMPACTED:** TJ Nelligan and son Sean; Sean taught those around him simple but important lessons: to be happy, accepting, and have a pure love of life.

foundly touching the lives of everyone around him.

*Live Like Sean* shares the story of TJ's son that is very relatable to other parents with special needs children and how their lives

may not be what had been originally planned, though these do not make them any less spectacular. As soon as we begin to view the world through their eyes, we can see more clearly.

*Live Like Sean* provides a first-person perspective of seeing the world through a special needs person and that life lessons can come from the most unlikely places. With each chapter of the book, readers can learn major lessons Sean teaches us about life, through a series of engaging, funny, and uplifting stories. *Live Like Sean* describes

how the experience of being Sean's father changed TJ's life for the better, and offers readers the chance to let Sean's love, kindness, and gratitude touch their lives, too.

To learn more about the book *Live Like Sean* please visit: [tjnelligan.com](http://tjnelligan.com)

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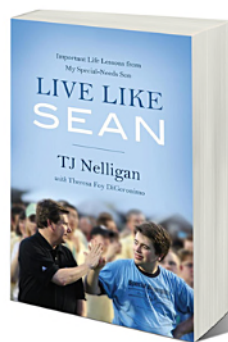
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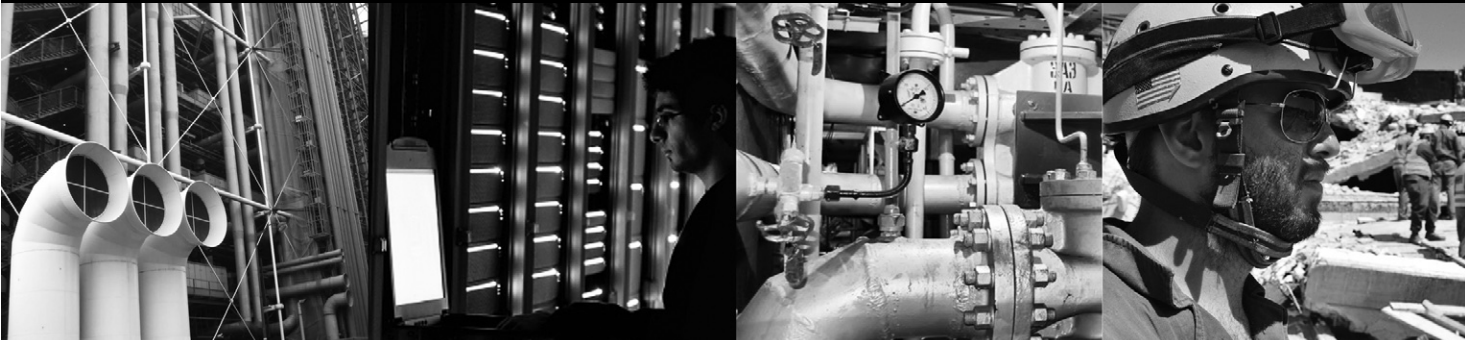
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LJS Fac/X, a twenty-two year old company, has undergone its own evolution since the 1990s. Larry Smith began as an individual electrical contractor, founding the company as LJS Electric as his commercial clients grew his business. Larry saw the need 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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# Why do we abuse children and adults with disabilities?

BY H. BARRY WALDMAN, DDS, MPH, PHD, STEVEN P. PERLMAN, DDS, MSCD, DHL (HON)  
LAUREN M. KOENIG AND ALLEN WONG, DDS, ED

In 2020, the World Health Organization (W.H.O.) reported that children with disabilities are almost four times more likely to experience violence than children without disabilities. The review indicated that children with disabilities are:

- 3.7 times more likely than children without disabilities to be victims of any sort of violence;
- 3.6 times more likely to be victims of physical violence;
- 2.9 times more likely to be victims of sexual violence.

Children with mental or intellectual impairments appear to be among the most vulnerable, with 4.6 times the risk of sexual violence than their non-disabled peers.<sup>1</sup>

*“...children who witness or experience victimization may learn that it is acceptable for a parent, other family member or caregiver to cause emotional and/or physical pain to another person. Research indicates that children who are abused or who witness violence may experience emotional, developmental and/or physical consequences... Those who experience sexual assault or long-term sexual abuse may exhibit difficulties with eating, sleeping and concentrating; feelings of being unclean; mood swings with no apparent cause; nightmares; intrusive thoughts of the assault; flashbacks; and feelings of guilt, anger, fear and shame... Children brought up in a violent home lack the benefits of a nurturing childhood... Over time, if support is not received, these children may demonstrate a general lack of trust, a decrease in self-confidence, and problems with substance abuse, eating disorders, depression and/or mental illness.”<sup>2</sup>*

*“Neglect and abuse of children is also present in rural communities. Incidence for all categories of maltreatment except educational neglect was higher in rural counties than in urban counties, with rural children being almost twice as likely to experience maltreatment, including overall abuse, sexual abuse, emotional abuse, and neglect.”<sup>3</sup>*

## IMPACT OF A CHILD'S DISABILITY ON THE FAMILY AND CHILD ABUSE

Families that include children with disabilities represent a sizeable share of all American households. Living with a child with a disability can have profound effects on the entire family with demands that can last a life time; affecting the health and wellbeing of the child, as well as any other siblings.

Many of these challenges cut across the type and severity of the disability, the age of the person, and the family situation. There is the financial burden associated with getting health, education and social services; as well as buying or renting equipment and devices, making accommodations to the home, transportation, medications, and special foods. While care coordination or case management is often the stated goal, there are many obstacles in implementation.

The day-to-day strain of providing care and assistance leads to exhaustion and fatigue, taxing the physical and emotional state and energy of family members. There are a whole set of issues that create emotional strain, including worry, guilt, anxiety, anger, and uncertainty about the cause of the disability, about the future,



## 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.



**NEGLECTING TO PROTECT:** Studies in the U.S. from the 1980s and 1990s found that 68% of children with disabilities were victims of sexual violence and 32% were victims of physical violence. Youngsters with cognitive disabilities may be overly trusting of others and easier to trick, bribe or coerce.

about the needs of other family members, about whether one is providing enough assistance, and so on. Grieving over the loss of function of the child with the disability is experienced at the time of onset, and often repeatedly at other stages in the person's life <sup>4</sup>

Specifically, what we know about disability and maltreatment:

- *Parents can more easily become stressed with the demands placed on them by parenting a child with a disability.*
- *Youngsters with behavior problems, i.e., Attention-Deficit/Hyperactivity Disorder (ADHD), fetal alcohol and autism spectrum disorders, may be more likely to experience physical abuse because parents can become frustrated by the child's difficult behavior and respond harshly.*
- *Children who are unable to do things independently are more reliant on adults for their care. These children may be more likely to be sexually abused or neglected by adults.*
- *Abusers may take advantage of children who have difficulty communicating or who don't understand social situations very well. They may be more likely to experience sexual abuse.* <sup>5</sup>

## THIS IS NOT A NEW PROBLEM

Studies from the 1980s and 1990s of children with disabilities in the U.S. found that: 1) 68% of the children with disabilities were victims of sexual violence; and 2) 32% were victims of physical violence.

In a retrospective study of hospital records over a ten year period with a population of 39,000, 6,000 children or 15% were vic-

tims of violence. Of the 6,000, 64% or 3,840 were children with disabilities. Over half the sample or 54% were exposed to multiple forms of violence. <sup>6</sup>

**Some risk factors** (by the National Resource Center on Domestic Violence):

Children with physical disabilities often depend on others to meet some or all of their basic needs. Care providers, including family, and paid or unpaid personal care workers, may be involved in close, frequent contact with the most intimate and personal parts of the individual's life, which can increase the opportunity for sexual or other abusive acts.

Youngsters with cognitive disabilities may be overly trusting of others and easier to trick, bribe or coerce.

Children who are blind or have low vision may not be fully aware of their surroundings, especially on public transportation or within the community. This can make them more vulnerable to exploitation by others.

Some persons with disabilities may have limited vocabulary or communication skills that can pose barriers to disclosing abuse or assault.

Many persons with disabilities are taught in school, through service providers and family members, to do as they are told, to comply with requests of others, and to control difficult behaviors.

Quite often, parents, caregivers and special education teachers do not teach children with disabilities about sexuality, abuse prevention, self-protection or personal safety strategies, in an effort to "protect" the child. <sup>2</sup>

## WHAT CAN YOU DO?

The Centers for Disease Control and Prevention (CDC) suggest how parents can prevent abuse and neglect of children:

- *Recognize the possible signs of abuse, such as:*
  - Sudden changes in, or unusual behavior
  - Cuts and bruises
  - Broken bones (not due to a medical condition)
  - Burns
  - Complaints about painful genitals
- *Know the signs of possible neglect, such as:*
  - Constant hunger or thirst (not due to a medical condition)
  - Dirty hair or skin
  - Chronic diaper rash (not due to a medical condition)
- *Know where your child is and what he/she is doing when he/she is not at home.*
- *Get to know your child's care givers. Only leave your child with someone you know and who can take care of them in a place where they will be safe from harm and danger.*
- *Know that your child's school must treat him/her with dignity. Your child should not be punished by being mistreated, restrained, or secluded.*
- *Take steps to make sure your house is a safe place for your child so he/she will not get injured.*
- *Communicate to your child about behavior and situations that are safe and not safe.*
- *Identify and remind your child of safe adults that he/she can turn to. Role-playing and practicing can help young children learn where to go.*

## TAKE CARE OF YOURSELF

Being a parent is the hardest job you will ever love. It is easy to become overwhelmed, especially if you have a child who has a disability or other special health care needs.

- *Be realistic about what your child can and cannot do.*
- *If you are frustrated, give yourself a time-out to calm down and refocus!*
- *Ask people who you trust to help you.*
- *Focus on the positive.*
- *Make time for yourself.*
- *Talk to a healthcare professional like your doctor or a therapist if you don't know how to handle your child's behavior.*<sup>5</sup>

## THE BOTTOM LINE

*"Here's a somber statistic: Individuals with intellectual and developmental disabilities are far more likely to be abused by someone they know than a stranger...Sadly, because an individual with intellectual and developmental disability may be perceived as an 'easy target,' the likelihood of abuse is four to 10 times higher than in typically developing peers. The abuse is more likely to occur repeatedly, over longer periods of time, and is presumed to be underrecognized and underreported."*<sup>7</sup>

In short, your child with a disability unfortunately may be being subjected to any number of heinous forms of abuse by members of your family, your friends, care providers, classmates, or just about anyone. Are you able to confront a member of your family if you suspect they are the perpetrator in the abuse of your child? (Note: Approximately 30% of child sexual abusers are family members of the child.<sup>8</sup>) Why are children and adults with disabilities continuing to be abused? Maybe it's because we are ashamed to even consider that someone close to us is the offender...

However, there is the Federal Child Abuse Prevention and Treatment Act (CAPTA) which requires each state to have provisions or procedures for requiring certain individuals to report known or suspected instances of child abuse and neglect.<sup>9</sup>

And there mandated reporting of abuse of older adults and adults with disabilities. Every state, with the exception of New York, has mandated reporter requirements but the list of who is included varies considerably.<sup>10</sup>

*In addition, the federal government and states, the District of Columbia, and some territories all have statutes to protect older adults from physical abuse, neglect, financial exploitation, psychological abuse, sexual abuse, and abandonment.*<sup>11</sup> •

**“Your child with a disability may be being subjected to any number of heinous forms of abuse by just about anyone. Are you able to confront a member of your family if you suspect they are the perpetrator in the abuse of your child?”**

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# AADMD SALUTES YOU

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A Massachusetts Disability Services Agency is  
Pioneering a New Model for Inclusion That Can Help  
Revitalize Local Malls

# Northeast Arc

BY JO ANN SIMONS

*In 2018, the leadership at Northeast Arc began envisioning a new approach to our agency's community-facing programs. We pondered a series of questions: Could we create a setting where individuals with disabilities acquired new skills, gained confidence and emerged as more active participants in their communities? Could we redefine what inclusive spaces looked like? Could this be centrally located in an area with access to public transportation?*

**T**he answers to those questions resulted in the Center for Linking Lives, 26,000 square feet of previously unused retail space at the Liberty Tree Mall in Danvers, Massachusetts that have now been redeveloped into a welcoming environment where individuals with disabilities can reach their full potential.

The Center for Linking Lives represents the latest innovation for an organization that has been working since 1954 to help individuals with disabilities become full participants in their communities.

Northeast Arc was founded by parents of children with developmental disabilities who wanted to provide inclusive opportunities for their sons and daughters. The organization created the systems that enabled children and adults with disabilities to attend public schools, develop friendships, reside in the neighborhoods of their choice, and to earn a paycheck. Over the past eight decades, the agency's programs have expanded to support children and adults requiring a broader range of support, including people with autism and physical disabilities. Today, Northeast Arc serves more than 15,000 in nearly 200 cities and towns across Massachusetts.

The Center for Linking Lives is a natural continuation of our agency's work, and we are introducing this innovative concept during an inflection point for disability service agencies and for malls.

Agencies like ours are providing essential services and programs

to a growing number of people with intellectual and developmental disabilities: According to estimates by the Center for Disease Control and Prevention, one in six children in the U.S. today has a developmental disability and the incidence of autism spectrum disorder (ASD) in the U.S. has been on a steady increase since 2004.

At the same time, changing buying habits and the ease of online shopping are re-shaping malls across America. This transition is driving mall owners and tenants to reimagine these spaces, from strictly retail destinations to vibrant community centers. Northeast

Arc is now part of this transformation at the Liberty Tree Mall.

The Center for Linking Lives will bring programming for individuals with disabilities directly into the community while redefining what shared community spaces look like. Access to stores, restaurants, services, and potential jobs in the mall will increase opportunities for both real independence and inclusion for the individuals served by Northeast Arc. We believe this is a

## ABOUT NORTHEAST ARC

**NortheastArc**

*Changing lives. Discovering abilities.*

Northeast Arc was founded in 1954 by parents of children with developmental disabilities who wanted to raise their sons and daughters as full members of the community. By having the courage to challenge professionals who told them their children could not be educated and would not live to become adults, these parents created the systems that enabled them to attend public schools, develop friendships, reside in the neighborhoods of their choice and to earn a paycheck. Over the years, Northeast Arc's programs have expanded to support children and adults with a broader range of disabilities, including autism and physical disabilities. Today Northeast Arc serves approximately 15,000 people in nearly 200 cities and towns. Learn more at [www.ne-arc.org](http://www.ne-arc.org)

transformational and replicable model for the future of malls around the United States.

The Center will address the physical and social isolation that are at the root of the poorest outcomes for people with disabilities: 80% of individuals with disabilities are not included in the workforce; 50% of this population are suffering from chronic loneli-



ness; and people with disabilities are at an exponentially higher risk for health problems due to a sedentary lifestyle and poor nutritional awareness.

This isolation has only been exacerbated during the COVID-19 pandemic, when individuals with disabilities have lost jobs that provided critical community connections, have been cut off from friends, and have spent long hours alone in their homes.

At Northeast Arc, inclusion has always been our “new normal” and the Center for Linking Lives is the embodiment of that philosophy.

Instead of providing services in a remote office park, Northeast Arc is now able to offer services in the heart of the community it serves, at a central location easily accessible by public transportation – a critical component, since nearly all of the individuals supported by Northeast Arc do not drive.

The Center for Linking Lives also brings a range of services together under one roof: support for families who have children diagnosed with autism or other intellectual disabilities, early intervention, residential and health services, supported employment, and skills training. By breaking down physical barriers between programs, the Northeast Arc is better able to drive connections between all programs, improving the services we can provide to the individuals we serve.

The space itself is innovative with an eye towards a post-pandemic world:

- *There is an assistive technology lending library to train individuals on the latest digital technologies as well as innovative devices that assist with cognitive, physical, and emotional impairment.*
- *The Ellard Family Test Kitchen provides experimental learning of basic food preparation in a controlled setting – a necessary life skill for individuals hoping to live independently.*
- *Small meeting rooms allow for one-on-one speech or cognitive therapies or mock interviews to prepare job seekers to meet with potential employers.*
- *Ample group space allows for easier collaboration with coworkers while providing options for recreational and other activities.*
- *Employees working remotely can take advantage of “hotel” spaces where they can work temporarily if they need to be on site for a meeting or event.*



**TESTING, TESTING:** The Ellard Family Test Kitchen provides experimental learning of basic food preparation in a controlled setting – a necessary life skill for individuals hoping to live independently.

For individuals and families served by Northeast Arc, the new space represents the opportunity for new experiences – and a more convenient model for service delivery.

## **“Access to stores, restaurants, services, and potential jobs in the mall will increase opportunities for both real independence and inclusion for the individuals served by Northeast Arc.”**

Sam Neisterowich of Danvers, a participant in the Northeast Arc’s Skills Training Exploration Program, is employed by Big Y supermarkets and the AMC movie theater at Liberty Tree Mall. “I’m excited for the Center for Linking Lives because it has a lot more space and it is close to my job at the

movie theater,” he says.

The Moline Family of North Reading has relied on the Northeast Arc’s Autism Support Center (ASC) since their son Bob was diagnosed in 2005. “The Arc has helped educate us about autism, advocacy, the ins and outs of educational services, and transition to adult services,” says Kathleen Moline, Bob’s mother and co-chair of the Autism Support Center’s advisory board. “We are excited that ASC is moving to new space at the Liberty Tree Mall and will be located in the heart of the community and can’t wait to see what new opportunities this space will create for all the families they serve.”

In designing the space, the Northeast Arc prioritized an environmentally sustainable model that would reduce our organization’s overall carbon footprint. Rather than purchasing or constructing a separate building, we opted to transform and reimagine an otherwise unused space. The Center for Linking Lives promotes community redevelopment and environmental sustainability, and we believe it will serve as a national model for other organizations seeking to enhance inclusion for people with disabilities in underutilized community settings.



**WHAT'S IN STORE:** Northeast Arc's Center for Linking Lives occupies 26,000 square feet of space at the Liberty Tree Mall in Danvers, Massachusetts. **parcels** is a boutique featuring products made by individuals with disabilities or by companies owned by individuals with disabilities.

There are malls like the Liberty Tree Mall all over the United States. Instead of seeing these malls fall into disrepair or transform into distribution centers, the Northeast Arc is offering a roadmap for how other retail centers can chart a new course as community spaces. What works in Danvers, Massachusetts can work anywhere in America.

"Malls are important hubs for community gathering, and the Center for Linking Lives is an exciting opportunity to bring individuals with disabilities into these spaces," says Mike Connell, Liberty Tree Mall manager. "We're thrilled to partner with Northeast Arc to help promote an inclusive environment, and we're hopeful that the success of this project at the Liberty Tree Mall can be replicated at properties across the country."

Because the Center for Linking Lives is located within a mall, Northeast Arc naturally needed a retail storefront. The result is **parcels**, a unique 1,000 square-foot boutique offering products created by people with disabilities, or from businesses owned by individuals with disabilities. The products range from art and jewelry to artisan foods, and are made by entrepreneurs from around the world.

**N**ot only will **parcels** provide a point-of-sale opportunity for these products, the store will serve as another training opportunity for people in the Northeast Arc's workforce development program. We know this model works, because it has already been implemented at other Northeast Arc social enterprises, such as Breaking Grounds, a coffee shop in Peabody, Massachusetts that provides individuals with hands-on training opportunities for food service careers.

The Center for Linking Lives is made possible by gifts through Northeast Arc's Campaign for Linking Lives, which has already raised more than \$1.5 million toward its \$3 million fundraising goal. The campaign is being co-chaired by Ralph James, a philanthropist and former Executive Director of External Relations at Harvard Business School, and Darcy Immerman, Chair of the Northeast Arc Board of Directors and Vice President at AECOM.

As the parent of an adult daughter with a disability, James knows the impact that a place like the Center for Linking Lives can have. "It's critical that young people get the education they deserve and, once formal education ends, they have a job that provides structure and positive feedback," James says. "The Center for Linking Lives addresses inclusion. It forms a community that will benefit the people it serves and everyone around them."

By introducing the general public to the array of services provided by the Northeast Arc, the Center for Linking Lives will demonstrate first-hand what people with disabilities can achieve if given the opportunity to succeed. I'm proud to be able to say that Northeast Arc is not just "of the community" but is now "in the community".•

**“Not only will *parcels* provide a point-of-sale opportunity for these products, the store will serve as another training opportunity for people in the Northeast Arc's workforce development program.”**

**ABOUT THE AUTHOR:**

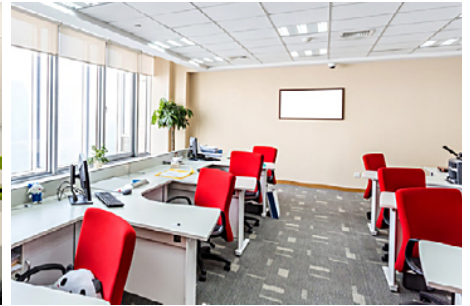
Jo Ann Simons is President and CEO of Northeast Arc. She has more than 40 years of experience creating inclusive opportunities for people with disabilities. Jo Ann lives in Swampscott, Massachusetts and has two children. Emily is an attorney and Jonathan, a man with Down syndrome, lives and works independently. They are the inspiration for her life's work.

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# CHILDREN AND ADULTS WITH DISABILITIES AT RISK HOW NUTRITION AND PHYSICAL ACTIVITY CAN PREVENT OR ADDRESS HEALTH ISSUES

BY LAUREN AGORATUS, M.A.

*People with disabilities, both children and adults, are at risk for complications due to poor nutrition and lack of physical activity. According to the National Institutes of Health, “Nutritional issues facing persons with ID include the risk of both underweight and overweight.”<sup>1</sup>*

The CDC (Centers for Disease Control and Prevention) states that children with special needs are almost 40% more likely to be obese than their non-disabled peers.<sup>2</sup> Further, the “obesity rate for adults with disabilities is 57% higher than for adults without disabilities.” In addition, “Adults with disabilities are physically active on a regular basis about half as often as adults without disabilities (12% vs. 22%).<sup>3</sup>

## DISABILITY AND HEALTHY NUTRITION

The CDC has information on food insecurity as well as healthy portions (see Resources). The MT Disability and Health Program on nutrition indicates that there are three levels of appropriate nutrition: adequate nutrition, individualized nutrition, health promoting nutrition.

**Adequate nutrition (level 1):** This means that the diet is adequate and safe both in quantity and quality. This includes appropriate food storage and preparation.

**Individualized nutrition (level 2):** Individual choices are respected. Nutrition takes into account medical and secondary conditions, and other special needs. This could be monitoring diets due to diabetes, kidney disease, or other conditions.

**Health Promoting Nutrition:** This takes into consideration cholesterol, fat, sugars, sodium and vitamins.

For those that need them, personal care assistants (PCAs) or family caregivers can help support nutrition by recording intake, offering three healthy meals/day, and supporting actual eating (e.g. feeding or adapted utensils). PCAs need to be aware of any food allergies, special diets, feeding/choking/swallowing (using food thickeners, caloric supplements, positioning)<sup>4</sup> issues.

The CDC also notes that secondary issues related to inappropriate nutrition can be obesity, depression, and bowel problems.<sup>5</sup> With obesity comes high cholesterol/blood pressure/blood sugar resulting in heart conditions and diabetes. The American Academy of Pediatrics (AAP) has a website for families on healthy nutrition for children (see Resources).

## COMBINING APPROPRIATE NUTRITION WITH PHYSICAL ACTIVITY RESULTS IN BEST OUTCOMES

The CDC has information on physical activity, including social distancing (see Resources). Suggestions include walking, including indoor walking. Other suggestions during COVID-19 include family workouts, doing chores, being outside, and exercising while watching TV. The AAP endorses Bright Futures, which has information on physical activity for children, including children with special needs.

There is additional information on the AAP family website.

A school-based program called “I Can Do It” helps children with disabilities remain active and healthy. West Virginia University Center of Excellence on Disability has a great website “Exercise is for EVERYbody.” At-home activities

include adapted yoga, improving hypotonia (low muscle tone), quick workouts for diverse motor abilities, and weight loss. Schools should have individualized programs and follow the IEP, for example, using adapted PE (physical education.) Being out in the community can include outdoor activities like parks and adaptive playgrounds (see [www.accessibleplayground.net/playground-directory](http://www.accessibleplayground.net/playground-directory)) or swimming. Community-based resources are discussed, like Special Olympics, and there is information on adapted baseball through Miracle League or Challenger Little League, as well as many YMCA’s having

**“NUTRITIONAL ISSUES FACING PERSONS WITH ID INCLUDE THE RISK OF BOTH UNDERWEIGHT AND OVERWEIGHT.”**

**- NATIONAL INSTITUTES OF HEALTH**

## NOURISHING THE FUTURE : RESOURCES HIGHLIGHTING NUTRITION AND PHYSICAL ACTIVITY



**CENTERS FOR DISEASE CONTROL AND PREVENTION**  
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[www.autism-society.orghttps://www.cdc.gov/healthyweight/healthy\\_eating/index.html](http://www.autism-society.orghttps://www.cdc.gov/healthyweight/healthy_eating/index.html)

Physical Activity

[www.cdc.gov/physicalactivity/](http://www.cdc.gov/physicalactivity/)



**HEALTHYCHILDREN.ORG** (AAP for Families)

Nutrition

[www.healthychildren.org/English/healthy-living/nutrition/Pages/default.aspx](http://www.healthychildren.org/English/healthy-living/nutrition/Pages/default.aspx)

Physical Activity

[www.healthychildren.org/English/healthy-living/fitness/Pages/default.aspx](http://www.healthychildren.org/English/healthy-living/fitness/Pages/default.aspx)

Bright Futures-physical activity (AAP endorsed)

[www.brightfutures.org/physicalactivity/](http://www.brightfutures.org/physicalactivity/)



**MT DISABILITY AND HEALTH PROGRAM** (Nutrition)

[http://mtdh.ruralinstitute.umd.edu/?page\\_id=813](http://mtdh.ruralinstitute.umd.edu/?page_id=813)



**I CAN DO IT**  
(School-based)

<https://acl.gov/sites/default/files/programs/2019-02/ICDIPProgramManual2019.pdf>



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Exercise is for EVERYbody / Physical Activity

<http://cedwvu.org/physical-activity>



**NEW JERSEY DEPARTMENT OF HUMAN SERVICES**

A Guide to Healthy Living for People with Disabilities (NJ)

[www.state.nj.us/humanservices/dds/documents/fitnessguide16.pdf](http://www.state.nj.us/humanservices/dds/documents/fitnessguide16.pdf)

adapted sports and classes. Ideas on getting active include using fitness trackers and an inclusive workout app. They provide a toolkit for various stages of programs such as thinking about it, preparing, engaging, and growing an existing program.

## ADAPTIVE PHYSICAL ACTIVITY EQUIPMENT

The NJ Department of Human Services guide, “Healthy Living for People with Disabilities,” covers various types for adaptive sports equipment. These include:

> **Court Chair:** A sport wheelchair

designed for wheelchair users on the courts (rugby, tennis basketball etc.).

- > **Hand Cycle:** Propelled by the arms rather than the legs, as an alternative to a bicycle.
- > **Push-Rim Racers:** Used by competitive track and marathon runners.
- > **Beach Access Chair:** All-terrain, specialized wheelchair that can be pushed in sand, snow and other soft soils.
- > **Special Seat Cushions to Prevent Skin Breakdown:** Decrease the likelihood of skin breakdown or pressure sores during exercise.

- > **Wrist and Hand Grips:** Gloves or grips improve ability to hold equipment and increase safety.
- > **Therapy Bands:** Provide resistance to movements to build muscle (can be used sitting on the floor, or for standing exercises).
- > **Stabilizing Straps:** Reduce unneeded movement and can prevent injuries or falls.
- > **Wrist or Ankle Weights:** Add extra weight to movements to build muscle.
- > **Fitness Bands/Pedometer:** Measure heart rate and exercise output. Note: for manual chair users, check if it counts arm/wheel turns similar to step trackers.

## BENEFITS OF PHYSICAL FITNESS FOR PEOPLE WITH DISABILITIES

Georgetown University notes the many benefits of physical activity for people with disabilities. Health problems can be prevented by watching weight/reducing fat and building muscle, which prevents heart and bone diseases. It is reported that people with disabilities who are physically active “have higher esteem, better body images and higher rates of academic success; are more confident and more likely to graduate from high school and matriculate in college.”<sup>6</sup>

Children and adults with disabilities need their nutritional requirements to be addressed. Pairing this with physical fitness aids in the prevention and treatment of disease results in the best health outcomes. •

### ABOUT THE AUTHOR:

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

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A young girl with brown hair in a braid, wearing red-rimmed glasses and a white top, is shown from the chest up, playing a keyboard piano. The background is a textured blue wall with white musical notes and symbols scattered across it. The text is overlaid on the image in white serif font within dark red rectangular boxes.

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**“EVERY TIME YOU EAT IS AN OPPORTUNITY TO NOURISH YOUR BODY”**

# GROWING A HEALTHY RELATIONSHIP WITH FOOD

BY GRETA LATVYTE, MPA, JOAN PERKS, PHD, APN-C, RN AND DARA LOBUONO, PHD, RD

*The Family Resource Network launched The Center on Nutrition and Disability, which aims to further assist families and professionals with fostering a healthy relationship with food for people with special health care needs, chronic conditions, and their caregivers.*

Get FIT@Stockton is an exercise and nutrition program led by an interdisciplinary team for individuals with intellectual and developmental disabilities (IDD). Prior to the pandemic, participants came to campus two evenings a week to attend a 90-minute interactive nutrition class and physical exercise session. Currently, the programs have been adapted and are being held via Zoom.

**T**o date, there are no known nutrition efforts in the United States focused solely on the needs of people with disabilities. The Center’s focus is to provide accurate and accessible information directly to families and service providers who need it most. Through the use of universal design for simple recipes, cookbooks, fact sheets, and ongoing webinar series, The Center aims to become an accessible and inclusive partner in creating and maintaining health.

The Family Resource Network (FRN) developed two key health initiatives – GetFIT and The Center on Nutrition and Disability. The development of both initiatives concentrates on the person-centered approach. Each approach is tailored to the needs and unique circumstances of the participant. GetFIT and the Center partner with universities, group homes, and day programs.





**A**nother program on Stockton's campus is Get FIT Kids: Fun, Food and Fitness. This program is an exercise, nutrition literacy and cooking program led by an interprofessional team aimed at assessing children with autism spectrum disorder (ASD) ages 8-15, and a parent or caregiver to improve the child's wellbeing through physical activity and healthy eating. The fitness and nutrition program is an eight-week (two per week) session.

Another university site is GetFIT @ Rowan, established in 2008. The first and longest-running Get FIT program in New Jersey, it serves 45 or more participants each year. Prior to the pandemic, one-on-one fitness sessions for adults with IDD or their family caregivers were offered on-campus, and led by Rowan students. Each academic semester, participants had the option to attend the program for 10 weeks and participate up to four times each week. In response to the pandemic, the Fall 2021 semester was offered via Zoom. Rowan student volunteers offered one-on-one virtual sessions and group fitness sessions for clients and family caregivers.

**A HEALTHY APPROACH:**  
The Center aims to become an accessible and inclusive partner in creating and maintaining health.



#### ABOUT THE CENTER ON NUTRITION AND DISABILITY



The Center on Nutrition and Disability was launched in 2013 to be the educational and training resource of the national Get FIT Movement. Get FIT, which was launched in 2008 by The Family Resource Network provides opportunities for people with disabilities, chronic illness and their caregivers to lead a healthy lifestyle by increasing physical activity levels and maintaining a healthy diet. The Center recognizes the significant impact that diet has on health-related quality of life, activities of daily living and chronic disease prevention and management. Visit [www.NutritionAndDisability.org](http://www.NutritionAndDisability.org) or like them on Facebook @TheCenterOnNutritionAndDisability

During the Fall 2020 semester, with the initiative of a student intern, four virtual "Snack and Chat" sessions were offered via zoom. "Snack and Chats" were a time where Get FIT clients, their families, and Rowan students would meet to make a healthy snack together. Looking ahead to the Spring 2021 semester, Get FIT @ Rowan plans to offer "Snack and Chats" more frequently throughout the semester to expand and enhance their nutrition education component.

"Since taking part in GetFIT, participants with developmental disabilities reported more interest in doing things like walking the dog and walking on the beach," shared a GetFIT Coordinator.

In 2020, The Center addressed health barriers that have surfaced and persisted throughout this pandemic. Sharing the County-Based Food Resource Bank with Health Insurance Navigators, Information and Referral Specialists, and community partners has allowed us to reach families at the onset of the pandemic to present day. The Center's Facebook page has been a focal access point for information on accessible local food banks and pantries.

With funding from the Robert Wood Johnson Foundation, The Center collected anecdotal data from family caregivers, direct support professionals, advocates, individuals with disabilities, and additional stakeholders in our state of New Jersey. Through a series of interviews, the main barriers became evident: lack of access to information and resources, budget and planning assistance, and resistance to foods/selective eating. The launch of the Health Education Webinar Series addressed the listed barriers with topics about the utilization of nutrition assistance programs in NJ, how to stretch

food dollars, how to teach adults with developmental disabilities to plan, cook, and enjoy meals, and the introduction to horticultural therapy for children with disabilities. All webinars are archived and housed on The Center's website for reoccurring access.

In 2021, with the support from the New Jersey Healthy Communities Network, The Center's Coalition will complete the development and application of *Inclusive Nutrition Standards of Care and Guidelines for Implementation* in collaboration with key stakeholders in the State. Our partners (New Jersey providers who support children and/or adults with disabilities: Rowan University, Stockton University, Rutgers Collaborative Extension, SPAN Parent Advocacy Network) will pilot the *Inclusive Nutrition Standards of Care and Guidelines for Implementation* through their active programs. This will serve as a guide to outline best practices for discussing dietary behaviors with patients and caregivers. •

#### ABOUT THE AUTHORS:

Greta Latvyte, MPA is the Health Advocacy Coordinator at the Family Resource Network where she implements health-related initiatives and programs to advance the health of people with special needs, chronic conditions, and family caregivers. She attended Kean University where she attained a Master's in Public Health Administration.

Joan Perks, PhD, APN-C, RN is an Associate Professor of Nursing at Stockton University where she collaborated with Mary Kientz, OTD and Alysia Mastrengelo, PhD, DPT to develop and implement the Get FIT@Stockton Programs. She has 40 years of nursing and teaching experience and was awarded her doctorate from Widener University. The Get FIT@Stockton Program is a collaborative effort between Stockton University, FACES 4 Autism, the Arc of Atlantic County and the Family Resource Network (FRN).

Dara LoBuono, PhD, RD is an Assistant Professor of Nutrition in the Department of Health and Exercise Science at Rowan University. She collaborates with Leslie Spencer, PhD to develop and implement the Get FIT @ Rowan Program. She has been a registered dietitian for seven years, and has worked with a variety of special populations and their family caregivers. She completed her doctoral studies and dietetic internship at the University of Rhode Island.

#### ABOUT THE FAMILY RESOURCE NETWORK



The Family Resource Network (FRN) is dedicated to offering individuals and their families with continuing needs the greatest opportunities, resources and services to support a full and happy life. Visit [www.familyresourcenetwork.org](http://www.familyresourcenetwork.org)



# PEDIATRIC TUBE FEEDING

## A DIETITIAN'S GUIDE FOR CAREGIVERS

BY CAITLIN WADDLE, MS, RDN, LD

**T**he decision to place a feeding tube can often feel overwhelming. There are many reasons that a caregiver, along with a child's treatment team, may come to the conclusion to provide nutrition through a feeding tube (also called enteral feeding or enteral nutrition). Most often, the feeding tube is placed related to a dysfunction in the eating process that inhibits the child from being able or willing to consume adequate nutrition by mouth. Lack of adequate nutrition can lead to malnutrition and developmental delay over time. The feeding tube provides the child with an opportunity to meet nutrition needs to promote overall health, growth and development. Studies that have focused on the benefits of tube feeding, specifically gastrostomy feeding, report improved health and weight gain in children and decreased caregiver stress. Caregivers reported spending less time focused on feeding and administering medications and decreased concern regarding adequate nutrition intake.<sup>1,2</sup>

Feeding a child, whether orally or via feeding tube, is a complex issue that requires a multidisciplinary team approach. Often, children on feeding tubes will have a care team that includes, at minimum, the following practitioners: gastroenterologist, nurse, registered dietitian, speech language pathologist, psychologist and social work. The team works together to ensure all of the child and caregiver's needs are met to support successful feeding outcomes.

Opting for a feeding tube is not synonymous with giving up on oral feeding. In fact, the feeding tube provides a mechanism for nutrition intake while the child is working on advancing oral feeding skills. The focus can shift away from anxiety surrounding calorie intake and growth to promoting adequate practice and repetition with oral feeding when a feeding tube is in place.

### SELECTING THE TYPE OF FEEDING TUBE

The selection of the feeding tube type is typically based on how long it is anticipated that the feeding tube will be needed. Short-term feeding tube use is considered around 4 to 6 weeks, but can be up to 12 weeks, and long term access is any length of time beyond 12 weeks.

**Short-Term Access Feeding Tubes:** Orogastric Tube: "OG" tubes are most often used for pre-term infants less than 34 weeks of age before the gag reflex is developed. The tube can be placed at bedside and goes through the mouth into the stomach.

Nasogastric Tube: "NG" tubes are placed in the nose and extend down to the stomach. NG tubes are the most common short-term access feeding tube.

**Long-Term Access Feeding Tubes:** Gastrostomy tubes are tubes that are surgically placed into the stomach to provide nutrition, fluid and medications. Gastrostomy tubes are typically referred to as "G-tubes".

Percutaneous endoscopic gastrostomy: "PEG" tubes are a common type of gastrostomy tube that is used for the first 8-12 weeks, post-surgery. The tube is held in place by a balloon or bumper and has a longer flexible tube that can be used for administration of medication, nutrition and fluids.

Low Profile Tubes/Buttons: There are several brands of low-profile tubes/buttons, and some are attached with balloons, and some are not.

Many families and children prefer low-profile tubes/buttons because they are easily hidden under clothes and do not have a flexible tube attached. These tubes come with an extension set that can be attached for administering medication, nutrition and fluid.

**"Feeding a child, whether orally or via feeding tube, is a complex issue that requires a multidisciplinary team approach. Often, children on feeding tubes will have a care team that includes, at minimum, the following practitioners: gastroenterologist, nurse, registered dietitian, speech language pathologist, psychologist and social work. The team works together to ensure all of the child and caregiver's needs are met to support successful feeding outcomes."**

Feeding tubes are typically placed in order to provide nutrition, medication and fluid directly into the stomach as is the most normal to the physiological process. However, there are instances in which a child may require the tube to extend further down into the gastrointestinal (GI) tract such as into the jejunum (a portion of the small intestine). The decision to extend the tube into the small intestine would be a conversation between caregivers and the gastroenterologist. A few examples of when a tube may need to be extended into the small intestine include aspiration concerns, severe reflux, or recurrent emesis.

## BEYOND FORMULAS

Whole food blend options have been a focus in nutrition research within the past several years. Multiple studies have pointed to the benefit of whole food blended diets and improved feeding tube tolerance. Specifically, one study focused on providing a pureed by G-tube diet in children post fundoplication to reduce gagging and retching.<sup>3</sup> The exact mechanism of why the puree by G-tube diet (PBGT) helps to reduce retching and gagging is unknown, but it is suspected that the thicker blend (higher viscosity) allows for slower emptying of the stomach. There are several com-

### A RANGE OF CHOICES : PROVIDING NUTRITION VIA FEEDING TUBE

Choosing a product to feed through a feeding tube can feel complicated. There are several factors that need to be considered before choosing what to provide for nutrition via tube, including the child's age, allergies or intolerances and, at times, what insurance will cover.



#### INFANTS

The age range for infants is less than or equal to 12 months. During this time period, the American Academy of Pediatrics (AAP) recommends breast milk or infant formula should be used to provide adequate nutrition and hydration.

If breast milk is unavailable, there are several types of infant formulas that can be provided through the feeding tube. Infant formula comes in three forms: powder, concentrate or ready to feed.

- **Cow's Milk-Based Formula:** Cow's milk-based formula is considered the "standard" infant formula. Examples include: Enfamil Infant, Similac Advance, Gerber Good Start.
- **Soy-Based Formula:** The primary indication for soy formula is a diagnosis of galactosemia or congenital lactase deficiency. Soy formulas have not been found to be beneficial for colic or cow's milk protein intolerance. Examples include: Enfamil ProSobee, Similac Soy Isomil, Gerber Good Start Soy, Parent's Choice Soy (Walmart), Earth's Best Organic (Soy)
- **Hypoallergenic Formula:** This formula is designed for infants who are unable to tolerate the intact protein of cow's milk or soy-based infant formula. The protein in the formula has been partially or fully broken down for better tolerance and absorption.
  - **Partially Hydrolyzed:** Similac Pro-Total Comfort, Gerber Good Start Soothe, Enfamil Gentlease
  - **Extensively Hydrolyzed:** Alimentum, Nutramigen, Alfamino. Extensively hydrolyzed formula (or fully broken-down protein) is appropriate for cow's milk protein allergy.
- **Amino Acid Formula:** Unlike hypoallergenic formula, amino acid formula contains protein that has been completely broken down into the simplest form (amino acids). Amino acid formula is used for children with cow's milk protein allergy who do not respond to extensively hydrolyzed formula. Examples include: Neocate, Elecare and Nutramigen.

Caregivers may wonder how to choose between formula brands, however, the formula industry is highly regulated by the FDA to ensure all formulas are meeting infant nutrient needs. The brand choice may come down to what is covered by WIC or insurance, but caregivers can be assured that any brand will meet nutrient needs. Additionally, specialty formulas are also available for pre-term infants as well as for infants with various medical conditions, including metabolic disorders, gastrointestinal disorders and renal disorders.

The type and volume of breast milk or formula that is provided to the infant is coordinated by the registered dietitian (RD) and gastroenterologist. The dietitian's role is to assess growth and calculate the nutrient needs required to support adequate growth and development and, in conjunction with the gastroenterologist or other specialty team members, choose a formula to meet the infant's nutrition needs, including vitamins and minerals.



#### CHILDREN AGES 1-13

Once a child reaches a year of age, nutrient needs change and the child is ready to advance beyond infant formula. By the time a child is a year of age, there are a variety of formulas to choose from, as well as pre-made real food blend options or home blends

- **Milk and Soy Protein-Based Formulas:** Many "standard" formulas are made from a combination of milk and soy-based proteins. Examples include: PediaSure or Boost Kid's Essentials. These options come in ready-to-feed form, and a variety of flavors that can be accepted by mouth. The formulas also can have added fiber.

Tube feeding "tolerance" is a common concern among both caregivers and providers. Tolerance of tube feeding essentially means that a child is able to digest and grow on an appropriate volume of tube feeding for their age and size without any adverse side effects, such as vomiting, retching, reflux or bowel movement concerns. At times, a formula change can help with tube feeding intolerance.

- **Pea Protein-Based Formulas:** If a child struggles to tolerate milk or soy-based formulas, Kate Farms produces formula made from pea protein and free of whey, lactose, casein, soy, gluten, nuts or corn.
- **Hypoallergenic Formulas:** Peptide (partially broken-down protein) formulas can help with tolerance concerns. Examples include: PediaSure Peptide, Peptamen Jr., or Kate Farms Pediatric Peptide.
- **Amino Acid Based Formula:** Just like in infants, amino acid formula is often used for severe allergies or intolerances. Examples include: Elecare Jr., Alfamino Jr. or Neocate Jr.



**MEAL PLAN:** When a feeding tube is in place, the caretaker's focus can shift away from anxiety surrounding calorie intake and growth to promoting adequate practice and repetition with oral feeding.

commercial options on the market for blended whole food formulas. Some blends provide a thicker viscosity which is helpful for retching and gagging, while others are thinner. The literature points to moderately thick and extremely blends being important for improving the retching, reflux and gagging symptoms, but whole food blends in general have been shown to help with overall GI tolerance. Below are the commercially available whole food blended options.

### Compleat Pediatric (Nestle)

The product is free of gluten, corn, and lactose. The protein source is chicken, milk protein and pea protein. The blend is considered thin.<sup>4</sup> The recommended delivery method is through an 8 French or larger feeding tube via gravity feed or pump.

### Pediasure Harvest (Abbott)

The product is free of dairy and the protein source is soy. The blend is considered slightly thick.<sup>4</sup> The recommended delivery method is via syringe bolus feeding or gravity feeding. The blend can be fed via pump in a continuous feed (including overnight

### Nourish (Functional Formularies)

The product is free of dairy, tree nuts, gluten, soy and corn. The protein source is brown rice protein, quinoa, garbanzo beans and green pea. The blend is considered mildly thick.<sup>4</sup> Nourish can be used with tubes that are a 6 French or larger. It can be delivered at room temperature through a pump or gravity bag and the hang time is 12 hours. Infinity brand pumps may be more suitable for delivery in comparison to Joey pumps.

### Kitchen Blends (Medline)

The product line has 3 different "meal" options and meals are free of dairy, gluten and soy. The blend is considered mildly thick<sup>5</sup> and can be administered via syringe, gravity or pump.

### Compleat Organic Blends (Nestle)

The product has two options: chicken garden blend or plant-based. Both products do not contain dairy, soy or corn. The chicken garden blend protein source is chicken and pea protein. The plant-

based blend protein source is pea protein and rice protein. The blends are considered moderately thick.<sup>4</sup> The blend can be delivered via syringe bolus or pump-assisted (Enteralite Infinity Pump System) feeding with a 12 French feeding tube or larger. The hang time is 8 hours. Gravity feeding is not recommended related to the viscosity of the formula.

### Real Food Blends (Nutricia)

The product line has 6 different "meal" options and are meant to be rotated to ensure adequate variety. The individual "meals" are not nutritionally complete and it is important to work with a Registered Dietitian to ensure all micronutrient needs are being met when the product is used as sole source nutrition. The products are free of gluten, dairy and nuts. The blends are considered extremely thick<sup>4</sup> and are meant to be bolus fed using a 60 mL syringe and a 14 French feeding tube or larger.

Caregivers may choose to blend food themselves to provide via G-tube. Caregivers can work with a registered dietitian to come up with a blended recipe that meets all of the child's nutrient needs to ensure adequate growth and development. For whole food home blends, it is recommended that the child has a 14-16 French tube and that the blend is administered as a syringe bolus feeding through a straight bolus extension kit. The blend can be given using a 60 mL O-ring syringe over 10-15 minutes, or longer if needed. Feeding Tube Awareness Foundation provides excellent videos on their website demonstrating administration of a home blend via G-tube.

A high-powered blender (Vitamix or Blendtec) will provide the best product when blending at home in order to ensure the blend is smooth and will not clog the tube. Home blends can range from mildly thick to extremely thick. There are several factors that can attribute to the thickness of the blend including amount of liquid included in the recipe as well as added later during feeding as well as the freeze/thaw cycle.<sup>4</sup> Defrosting a large batch of home blend can reduce the thickness. In order to maintain the viscosity of the blend, it is recommended to give water 1-2 hours post feeding to avoid dilution of the blend.

## NUTRITION FEEDING SCHEDULE

Once a feeding tube type and a formula or whole food blend is selected, establishing the feeding schedule is an important final component of completing the enteral nutrition plan. There are several options for creating the tube feeding schedule, and caregivers, registered dietitians and GI doctors can work together to determine the best plan for the child.

### Bolus Feeds

A bolus feed is defined as giving a set volume to the child within the time it would take for a child to eat a meal (about 20-30 minutes). Typically, bolus feeds are given via syringe, but some families opt to provide the feed via pump over 30 minutes. Bolus feeds provide the most natural physiological experience for enteral feeding as the feeds are set up like standard meals and snacks and are provided during the day at natural meal times, typically 2-3 hours apart.

#### Example Schedule (1,000 mL/day)

Time of Feeding	Volume of Feeding
7:30-8:00 AM	200 mL
10:00-10:30 AM	200 mL
1:00-1:30 PM	200 mL
3:30-4:00 PM	200 mL
6:30-7:00 AM	200 mL

### Continuous Feeds

There are situations in which a child requires continuous feeding throughout the day and night including volume tolerance issues, concern for aspiration or j-tube feeding. Continuous feeds provide a small volume of feeding over multiple hours throughout the day. Children who require continuous feeds may need to use a backpack with a portable pump as they will be receiving feeds for the majority of the day and night. Continuous feeds are less natural as children don't typically receive nutrients slowly throughout the day and throughout the night.

#### Example Schedule (1,000 mL/day)

Time of Feeding	Volume of Feeding
7:30 AM -12:30 PM	250 mL (50 mL/hour)
12:30 PM -2:30 PM	Break (2 hours)
2:30 PM -7:30 PM	250 mL (50 mL/hour)
7:30 PM -8:30 PM	Break (1 hours)
8:30 PM – 6:30 AM	500 mL (50 mL/hour), then hour break before morning feed at 7:30

### Combination of Bolus and Continuous Feeds

Some children will have a schedule that combines bolus feeding during the day and continuous feeding overnight. This schedule may be a solution for children who can tolerate only a certain volume of a bolus feeding, but need the continuous feeding overnight to meet the remaining calorie needs. Additionally, children will sometimes eat what they can during the day and receive overnight tube feeding to make up the additional calories they are unable to consume during the day.

#### Example Schedule (1,000 mL/day)

Time of Feeding	Volume of Feeding
7:30-8:00 AM	120 mL
10:00-10:30 AM	120 mL
1:00-1:30 PM	120 mL
3:30-4:00 PM	120 mL
6:30-7:00 AM	120 mL
6:30-7:00 AM	400 mL (50 mL/hour)

## INCLUDING ORAL FEEDING IN THE TUBE FEEDING SCHEDULE

When possible for the child and caregivers, it is helpful to have a bolus feeding schedule or at least a combination of a bolus feeding schedule with an overnight feeding schedule when working on oral feeding. As mentioned previously, a bolus feeding schedule provides the most natural and physiological feeding schedule. It can help children establish a regular "eating" routine and promote the ability to establish hunger cues. It may be difficult for a child to feel hunger or show interest in eating if they are being fed all throughout the day and overnight. Working with a registered dietitian to establish a feeding schedule that is conducive to oral intake can make a big difference in acceptance and interest in feeding by mouth. Optimizing the feeding schedule to provide opportunity for oral intake can help to set the child up for success when working on oral feeding. Additionally, the registered dietitian can help caregivers navigate how to wean tube feeding based on the volume consumed by mouth in order to give the child "credit" for the volume that they were able to consume. Adjusting tube feeding based on oral intake can help to avoid overfeeding the child and ensure an appropriate physical experience after eating.

**N**avigating the world of tube feeding can feel complicated, but there are many excellent resources to help including Feeding Tube Awareness Foundation and Oley Foundation. At the end of the day, when a child is able to receive adequate nutrition, whether it is by mouth or by tube, they are set up for a successful future of growth and development. •

#### ABOUT THE AUTHOR:

Caitlin Waddle, MS, RDN, LD is a pediatric registered dietitian in the Atlanta, GA area. Caitlin's primary areas of interest and clinical work include nutrition in children born prematurely, children with allergies, avoidant/restrictive food intake disorder and weaning children from tube feeding.

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# A MEASURED APPROACH TO FEEDING

BY ROBIN COOK, MS, RD, CSP, LDN

All parents want their children to eat a healthy, balanced diet to nourish their growing bodies and meet their developmental needs. But for families who have children who can't eat by mouth, it can be a daily struggle to ensure their medically-fragile children receive proper nutrition. Until recently, these families were limited to two feeding options:

- *Commercially available formulas that were nutritionally balanced, but limited in ingredient selection*
- *Real-food, home-based formulas that were time consuming to create and difficult to ensure contained nutritional adequacy*

In March 2020, Children's Hospital of Philadelphia (CHOP) and Nestlé Health Science launched a Blenderized Tube Feeding Recipe Builder web tool that provides an innovative approach to offering whole food-based and nutritionally complete recipes for tube-fed children aged 1 to 13.

The unique, online tool makes it easier for families to give their feeding-tube-dependent children real food, under the guidance of a health-care provider. The project is the culmination of more than eight years of research and fine-tuning at CHOP, partnerships with CHOP's Department of Clinical Nutrition, Office of Entrepreneurship and Innovation, and Technology Transfer, as well as insight from patient families, students at Temple University's Fox School of Business and Nestlé Health Science.

## THE EVOLUTION OF TUBE FEEDING

Some children — for a variety of reasons such as gastrointestinal disease, congenital gastrointestinal anomalies, genetic conditions or an inability to swallow — need to receive their nutrition from a feeding tube. Parents of children who may require enteral (direct to the GI tract) nutrition for a long time often opt for a gastrostomy tube, or G-tube, placed directly into their stomach.

Decades ago, it was not unusual for table food to be blended and given to patients through their G-tube. But, as commercially-prepared formulas were introduced that were nutritionally complete, sterile and easily delivered, feeding shifted to giving these formulas to tube-fed children of all ages.

About eight years ago, parents at CHOP began expressing interest in moving away from commercially available formulas, and instead giving real food to their tube-fed children in the same way they would for all members of the family.

The challenge was how to make sure children received the correct number of calories and the correct mix of macro- and micronutrients to promote optimal growth and development. So began the creation of a spreadsheet that would act as a road map for families who wanted to give their tube-fed children a homemade, blenderized diet that met their specific nutritional needs, as well for healthcare providers who could support this practice.

While the spreadsheet served the purpose to create nutritionally complete recipes, it was still cumbersome for some families and was limited to clinicians at CHOP. We thought some of the manual steps would be much easier in the form of a web-based application that could be

available on a larger scale outside the CHOP community. The idea was brought to our Office of Innovation and Entrepreneurship (OEI) and a chance encounter with patient family led us to our first partnership — with a group of students at Temple University's Fox School of Business.

## EXPLORING OPTIONS TO TRANSFORM CONCEPT INTO REALITY

During our initial meeting with the students, OEI and I explained the basics of feeding tubes, enteral nutrition, blenderized tube feeding and CHOP's new-product incubation program and process. The students, completely unfamiliar with medical nutrition therapy, used their technologic skills to bring the idea of a web-based platform to life. After creating digital wire frames, the students turned over their concepts to CHOP's OEI to continue to advance the project.

The wire frames were used to obtain feedback from both CHOP dietitians and families who were using or considering using a blender-

**“The Recipe Builder helps eliminate some of the trial and error that families experienced when the spreadsheet was their only resource.”**

ized diet for their child. The response was overwhelmingly positive and we began looking for a commercial partner with the resources to build the application and market it widely.

Nestlé Health Science, a major organization in enteral feeding and a company who understands and supports parents who want to incorporate more real, recognizable food into their child's diet — regardless of how they eat — was our first point of contact. After months of collaboration, the Blenderized Tube Feeding Recipe Builder was launched.

The Recipe Builder helps eliminate some of the trial and error that families experienced when the spreadsheet was their only resource. It helps families optimize nutrition and calories for children who may be only able to tolerate limited volumes per feed. Though still time-intensive for families, the website streamlines the decision-making and calculating, while preserving the intent to provide individualized food blends. And, families — no matter where they live or if they are CHOP patients (add space) — can choose and give a blenderized diet to their child under the guidance of a healthcare professional

The Recipe Builder can be customized to each child's unique needs, including calories, volume limitations and allergies. It contains numerous features, including the ability to save recipes and meal plans for up to seven days, print or email shopping lists, and create a summary document containing the child's last recipe (complete with nutritional information), which can then be sent to the child's healthcare team. The tool is available at [www.compleat.com/recipes](http://www.compleat.com/recipes) •

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# ORAL HEALTH AND NUTRITION CONCERNS IN AUTISM SPECTRUM DISORDERS

BY JANE ZIEGLER, DCN, RDN, LDN, EVAN SPIVACK, DDS AND KAREN STANFAR, MPH, RDN, LD

**A**utism spectrum disorder (ASD) is the umbrella term for a complex and diverse group of developmental disorders characterized by deficits in communication, behavior and socialization. (Hyman, Levy, and Myers 2020) The number of children being diagnosed as “being on the spectrum” has risen dramatically, with current estimates placing the number of children with ASD at 1 in 54 nationally. (Hyman, Levy, and Myers 2020) The prevalence of autism has increased globally as improvements in diagnosis have coupled with greater recognition and awareness of the disorder. The lack of definitive biomarkers and the complexity of ASD, however, have made prevalence difficult to track. (Maenner et al. 2020)

Recognizing the complexity of the disorder, there has been a recent shift towards adopting an interdisciplinary approach in addressing the needs of individuals with ASD. The relationship between oral health and nutrition in ASD is becoming increasingly solidified in both the clinical and academic realms. (Leiva-García et al. 2019)

Unlike what is seen in numerous genetic disorders, there are no oral health concerns specific to ASD. Studies indicate that caries incidence in this population may be similar to or lower than that in the population at large, while there may be an increased prevalence of periodontal disease as a result of poor oral hygiene practices. (DeMattei, Cuvo, and Maurizio 2007; Jaber 2011) Oral health issues may arise, however, due to autism-related behaviors, dietary habits, medical comorbidities and medication use. (DeMattei, Cuvo, and Maurizio 2007; Jaber 2011)

Seizure disorder is commonly seen in individuals with ASD. Although present in 1 to 2 percent of the neurotypical population, it may be observed in up to 30 percent of those with autism. (Besag 2018; Reilly et al. 2014) Pain and infection are common triggers for seizure activity, increasing the importance of appropriate and timely dental surveillance and treatment of active disease. Oral hygiene should be stressed, as increased amounts of plaque and calculus can exacerbate gingival tissue overgrowth often seen with several common anticonvulsant medications. (Brodie and Dichter 1996)

Damage to tooth structure may occur as a result of several possible causes. Bruxism (grinding or clenching of the teeth) is an involuntary parafunctional habit that leads to loss of enamel from the occluding and other tooth surfaces; often, it results from sleep disorders. (Kato et al. 2013) In the ASD population, disordered sleep is experienced by up to 83 percent of children, as opposed to only 25 percent of their neurotypical peers. (Devnani and Hegde 2015) Factors contributing to sleep disorders in ASD include obstructive sleep apnea (OSA), seizures and food allergies or intolerances. (Spicuzza, Caruso, and Di Maria 2015)

Damage to the teeth and other oral structures, such as the tongue and lips, may also occur as a result of self-injurious behaviors (SIBs). Hitting, biting, scratching and lip and tongue biting may be associated with communication difficulties, concurrent psychiatric disorders or comorbid intellectual disability. (Folch et al. 2018)

Anticonvulsants, antidepressants and other neuroacting medications may also have oral implications. Among the most significant and common of these is xerostomia (dry mouth), a side effect observed as a result of several hundred medications. Dry mouth may be uncomfortable, lead to oral fungal infections and contribute to poor oral hygiene and failing dental restorations. (Turner 2016) Tardive dyskinesia, a neurological disorder causing involuntary and repetitive movements often affecting the face, mouth and tongue, is also an adverse effect of numerous neuroacting medications. Other oral adverse effects of a broad spectrum of commonly-used medications include inflammation, altered taste, abnormal bleeding and bone loss.

While diet and medication use may impact oral structures, those factors may also exert significant effect on other body systems. Constipation is among the most common gastrointestinal problems, affecting over 25 percent of this population. Individuals with autism often have a diet that is poor in fiber, or they may have low fluid intake. (Lefter et al. 2019) These nutritional findings will often lead to hard stool and the chronic need for stool softeners or manual disimpaction. (Sanchez and Bercik 2011)



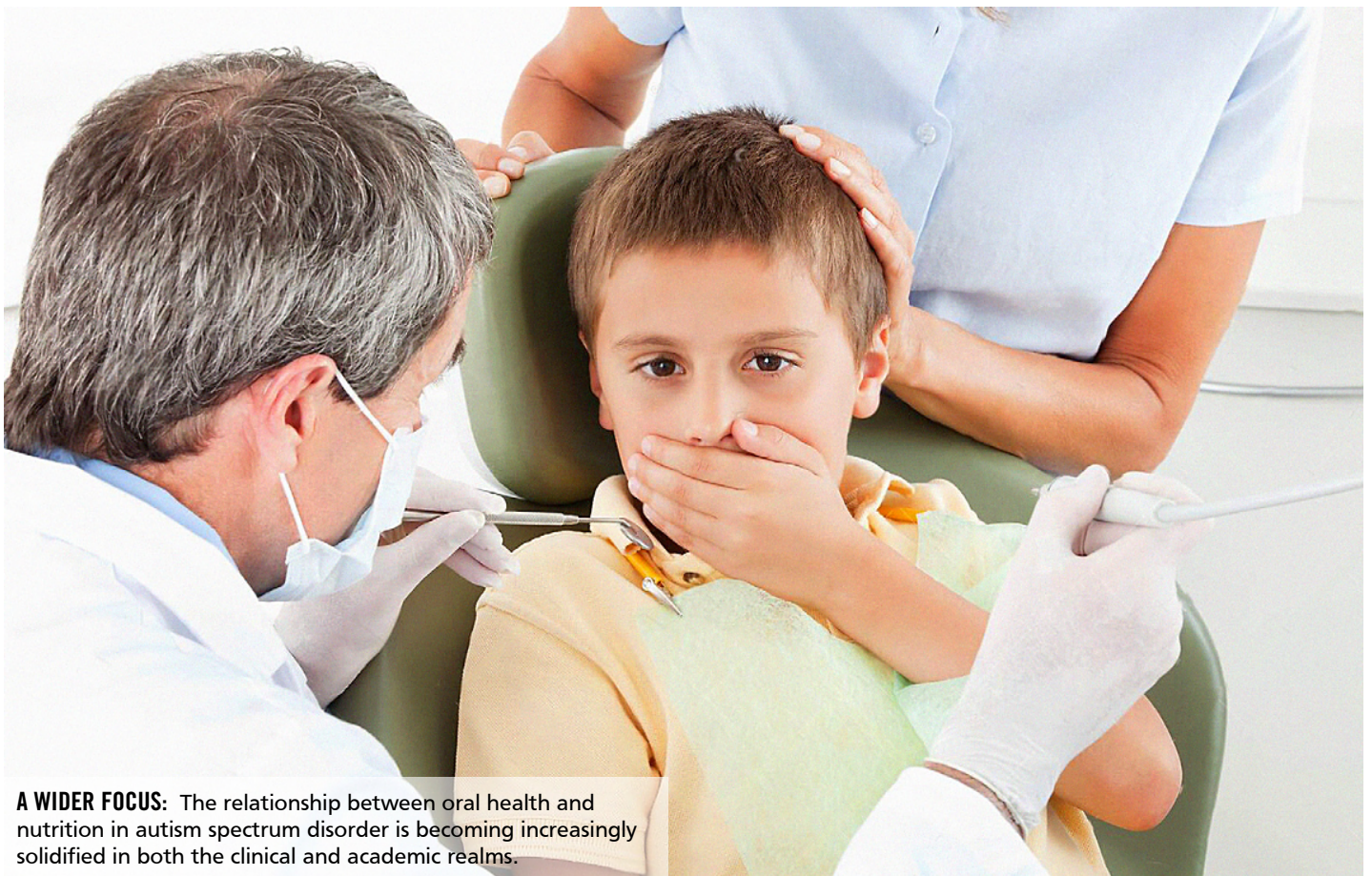
Dysautonomia, or autonomic nervous system dysfunction, has been associated with autism. (Ming et al. 2005) The autonomic nervous system plays a major role in the gastrointestinal system and its dysfunction is linked to constipation, reflux, diarrhea and other issues often leading to nutritional concerns. (Keller et al. 2018)

Individuals with ASD are far more likely than their neurotypical peers to exhibit feeding issues and food allergies. (Lefter et al. 2019) Dietary intervention has become more common in autism, with lay advice advocating the benefits of casein and gluten restriction. This diet eliminates foods and beverages that contain the proteins gluten (found in wheat, barley and rye) and casein (found in milk and other dairy products). It was originally hypothesized that children with ASD had difficulty digesting these two proteins, resulting in physical discomfort and subsequent behavioral symptoms. It was further hypothesized that a change in brain chemistry occurred as a result of some of these proteins entering the circulatory system and then the brain. (Mulloy et al. 2010; Mari-Bauset et al. 2014; Sathe et al. 2017) Multiple studies have failed to demonstrate a relationship between ASD and abnormal intestinal permeability or specific GI pathology. (Mulloy et al. 2010) Adverse consequences that may be associated with this diet include decreased bone cortical thickness and stigmatization as well as potential nutritional deficiencies secondary to restrictive eating patterns (Neumeyer et al. 2018; Neumeyer et al. 2016; Ranjan and Nasser 2015) Nutritional deficiencies in calcium, vitamin C and vitamin D are often noted. The lack of calcium and vitamin D, in particular, have been shown to have deleterious effects on the dentition, requiring supplementation if a casein-free diet is utilized. (Ranjan and Nasser 2015)

**S**ensory sensitivities are commonly seen in autism. (Cermak, Curtin, and Bandini 2010; Dovey et al. 2008) Light, sound and smell can trigger behavioral responses in this population, and strong tactile preferences are often evident. Gustatory preferences are common as well, with many adults and children with autism having only a very limited list of foods that they will eat. This presents obvious difficulties in attempting to guide the patient towards a healthy and noncariogenic diet. Food selectivity and sensory sensitivity appear to be significant problems for individuals with ASD. Food selectivity may occur due to oral over-responsiveness or oral defensiveness which results in difficulty with food textures. Oral under-responsiveness, on the other hand, may occur where the child does not seem to perceive sensations and may overeat or overstuff their mouth. Other behaviors include oral seeking behaviors in which the child puts non-food items in his or her mouth for purposes of oral stimulation. These oral aversions can result in restriction of types, textures and variety of foods. (Cermak, Curtin, and Bandini 2010; Dovey et al. 2008; Chistol et al. 2018)

## CONCLUSIONS

Children with ASD present with numerous challenges, with common concerns affecting both oral health and nutritional status (Table 1). An interdisciplinary approach, involving both dentist and nutritionist, will allow for the development of a care plan that accounts for not just autism itself, but any existing comorbidities, medications and associated behaviors. Table 2 presents numerous interventions demonstrating the importance of adopting a coordinated and multi-specialist approach to instituting this care plan.



**A WIDER FOCUS:** The relationship between oral health and nutrition in autism spectrum disorder is becoming increasingly solidified in both the clinical and academic realms.

**Table 1. Common Oral Health and Nutrition Concerns in the ID/DD Population (DeMattei, Cuvo, and Maurizio 2007; Jaber 2011; Cermak, Curtin, and Bandini 2010; Dovey et al. 2008)**

Oral Health Concerns	Nutrition Concerns
<ul style="list-style-type: none"> <li>Retaining food in mouth</li> <li>Oral hypersensitivities</li> <li>Gingivitis</li> <li>Bruxism</li> <li>Behavior issues                             <ul style="list-style-type: none"> <li>uncooperative</li> <li>difficulties managing oral health prevention strategies</li> </ul> </li> </ul>	<ul style="list-style-type: none"> <li>Poor calorie/nutrient intake</li> <li>Limited food intake or food selectivity</li> <li>Chewing difficulties</li> <li>Drug-nutrient - supplement interactions</li> <li>Altered GI function</li> <li>Underweight</li> <li>Overweight/obesity</li> <li>Restrictive diets</li> </ul>

**Table 2. Diet and Oral Health Interventions for Individuals with ID/DD (adapted from: Jaber 2011; Cermak, Curtin, and Bandini 2010; Dovey et al. 2008)**

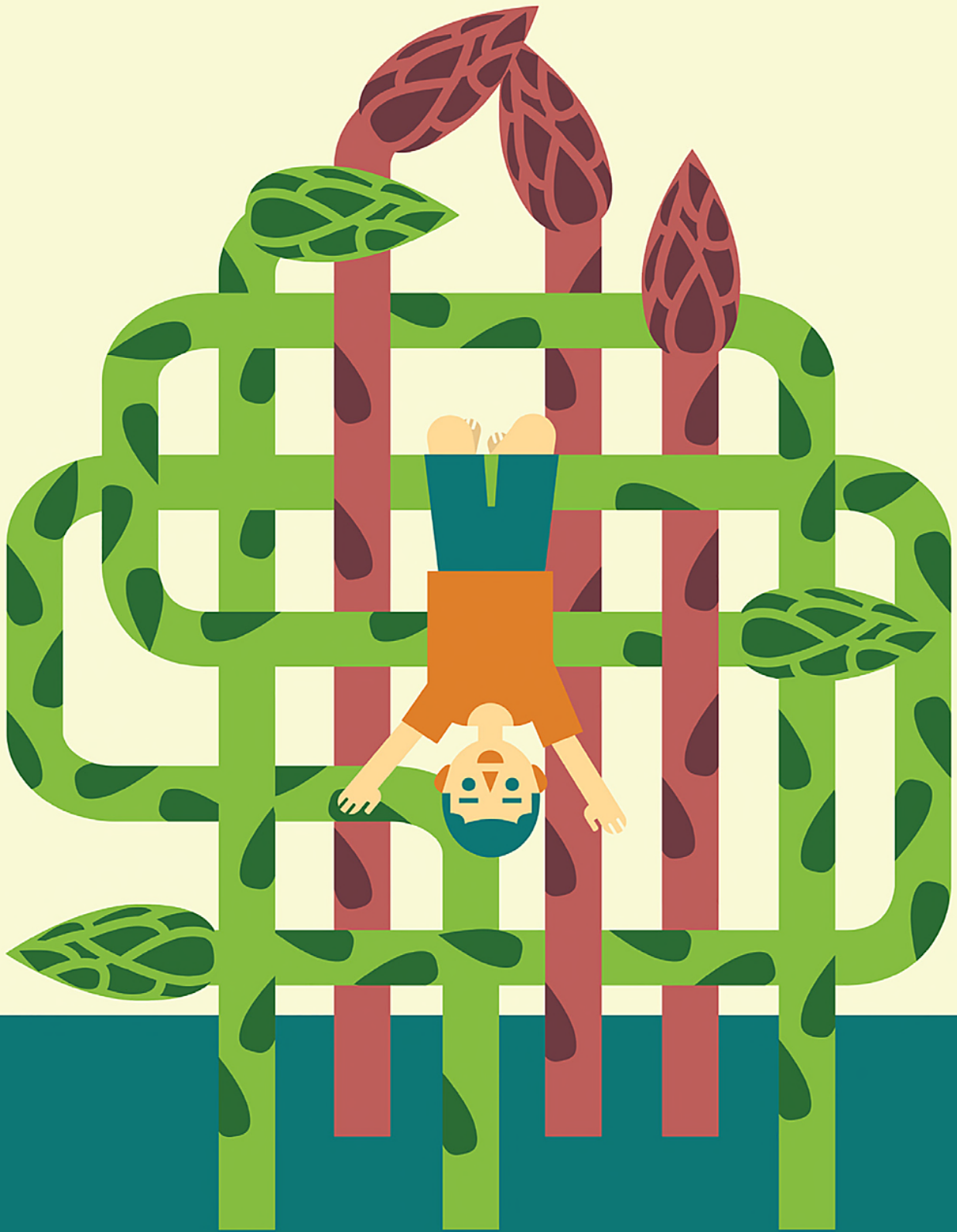
Concerns/Issues	Interventions
<ul style="list-style-type: none"> <li>Modified / restrictive diets including gluten free casein-free/soy free diet</li> </ul>	<ul style="list-style-type: none"> <li>Assess diet for nutrient adequacy based on age/sex.</li> <li>Specifically assess adequacy of calcium, vitamin D, protein and other micronutrients.</li> <li>Refer to feeding clinic with registered dietitian nutritionist (RDN).</li> </ul>
<ul style="list-style-type: none"> <li>Food selectivity</li> </ul>	<ul style="list-style-type: none"> <li>Assess textures and types of food consumed.</li> <li>Refer to feeding clinic and RDN for in-depth nutrition intervention.</li> </ul>
<ul style="list-style-type: none"> <li>Behavioral feeding issues</li> </ul>	<ul style="list-style-type: none"> <li>Referral to psychologist for strategies to address manipulative behaviors</li> </ul>
<ul style="list-style-type: none"> <li>Frequent intake of fermentable carbohydrates</li> </ul>	<ul style="list-style-type: none"> <li>Encourage tooth-friendly snacks at defined times between meals. Cheeses, unsweetened yogurt with fresh fruit, vegetables. Drink water between meals.</li> </ul>

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# Nutritional Requirements for Children with Special Needs

By Michael Roth, DC and Richard Drucker, BS, MS, ND, PhD



In the last few decades there has been an alarming and disturbing increase in infant and childhood behavioral and physiologic disorders. These include, but are not limited to, attention deficit hyperactivity disorder (ADHD), dyslexia, dyspraxia, autism, cerebral palsy, mental retardation, and Down syndrome to name just a few. Our society has grown so accustomed to hearing these terms, they are almost deemed to be normal variants among children. But should we consider these disorders "normal?"

Forty or 50 years ago, for example, many of the learning disabilities so commonplace today were virtually non-existent. Why is that? The current argument among alternative health experts in the field is that increasingly poor (or synthetic/chemical) nutrition may be a primary cause of today's modern epidemic health problems among children. One look at a popular children's cereal, for example, confirms this fact. Included in the ingredients are the following processed or man-made ingredients: refined sugar, corn

flour, wheat flour, gluten and oat flour; partially hydrogenated vegetable oil, yeast, salt, red #40, blue #2, zinc oxide, yellow #6, turmeric color, blue # 1, annatto color, and BHT (preservative). These can actually comprise over 50 percent of the ingredients in many cereals. Even something as seemingly "healthy" and popular as chicken nuggets that many fast food restaurants now offer, contains synthetic chemicals far too many to list in this short article.

Did you know children over one year of age should be on nutritional supplementation with a proper and complete combination of vitamins and minerals? But, there is an overwhelming selection of choices when it comes to children's nutrition. How does one go about choosing the right supplement amongst all the hype? The first thing to remember is that the cheapest product is not always the best. Quality products may demand higher prices. Begin to research the company by reading the available material on the Web site and/or contact the company and ask for information. Look on the label and see

if potency is guaranteed. Check the sugar and additive content. The proper balance of nutrients must be offered since they work synergistically; certain vitamins and minerals work cooperatively in different metabolic pathways in our cells and tissues. Correcting a deficiency of only one vitamin may cause a deficiency in other areas. The right nutritional supplements may help children build stronger bones, support the immune system, prevent and shorten colds and flu, allergies, and sensitivities, and improve their overall health and well being.

Most nutritional patterns are forged in the first few years of life and pave the way for continued eating habits into adulthood. For developing humans, this is a vital time in their lives-when good, solid nutrition is absolutely essential. We already know that children have a greater need for proper and more complete nutrition than adults for a variety of reasons; their bodies are in the developmental stages so excellent nutrition is vital for the proper development of their organ systems, immunity, and their five special senses (sight, hearing, touch, taste, and smell).

But, as important as nutrition is for the child population in general, children with special needs require even greater attention to whole and complete natural nutrition. Poor eating practices and nutrition have pronounced effects on mental and physical development. One clinical and epidemiological study was conducted, which included 2,397 school-aged children with varying levels of iodine deficiency, ranging from high deficiency to no deficiency. An increased frequency of cases with IQ scores not more than 80-85 was observed in iodine deficient areas. Attention deficit disorder (without hyperactivity), anxiety-depressive disorders as well as asthenic symptoms were observed most frequently.

Studies have shown that children with cognitive disorders can be helped through high quality supplemental nutrition. One such study has shown the value of supplementation with flax oil and vitamin C. According to the study:

# Nutritional Requirements

"Considerable clinical and experimental evidence now supports the idea that deficiencies or imbalances in certain highly unsaturated fatty acids may contribute to a range of common developmental disorders, including attention deficit hyperactivity disorder (ADHD). There was significant improvement in the symptoms of ADHD reflected by reduction in total hyperactivity scores of children with ADHD derived from ADHD rating scales [with supplementation of flax oil and vitamin C]." Children with neurobehavioral disorders have also shown improvement when supplementing with magnesium-vitamin B61.

Unfortunately, poor dietary habits in children are the norm in recent years, not the exception. A large study was done of over 3,000 children, which appeared in the medical journal, Pediatrics, and showed that only 1 percent of the children in the study met the requirements for the recommended food pyramid. Additionally, this same study showed these children as being low in vitamin B6, iron, calcium, zinc, and fiber.

Not only are the types of foods children eat important, but the amount of food consumed should be managed as well. Depending on the source, reports indicate on average, 10 percent to 25 percent of today's children are overweight or obese. That is a significant increase over the national average 25 years ago of only 6 percent.

In addition to the increase in adolescent diabetes, studies have shown that overweight children are also prone to ADHD. One study described and presented a subgroup of children with obesity and ADHD and assessed a possible casual relationship. During a four year period, 32 school-aged children were hospitalized for obesi-

ty, and 26 were included in the study. It was found that over one half had ADHD. The pattern of behavior found in ADHD may be a factor for the development of abnormal eating behaviors in children leading to obesity. The study suggests that obese children should be screened routinely for ADHD.

Autism and hyperactivity have shown improvements when nutritional changes are made. In one study, 15 children with autism were divided into three groups; parents of patients in Group I received counseling regarding casein free diets (casein is a white, tasteless, odorless protein precipitated from milk by rennin. It is the basis of cheese and is used to make plastics, adhesives, paints, and foods). Those in Group II received counseling regarding gluten free diets, and those in Group III received counseling regarding gluten and casein free diets. Dietary exclusion of casein resulted in reduced hyperactivity in three children, reduced anxiety in one child, and improved digestion in three children. Gluten exclusion resulted in improved attention in two children, reduced hyperactivity in one child, and improved digestion in one child. All behavior scores (except for socialization) improved in patients in Group III.

Many more studies are being conducted, which may indicate that many juvenile disorders can be helped or even prevented by reversing the poor eating patterns that we and our children have been educated to follow. Childhood is a time when young ones need to be protected from the overwhelming bombardment of poor nutritional advice and the food advertising that is so ever-present today in a world of self-proclaimed experts.

In addition to the lack of proper nutriti-

onal education, food advertising claims can be exaggerated or may be completely false. Although many regulations have been set to try and protect consumers, many food manufacturer ads are still misleading to the public. Two common examples are cereal and fruit juice advertisements. For example, in some cereal ads we may see a bowl of children's cereal (which is comprised mostly of sugar, starch, toxic synthetic chemical nutrients, and preservatives) in the midst of a whole grain, fruit, and fruit juice morning meal, and we may be led to believe that the cereal is part of this nutritious breakfast. What we may not be told is that it's the worst part! Additionally, fruit juices may claim they are "natural" or contain "100 percent real fruit juice." However, current regulations allow manufacturers to make that claim even if there's only a thimble-full of real juice in their product.

Today's children may also be facing more obstacles in the way of their health than just poor nutrition. Not only are they suffering from eating the wrong foods, they may be eating good foods that are actually very low in nutrition and may contain harmful additives and toxic synthetic chemical nutrients. Moreover, when our children do become ill, rather than helping them with more natural remedies, we tend to use all prescription or over-the-counter (OTC) medications, which may contain known and unknown short and long term side-effects, contraindications, dependencies, etc.

Today's children may be exposed to much more toxicity and pollution than those of one or two generations prior. Free radical damage and oxidative stress is a daily occurrence and is likely in higher amounts. Air pollution, water pollution, pesticides, preservatives, radiation, smoke, fatty foods, and various levels of stress are factors that raise free radical levels. These free radicals may increase risks of degenerative diseases since they cause cellular and tissue damage within the body. There is a great need for diets rich in carbon-based (organically bound) vitamins, minerals, and antioxidants to combat free radical damage. Children receiving the right amount and combination of minerals and

*There is a great need for diets rich in carbon-based (organically bound) vitamins, minerals, and antioxidants to combat free radical damage.*



vitamins may be better able to counter the effects of extra toxins to which they are continually subjected.

Amazingly, despite the increase in childhood illnesses, reports from the medical community claim that our current food supply is completely adequate for nutrients. Yet, for the most part, much of the medical community does not have a thorough enough nutritional education to make such a statement. In a recent

Survey of Nutrition Education in U.S. Medical Schools: An Instructor-Based

Analysis, the following excerpt is taken: "Nutrition plays a critical role in numerous pathophysiological conditions, including such prevalent diseases as diabetes, cancer, and cardiovascular disease. Despite the recognition that physicians are often called upon to provide guidance in nutritional aspects of disease and disease prevention, nutrition has not been consistently emphasized in medical school curricula. Indeed, numerous reports suggest that nutrition education of physicians remains inadequate."

So, where do we get accurate nutritional advice? Start by asking those who do have a good nutritional background and education. Most alternative healthcare providers (HCPs) have this kind of experience and education and also tend to have a handle on current nutritional issues. Ask your HCP what his or her nutrition background is. And, do some research yourself. Thanks to the Internet, a wealth of information is available right at our fingertips. By doing adequate searches and comparisons, you can make informed decisions, using a collection of research that was unavailable as little as 10 years ago.

Using the expertise and knowledge available to us, children can start benefiting from proper nutrition before they're even born! The nutrition that parents receive themselves will ultimately affect the development of the growing fetus. If the mother is making and following wise nutritional choices, the fetus may have a much better chance of developing into a strong and healthy newborn.

The next step is feeding our children the best possible nutrients from birth until they can make proper nutritional

*"...minerals are not found in the same abundance today as they used to be, due to the agricultural procedures practiced over the past several decades. Thus, just eating a well-balanced diet no longer adequately supplies life-sustaining minerals."*



choices themselves. This includes the mother eating properly while nursing to give her baby excellent nutrition through her own milk, then educating her children to limit or avoid improper nutrition (e.g. excessive sugars and complex carbs) and make healthy choices in both foods and supplementation. This can be accomplished by parental education, responsibility, and examples and by showing them the difference between good and bad foods when they shop, eat at restaurants, or eat home-prepared meals.

However, as important as avoiding the wrong foods and eating the right foods is, it's simply not enough. A point that must be emphasized continuously is that today's foods, even naturally grown foods, are lacking in vital minerals and vitamins. Dr. Richard Drucker states, "... minerals are not found in the same abundance today as they used to be, due to the agricultural procedures practiced over the past several decades. Thus, just eating a well-balanced diet no longer adequately supplies life-sustaining minerals. Your health and wellness are at risk unless you replace the minerals that have been diminished in our foods." A categorical statement by two-time Nobel Prize winner, Linus Pauling, states, 'Every ailment, every sickness, and every disease can be traced to an organic trace mineral deficiency.' You must ingest the appropriate amount and quality of both trace and macro minerals, or you will be vulnerable to illness and disease. People are not getting the proper organically complexed (carbon bound) trace minerals and nutrients to provide homeostasis (body balance) as nature intended. According to recent research, the body is imbalanced when it is deficient in organically bound trace minerals. This may cause disease,

which can then manifest in the body with disastrous results." Additionally, Dr. Drucker writes, "... the steady addition of toxic chemicals, herbicides, pesticides, etc., has triggered long-term soil imbalances, leading to an inability to neutralize the toxic chemicals and re-create new organic complexes and other critical minerals and nutrients. Thus, our foods have become interlaced with inorganic, toxic chemicals in place of naturally occurring, organically complexed minerals and nutrients. Again, who suffers? We all do."

In short, today's children, especially those with special needs, must avoid the unhealthy consumption of synthetic, chemically-produced foods (and nutrients), and replace them with proper nutrients. The body simply works better when it is receiving a regular supply of healthy, organic, carbon-bound nutrition.

To receive a version of this article containing references and works cited, please make request to [jhollingsworth@eparment.com](mailto:jhollingsworth@eparment.com). •

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Michael Roth, DC obtained his Chiropractic degree from Life Chiropractic College in Marietta, Ga. Dr. Roth has nearly 25 years experience in health and nutrition. He is currently the patient protocol consultant for Drucker Labs, Inc., who manufactures and distributes health, wellness, and nutritional products.

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Richard Drucker, BS, MS, ND, PhD has a Masters of Science in Natural Health and Doctorate in Naturopathy as well as a Doctorate in Natural Health with a specialty in natural Immunology. He is a highly respected doctor in the field of natural health and the CEO of Drucker Labs, which manufactures and distributes health, wellness, and nutritional products. These products use a breakthrough technology called intraCELL™ V, which yields unique carbon-bond organic microcomplexed™ structures that are highly bio-available and extremely effective.



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# HOW ACCESSIBLE IS YOUR SOCIAL MEDIA?



SUBMITTED BY THE CENTER FOR INCLUSIVE DESIGN & INNOVATION,  
GEORGIA INSTITUTE OF TECHNOLOGY

*Social media has always been a resource for sharing information, connecting communities, and enhancing the learning experience. Having a disability during a pandemic has made social media a vital tool for avoiding isolation, having fun, and staying informed. The Center for Inclusive Design and Innovation (CIDI) at Georgia Institute of Technology has been committed to serving the disability community for more than 20 years.*

**C**IDI ([www.cidi.gatech.edu](http://www.cidi.gatech.edu)) has partnered with the CDC Foundation ([www.cdcfoundation.org](http://www.cdcfoundation.org)) to ensure information related to COVID-19 is available to all people by developing and circulating accessible CDC guidance. The Centers for Disease Control and Prevention ([www.cdc.gov](http://www.cdc.gov)) has provided technical assistance to this project.

“Research has found there is a significantly higher death rate from COVID-19 for people with certain disabilities, often because

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**REMOVING BARRIERS:** Tools for Life’s Best Practices recommendations include appropriate color contrast of all posts, alt text for all images, short and concise text for posts and captions for all videos.

they also have underlying conditions that put them at higher risk for severe illness,” says Carolyn Phillips, Co-Director of CIDI. “As a parent of a child with disabilities, I witness first-hand the critical need to make social media accessible so everyone can access the same information in a way that makes the most sense to them.” As social media is a main source for delivering information, it is increasingly important to make sure it is accessible to the people who are in need of it the most.

The CIDI/CDC Foundation partnership has overseen the development and production of braille documents, mailed free of charge to consumers, downloadable and accessible Word and PDF documents, documents with easy-to-read language, and related resources to offer to various communities. There are ongoing efforts to produce more accessible documents, community partnerships, and resources such as American Sign Language videos and webinars to assist in spreading awareness and safety for everyone.

“When creating public health messages, it’s imperative that all individuals are able to easily access and understand these communications,” said Lauren Smith, MD, MPH, chief health equity and strategy officer, CDC Foundation. “Our work with CIDI and CDC allows people with disabilities to receive and understand these important health messages especially during the challenging times we are facing now with COVID-19.”

With social media being a major outlet for news and entertainment, being accessible is not always an included feature of its design. Utilizing social media as a means to reach various disability communities has been particularly important in community-building online, but there still remains a gap in accessibility. This gap limits messaging from reaching the intended audience.

A program within CIDI, known as Tools for Life, has taken the lead in delivering important information on making social media accessible. Tools for Life (<https://gatfl.gatech.edu/index.php>), Georgia’s Assistive Technology Act Program, is a program dedicated to increasing access to and acquisition of assistive technology (AT) devices and services for people of all ages and disabilities. The mission of Tools for Life helps people live, work, learn, and play independently and achieve greater freedom in the community of their choice.

A critical component to remaining compliant, is understanding how to be accessible within social media platforms. All the information that CIDI produces must be accessible. The units within CIDI cater to a variety of communities in-person, and through e-mail, internet forums, phone, and physical documents. Developing and publishing accessible social media messaging is as important

as any other communication method available to everyone, and at times, is the most effective at sharing real-time information and updates.

As platforms continue to update and conform to accessibility compliance, it becomes the responsibility of the person posting to social media to make sure that the intended audience can receive and understand their messaging. Whether it is a formatting issue or finding a work-around for the incompatibility of certain AT tools, each social media platform has challenges that require solutions tested by those within the community.

A key focus within the CIDI/CDC Foundation partnership has been hosting webinars to educate the public on accessibility and safety during COVID-19. The upcoming webinar, Making Social Media Accessible for People with Disabilities (<https://cidi.gatech.edu/covid/training>), will be led by Danny Housley and Tori Hughes of Tools for Life, and John Rempel of CIDI. They will be

using their social media and accessibility expertise to discuss the impact of social media and how to reach a variety of audiences within the disability community.

John Rempel, the Information and Communications Technology (ICT) and User Experience (UX) manager at CIDI, will be leading a portion of the webinar from an accessibility compliance aspect and will be covering the standards and guidelines related to digital content, which

transfers over to social media content and access. “Social media is an essential means of sending and receiving critical information for individuals, higher education institutions, businesses, and government,” says John. “Ensuring access to content for people with disabilities is paramount to their quality of life and well-being.”

Tori Hughes, an Outreach Specialist for Tools for Life, will educate webinar attendees by highlighting different social media platforms and their accessibility differences, built in accessibility tools, and accessibility upgrades and updates made to specific platforms. Danny Housley, the AT Acquisition manager for Tools for Life, will be talking on how social media can be used, AT tools for accessing social media, and standards for accessible content.

“Social media accessibility is needed to ensure that everyone has the opportunity to be connected, enjoy content and share what they like,” Danny shares. “From content consumption to creation, people with disabilities should be afforded the same opportunities to engage as anyone else.”

*You can register for the accessible social media webinar and view archived webinars by visiting [www.cidi.gatech.edu/covid/training](http://www.cidi.gatech.edu/covid/training) •*



**SHARING EQUALLY:** If social media content is not accessible or does not take the needs of people with disabilities in mind, then access to important information, including COVID-19 guidance, is missed.

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**EP MAGAZINE: THE JOURNAL FOR SPECIAL NEEDS FAMILIES AND PROFESSIONALS**

The research that has emerged as to COVID-19 and its impact on people with IDD tells a terrible story and is a sobering warning to all of us who are any part of this field.

# DID WE DO ENOUGH?

BY DAVID A. ERVIN, BSC, MA, FAAIDD

*Just yesterday, I happily got dose 1 of the vaccine. I was, and remain giddy at my privilege of being vaccinated early. Still, it's hard not to reflect on the year that's passed. My dad, my CFO, and 26 of my co-workers, 15 people with intellectual and/or developmental disabilities (IDD) who we support—and at this writing, 22.6 million Americans—form an unwelcome, uneasy fraternity. All have contracted COVID-19.*

**A**s I stare once more at the Johns Hopkins Coronavirus Resource Center, the number of deaths is incomprehensible. More than 385,000 in the United States alone. At the agency for which I work, which supports 220+ adults with IDD, and across the region in which we do our work, lives of people with IDD were taken by this wretched virus. The burden of these lives lost dampens my enthusiasm at having gotten 'the shot.'

Many, many people, through the months, have asked, "how are you managing?" The subtext of the question and countless others that seek to understand how we're navigating the crisis acknowledges certain inevitable realities: We were not prepared

for a global pandemic. We had no precedent on which to rely. We had no inkling as to just how contagious... and deadly... COVID-19 would prove itself to be. All these things were then, at the outset of the pandemic in the US, and remain now true. And none of these things mattered very much when it came time to reacting to the realities we faced then and face now.

Our first scare at my organization came on March 7 last year, seemingly a lifetime ago. Someone we support in community living supports attended a community event at which, we would later learn, he was exposed to the region's so-called patient zero. As it turned out, the person we support did not contract the virus. Less than a month later, two different people to whom we provide supports were not as lucky, as they became our first COVID-19 'cases.' Both were hospitalized. Both were intubated. Both eventually came off the ventilators required to keep them alive, but only one would survive.

There was no doubt as to how folks we support in community living would be exposed—the direct support professionals (DSP) to whom our agency and our field owes so much were, paradoxically...and tragically...the greatest threat to people we support who, from the end of March, per Executive Orders from the Governors of both Maryland and Virginia, were effectively locked down in their homes. The typical comings and goings of the rotating, shift-based staffing model traditional to our organization and countless others, was the source of the threat, introducing new staff at each shift who were at huge risk of being asymptomatic carriers of the novel coronavirus.

By late April, we'd implemented, across all of our community living/group home supports a live-in model. Our DSPs committed to 'stints' of not less than two weeks, and we equipped them



**LOOKING WITHIN:** Questions must be asked – did we do the right things at the right times for the right reasons? What was the impact of choices we made, and did means justify ends? Was our reaction and were our protocols over- or under-reach? Were we suitably proactive or dangerously reactive? And, the one I can't shake: Did we do enough?

with what has turned into tens of thousands of dollars of supplies to support the model. From towels and bed linens, to air mattresses and cots, to personal hygiene supplies and items of creature comfort, we supported our staff who were leaving their own families to move in to their workplaces.

**W**e set up armies of volunteers to deliver groceries and household supplies, gaming systems and all manner of activities, surprise gift boxes and care packages to homes across our community. We precluded family visits and restricted anyone from coming or going as was once the norm into or out of peoples' homes. On May 7, 2020, more than eight months ago, we had our last (please, everyone, knock wood) COVID-19 positive case among the folks we support in group home supports.

Sounds impressive enough. And, it's true, the change to our model was seminal in our fight against COVID-19. But, remember those two first cases? Only one survived their battle. We lost the first member of our family to the virus. It didn't come quickly. He was, this exquisite human being, a fighter. For three months, he fought and he scrapped to regain his strength, to battle back to health.

Each day that passed brought us closer, we imagined, to his full recovery. He would star in, we imagined, one of the news stories, leaving the hospital to rapturous applause for his spunk and his will to survive. Nearly three months after his first symptom emerged, he lost his battle to COVID-19.

We were crestfallen. Defeated. Utterly crushed by the enormity of the loss. It remains, nine months after he was hospitalized, raw.

Our focus remained unwaveringly on everything necessary to mitigate risk, to look carefully after our DSPs, to develop risk mit-

igation, infection control, testing, and a host of other far-reaching protocols to address everything we could contemplate. We were then, and remain now, incredibly lucky to have the financial support of our community, so we were able to dedicate financial resources that other agencies don't have to our work. Pay differentials were installed for people working/living-in. Overtime costs were approved with little fanfare or the sort of scrutiny typical of 'normal' operations. A testing protocol was developed, a contract with a clinic in the region executed to test all staff prior to any contact with the folks we support, all

at our cost. Personal Protective Equipment, about which organizations like mine knew very little prior to this crisis, was purchased at unimaginable scale from suppliers across the globe.

**“People have asked ‘how are you managing?’ The question acknowledges certain inevitable realities: We were not prepared for a global pandemic. We had no inkling as to just how deadly COVID-19 would prove to be.”**

Fundraising campaigns were quickly cobbled together to plead for help. Looking under every rock for financial support through the likes of the Paycheck Protection Program, Appendix K, and the Provider Relief Fund became the singular focus of our finance and business office staff. Weekly communication platforms were created to keep our Board of Directors, folks we support and their families, and our broader community updated on the good, the bad and the sometimes really scary realities of our experience of the pandemic and to share critical information across our networks. New partnerships—odd ones against the context of what was once normal—were struck, collaboratives built.

We've saddled up with national and local associations and organizations to create networks of content experts, from virologists and primary care physicians and dentists, to public policy wonks, to researchers and academicians to inform the science and learn from the smartest and best-informed people we can find. Advocacy activities were undertaken, ranging from newspaper articles that decried the lack of testing and PPE resources available, for not just folks with IDD that my agency supports, but that all people with IDD need and, frankly, deserve,

to letters and phone calls and e-mails to elected officials at the local, state and federal levels pleading for help.

Virtual supports were researched, built, implemented, and evolved in real time. Resources dedicated to the mental health needs of staff and people we support have been identified and deployed as what we'd hoped initially might be only a few months turned into what will likely be more than a year. Employee assistance program benefits were significantly enhanced and extended. Death and dying counseling and critical incident debriefing sessions were created and delivered. We created a Medical Advisory Panel to inform policy and protocol, to educate staff and people we support, to provide expertise and, frankly, counseling to our community. We published journal articles and white papers and guidelines so that the field was informed and provided information that might, if we were good and lucky and timely enough, to save lives. And all of this barely scratches the surface...

In Maryland, as of January 7, 2021, the case fatality rate of people with IDD is nearly 2.5 times the case fatality rate of the general population. In Virginia, it's 3.0 times the rate of the general population. In Washington, DC, it's 4.8X. The list goes on. In nine states and DC, the case fatality rate among people with IDD ranges from 1.4 to 4.8 times the rate of their peers in the general populations of those jurisdictions. The research that has emerged as to COVID-19 and its impact on people with IDD tells a terrible story and is a sobering warning to all of us who are any part of this field.

At my agency, we've only just begun to fully comprehend the lessons that have and will continue to come of our experience. We have collected mountains of data so that we can separate the met-



**“We remain committed to facing whatever is still to come with our eyes wide open. We are shattered by our loss of life, and we are inspired their memories to fight forward.”**

rics of our experiences over these last 10 months and those that lie in wait in front of us from the emotions and sheer exhaustion of them. My hope is that we learn the critical, essential lessons of the pandemic and how we navigated it. Questions must be asked – did we do the right things at the right times for the right reasons? What was the impact of choices we made, and did means justify ends? Was our reaction and were our protocols over- or under-reach? Did we trample on our commitment to self-determination and meaningful choice for all humans but for the sake of protecting people, and if so, at what cost? Were we suitably proactive or dangerously reactive?

And, the one I can't shake: Did we do enough?

It's hard to know what the next days and weeks and months

hold. Over the three days during which I've written this article, we have had nearly 100 of our staff receive the first doses of the vaccine (yes, we've written a Vaccination Protocol), and the people we support are scheduled for vaccination clinics beginning late January. We are, it would seem, closer to the light at the end of the tunnel. But until we're there, we must continue to manage this crisis with-

out precedent. We must continue to build the airplane as we fly it. There is still no playbook.

We are grizzled by the experiences of these past 10 months, and we remain committed to facing whatever is still to come with our eyes wide open. We are shattered by our loss of life, and we are inspired by their memories to fight forward. We are drained and exhausted, but we are energized by opportunities to learn and to grow. We wish to be done with COVID-19, to fully and finally talk about it in the past tense, but we remain alert and aware of the danger, singularly focused on surviving this crisis and thriving in its wake, wiser, even if a bit battered, for the experience. •

#### ABOUT THE AUTHOR:



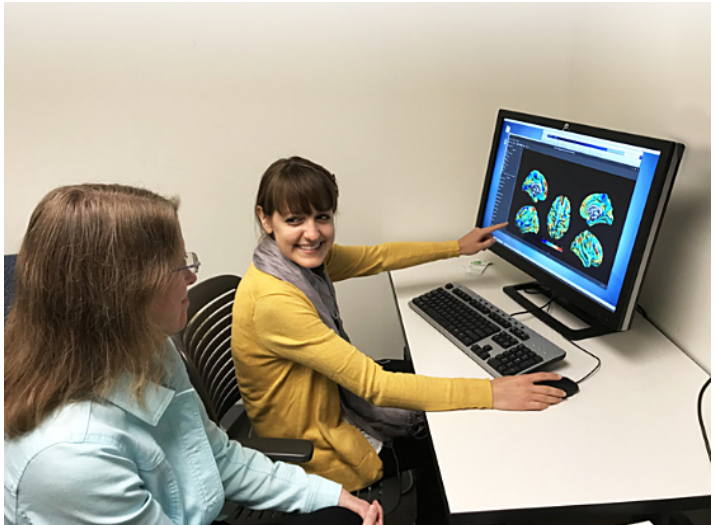
David A. Ervin, BSc, MA, FAAIDD is CEO of Jewish Foundation for Group Homes, a Maryland-based non-profit supporting people with intellectual and developmental disabilities (IDD) in Maryland and Virginia. With more than 30 years in the field, David has extensive professional experience working in and/or consulting to organizations and governments in the US and abroad. He is a published author and speaks internationally on health and wellness and healthcare for people with IDD and other areas of expertise. David's current research

interests include cultural competence in healthcare delivery to people with IDD and the impact of integrating multiple systems of care. He was a contributing author to the Rubin, et al. seminal volume, *Health Care for People with Intellectual and Developmental Disabilities across the Lifespan*, and has co-authored several peer-reviewed articles in 2019 and 2020 on health outcomes achieved by people with IDD through access to multidisciplinary healthcare models and, most recently, the impact of COVID-19 on people with IDD. David serves on a number of policy and practice committees, including the American Association on Intellectual and Developmental Disabilities/The Arc of the US Joint Committee on Long Term Services and Supports, and is on the Board of vaACCSES, a Virginia community service provider association



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# MAKE FRIENDS WITH OTHER PARENTS OF KIDS WITH AUTISM



BY KIMBERLEE RUTAN MCCAFFERTY

**Sixteen years ago this fall, my family and I entered the world of autism through our son's diagnosis at seventeen months of age. I remember being so overwhelmed with my new "to-do" list; diets, Early Intervention, ABA, sensory issues, sleep (or lack thereof) disturbances, eating problems, etc. It was difficult to know where to begin.**





**SOMETHING IN COMMON:** "I have two children on the spectrum, one mild and one not, and I've found I needed to bond with moms and dads who were raising both types of autism in order to find the sounding boards I needed."

*The truth is, all of my personal needs went on hold for, well, years, but there was one need I did pursue, and I am grateful to this day I have always made time for this endeavor.*

**A**nd that, my readers, is making friends with other autism parents. I have dear friends from all walks of my life – high school, college, work, and the ones I inherited from my husband who became my own. They are all wonderful and supportive people, and I do often talk to them about the challenges of raising my severely autistic son. They get it to a degree, as much as anyone can who is not walking in my family's shoes. I am fortunate to have these outlets, and have had these people stick by me, especially during the years I was so enmeshed in autism I didn't have much time for friendship. I value them all.

But at the end of the day, sometimes you just need a friend who gets that when you say your son hasn't slept for three nights, what you're really saying is that you're afraid he'll never sleep again. And you need that friend to calm you down.

I have had the great fortune to make a number of "autism friends" over the years. I have two children on the spectrum, one mild and one not, and to be honest, I've found I

needed to bond with moms and dads who were raising both types of autism in order to find the sounding boards I needed. I've found their two types of autism to be so different there is almost no commonality – subsequently it was important to me to befriend people who had similar experiences to the ones I was having with both of my kids.

I want to share with you now, that along with exercising and chocolate (I know, they shouldn't mix well but they do), having people to vent to has saved my sanity numerous times over the years. The connections I've made have been invaluable, and here's how I've made them. As an aside, all of these opportunities were pre-COVID of course, but hopefully will be again available soon! •

#### **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 [autism-mommytherapist.wordpress.com](http://autism-mommytherapist.wordpress.com). Kim's book *Raising Autism: Surviving the Early Years* is on sale on Amazon [here](#).

### **NICE TO KNOW YOU : SHARED EXPERIENCES AND MAKING FRIENDS**

**1. When your child enters school, see if you can make contact with other parents in your child's classroom.** One of the best ways I did this was attending every little performance they did and chatting with the moms before and afterwards. If your child's teacher does not offer opportunities to come to school, I would suggest asking him or her if you can send notes home through each child's backpack. I know it's awkward to approach someone you don't know, but some people will love that opportunity and be thrilled to reciprocate. One of my closest autism friend's son was my son's preschool classmate, and they are friends to this day. Playdates can be a wonderful offshoot, don't forget to include that request!

**2. If your school has any type of special education PTA, beg borrow or steal a babysitter and get yourself there.** Not only do they usually have very pertinent topics discussed at these meetings, but it's usually a wonderful environment to meet people. Many will be a bit further along in the autism world than you, and can be invaluable resources. Sometimes, staff from your child's school will

attend, and it's a great opportunity to meet them in a more relaxed setting than across the table from each other at an IEP meeting. I attended my son's district special education PTA meetings, and learned invaluable information that really helped me make decisions down the road.

**3. If there is a local autism organization in your area, join!** I live on the Jersey shore, and we are so fortunate to have POAC Autism services in our backyard. They run parent support groups which are wonderful ways to meet other parents, and dozens of fun events for families which are also a mecca for meeting people. Attending these events will also get both you and your child out, and start acclimating them to being in public, which is so important. I met one of my dearest friends through a support group.

**4. Last, if you can swing it (and you get a day or night out too!) participate in some local charity events.** We met a wonderful couple through a charity gala, the wife of whom I became friends with ten years later. This checks two boxes – meeting people and having fun, which is equally important to your sanity!



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[www.ep-magazine.com](http://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.

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# PROMISING PRACTICE: NAVIGATING MEDICAID INSURANCE COVERAGE ACROSS STATE LINES

BY LAURA GEORGE

*If you have chosen to read this article, then you either have experienced a problem with Medicaid and your child, have many unanswered questions, or are hopeful that there is a positive story out there on the topic instead of the negativity you usually hear. A promising practice is a created innovation that, based on early application, accomplishes an outcome, which then has the ability to become a common and widely used practice. Hopefully this “Promising Practice” will gain momentum and help anyone who has an exceptional child with state-to-state insurance questions.*

**M**y story begins with being not a professional who works with people with disabilities, but as a mother of a child with a rare autoimmune disorder, allergies, and a rare allergy called colophony. Colophony simply is an allergy to pine tar or pine rosin which can be found in food, medicine, flooring, walls, markers, clothing, pesticides, corn products, perfume, and more. While most have skin issues with it, my child reacts to the fumes given off. Yes, this means grocery shopping can be an easy environment for her to have a reaction to. In her case, it is not the breathing that stops; it her body shutting down due to instructions from her brain.

So when an amazing opportunity came up for us to move to Florida, into a home that would be by design much freer from pine tar or pine rosin amongst many other benefits, we jumped at the chance. Buying a home is stressful at best. But it could not compare to the level of stress and concern felt during this time of COVID-19, wondering how the insurance coverage would continue on in a new state.

Some of you may have learned by experience, that when in a disaster, being evacuated to another state meant that your child suddenly lost access to the Medicaid insurance program they were in. So if there was an emergent medical need, the cost was out of pocket. Additionally, finding a medical professional who was willing to see a child with disabilities without insurance, can be extremely hard to find. Is there legislation addressing this problem? That will be answered later in this article.

About a month prior to the move through calling my current state Medicaid office, it was learned that my child's insurance would have to be turned off, we move to the new state, find the new program, go through the application process, wait for approval, navigate the payment time frames, wait for the proof of new insurance to arrive, and then wait several weeks to see a doctor as a new patient. Making a personal vow, I promised myself to not let my child endure the frustration of not being able to see doctors for her health due to lack of insurance. It was not known at the beginning of the journey that the vow I made would require intense proactive aggressiveness, patience, and dutiful follow-up.

First, I called the Medicaid program in my state, and had a frank conversation on what was occurring, what was needed for my child, and what I hoped to accomplish, which was having back-to-back insurance coverage over state lines without interruptions. No changes were made at this time. Then, I called the Medicaid program in Florida, having the same conversation as before and again, repeating the desired goal for my child. During this time, we had not moved to Florida, but I was able to begin the application process about a week before the scheduled closing on the new home. A few days later a call was made to verify that Florida received the application, my daughter's story was told again, and the next steps along with the expected time frames were obtained. The contact in my state was called, and kept up-to-date with each step I made. On the day it was expected that the Florida application was to be approved, another call was made, her story was again repeated, and it was learned that she would be referred to another section of the state Medicaid program as her need for insurance coverage was critically important. Again, time frames for understanding when this step would be completed were obtained and the urgency explained. Another update call to the contact in my state was made.

While all this was happening, the closing on our house occurred and, two later days, we moved down to Florida. Upon arriving in Florida, another call was made to Florida's Medicaid program, to get the status of my daughter's insurance coverage. She, “is in the system,” I was told. Yet, in my mind that didn't mean much. I wanted proof. Those insurance cards were needed. My daughter's story was again told to yet another customer service representative in Florida, next steps and time frames were obtained. My update call was placed. But this time, because I was now calling from Florida, there was a change. “Her file is now closed due to living in Florida. Her case will remain open for a few more weeks; to the end of the month, to make sure she has coverage just in case.”

Privately (even at this stage) I was clinging to hope and faith that my child would not be caught without insurance and have to endure the concern I was trying to hide. Already in the first two

weeks at our new home she had several small colophony reactions (at the grocery store, the bank, the school, and the peel-and-stick flooring sitting in the garage), but fortunately I was able to help her through them.

Another call was made to the Florida Medicaid program and I was surprised to learn of a procedural step that not any of the representatives I had spoken with had taken the time to mention. Because her initial insurance payment was made after the 14th of the month, we had to wait until the 15th of the following month before her cards would even be issued. Card issuance took an additional 10 days to process, and then another business week at least before the cards would be received. Thus, at the current rate, the cards might not arrive until after the old state's insurance was turned off. Feeling discouraged, I allowed a few days to pass and another call was placed to obtain the current status of the insurance coverage. This time, after repeating my daughter's story, I was told, "Your daughter has been covered by Florida for the past two weeks. Let me get you the phone number to her assigned insurance company." Without wasting a moment, I immediately called the assigned insurance company. I gave them the state assigned account number, told them my daughter's story, and they gave me her insurance account number, assigned doctors, and other important information that I would need to make sure she had the appropriate care and coverage.

However, I still did not have the insurance cards. There were only handwritten notes on paper. Where was the proof? The representative who I spoke with offered to help out and expedited the process for sending the insurance card so that my child could meet with medical professionals quickly for her autoimmune issues. Five days later, the delivered mail held the answer to my dogged persistence in making sure my daughter would have insurance coverage she and all other children should have in this situation. Holding the envelope in my hands, I stared at it somewhat shocked that this goal for my child would be complete. With shaky hands, I tore the envelope open and the insurance card was revealed in all its glory. Immediately I showed it to my daughter and tears ran down my cheeks.

Instead of the average four-month process for canceling one state Medicaid insurance program and connecting with another, the whole process took about 49 days. It was started two weeks before the house closing and maintained through the closing process, moving, and arrival to Florida. For each and every call, the customer service representative's name, number, date and time of call were noted, the bullets to the conversation, the steps that were to occur, the time frames to be observed, and concise preface to each

conversation of my daughter's story given with her need for the insurance approval process to be sped up. At the end of every time frame given, a call was also made to confirm that the prior step had been completed and the proper paperwork had been processed. Being patient, cheerful, concise, dutiful and, most of all, aggressively proactive were the most helpful skills to have in making this Promising Practice occur.

**E**arlier in the article there was a hint about possible legislation to correct this in a disaster. The "Disaster Relief Medicaid Act (DRMA)," according to The Partnership for Disaster Strategies (PIDS) website (<https://reaadi.com/what-is-drma>) states among other items that the act is being created to, "provide uninterrupted access to Medicaid services when recipients must evacuate across state lines, increasing health maintenance and community living and preventing institutionalization during disasters." This bill was introduced in the 115th Congress, was initiated by PIDS, and written in conjunction with another bill called the, "Real Emergency Access for Aging and Disability Inclusion for Disasters Act (REAADI) (<https://reaadi.com/what-is-reaadi>)," which among other items will, "work to provide solutions that help individuals maintain the health, safety and independence before, during and after disasters," along with supporting DRMA. For more information on these pieces of legislation or for other questions, call their Disaster Hotline at (800) 626-4959.

While my child may not have some of the more serious medical

conditions out there that, sadly, occur to other children, having to contend daily with immune reactions can be concerning, let alone adding COVID-19 to the situation. It is my deepest hope that by sharing this experience publicly, that it will become a widely accepted Promising Practice and help at least one other family with an exceptional child. With intense passion, I hope the above acts are passed into law, so children everywhere can still maintain their health, independence, and well-being regardless of being in a disaster or moving from state to state. •

#### ABOUT THE AUTHOR:

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



**“WITH INTENSE PASSION, I HOPE THESE ACTS ARE PASSED INTO LAW, SO CHILDREN EVERYWHERE CAN STILL MAINTAIN THEIR HEALTH, INDEPENDENCE, AND WELL-BEING REGARDLESS OF BEING IN A DISASTER OR MOVING FROM STATE TO STATE.”**

# 18 minus 64

BY ROB WRUBEL, CFP®

*18 minus 64. The math doesn't add up. It does not make any sense. What kind of financial planner comes up with a negative number anyway? And why take the time to write about it?*

**T**here are key times in our lives as families with a member with a developmental disability. For some, it's the first year of school. For others it's the leap from middle school to high school and the enormous change that entails. There are other timeline dates that come up and include expected medical procedures, the drive to independent living and preparing for our own aging.

For me, right now, the next major milestone comes when my daughter turns 18 and that happens 64 days from when I am writing this (but hey, who is counting?). 18 years minus 64 days. A lot needs to happen in those 64 days.

Most of my articles for *EP Magazine* offer financial planning tips and techniques on how to get important planning steps in place even as we fight our fears, behaviors and worries about doing so. This one is a little different – and if you've been through the planning steps and transitions that come when your family member turns 18 and have some advice to share, please send comments to the magazine or to me.

One reason I am so passionate about people taking the time to get their estate and financial plans in place is that it frees up emotional and mental space to enjoy life and focus any new challenges or needs that arise. It's hard to put energy to something new when your mind and heart are tied up with stress and worry.

Yesterday, parents of a child with developmental disabilities were in my office. We started working with them two years ago and they were committed to their planning. They met with an attorney and

updated their estate plan to include special needs provisions. They dedicated themselves to saving and their accounts now have more money in them than they thought they'd be able to save, ever, and they only just started. Huge wins. They were more relaxed about their financial life and have been able to embrace the rest of their lives – parenting, career, moving to a new home – as a result.

It's exciting to watch a family make progress and to know that by doing so they can create the life they want to live today and prepare for the future.

My work begins this month on my next set of planning steps. Math and money vex my daughter with Down syndrome. She does not know the value difference of a dollar or twenty or hundred dollar bill. She lacks the ability to understand medical terms and to make decisions about her health in a consistent way. So, for now, she will need her parents as guardians. Maybe that will change as she matures and I hope it does. The next steps for me are to apply for guardianship with the court here in Colorado, apply for SSI so she has her income benefits and, by doing so, preserve her Medicaid for health insurance and community supports.

**T**hese are major moments in our family's life and important steps to take so that my daughter can live a fulfilling life. SSI provides her needed income until such a time when the job market embraces her unique talents. There has to be a role in companies for someone who loves to sing and dance, and greets people with compassion and joy. She won't have employer-provided health insurance and Medicaid will fill that role.

Ideally, she lives independently at some point, even as I support her as I can. Our family will benefit from local nonprofits that can help her learn life skills, check in on her, and be involved when I cannot or am no longer capable.

We look forward to her turning 18 and graduating from high school (go class of 2021!). It's a time filled with new challenges and fears and with new opportunities for growth as she heads into her next phase of life.

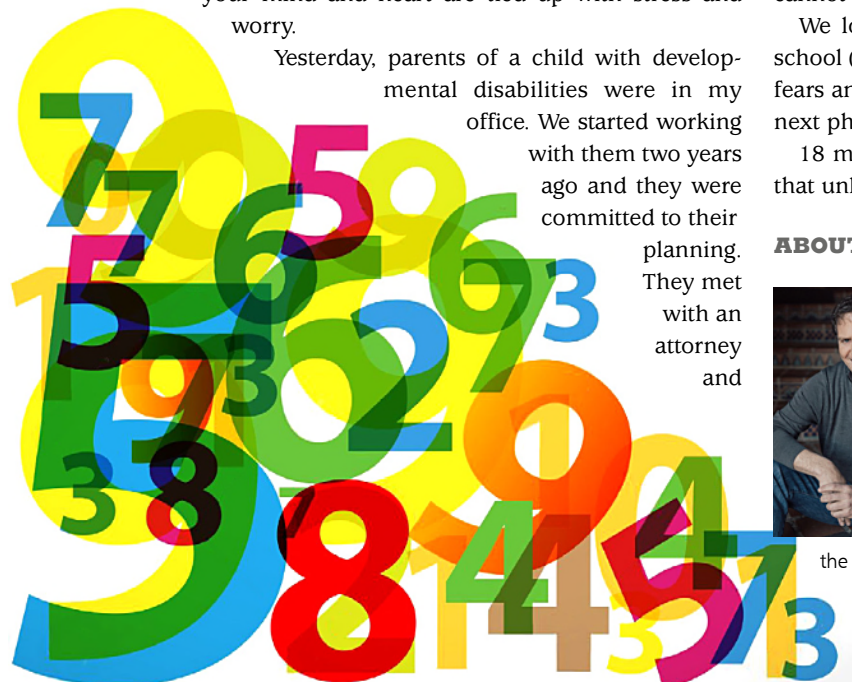
18 minus 64. I am not sure what this will add up to. I do know that unlike the basic arithmetic, it will be positive for our family. •

## ABOUT THE AUTHOR:

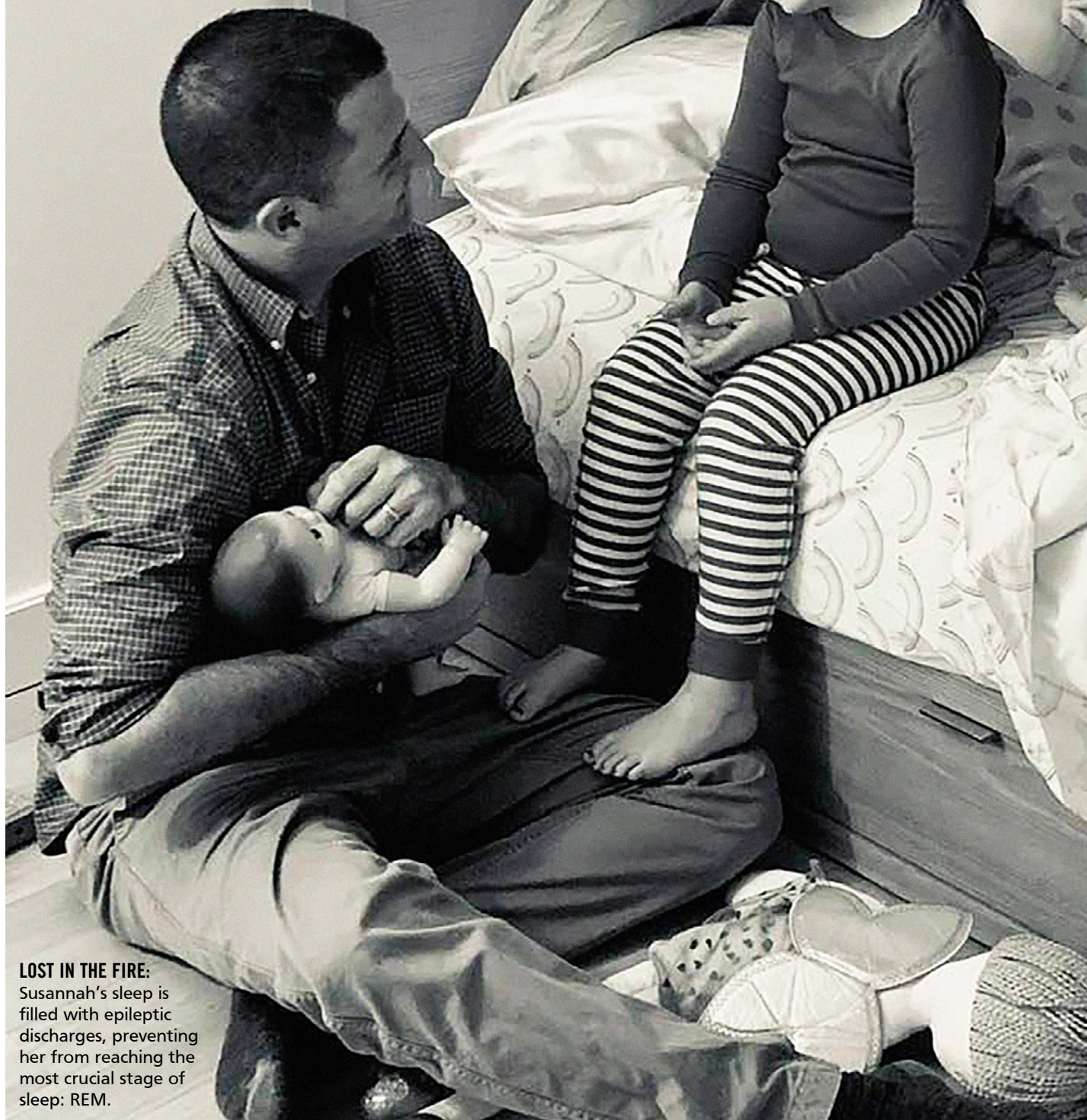


Rob Wrubel is a CFP who has a daughter with Down syndrome. He is recognized as a leading expert on financial planning for families with special needs members. Wrubel has written two books about financial planning and special needs families – *Financial Freedom for Special Needs Families: 9 Building Blocks 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.



KIF1A steals away steps, words and vision. These are measurable deficits, painful reminders that her disease is progressive — but tangible. ...Dreams, however, are magical and intangible events; intimate worlds far too complex to capture or describe in detail. Dreams are deliciously ambiguous, private secrets that inspire action. Is Susannah's disease so ruthless that it robs children of the ability to dream too?



**LOST IN THE FIRE:** Susannah's sleep is filled with epileptic discharges, preventing her from reaching the most crucial stage of sleep: REM.

# THE FIRESTORM OF RARE EPILEPSY: OUR GIRL'S DREAMLESS NIGHTS

BY LUKE ROSEN

*Susannah does not wear pajamas to bed, she wears battle gear. After her bath is finished, teeth brushed, stories read and songs sang, it is time for the grueling marathon that is Susannah's rare, nocturnal epilepsy. Her nine-year-old brother, Nat, flies into the bedroom like Superman and hugs her tight. "Night Shasha!"*

**B**efore he flies back upstairs to save the world, Nat asks which one of us will sleep with Susannah tonight. We answer with a smile. Our remarkable son is too kind to ever let on, but we see it in his eyes. He would do anything to have both parents to himself just for one night.

And he's off.

I kiss Susannah, tell her I am proud of everything she does, and that I love her too much to even say. Sally softly sings again, and we wait anxiously as Susannah's heavy brown eyes fall closed. And like that, our little girl is off to battle. When Susannah falls asleep, she does not journey into dreams of Rapunzel's tower or Elsa's castle. Instead, her brain slips into a nightly firestorm of continuous spikes, waves and seizure-like activity. A neurological nightmare that some children never wake up from. For the next ten hours our girl's life is extremely fragile.

When Susannah was diagnosed in 2016, she was the only person known to have a rare neurodegenerative disease caused by one specific mutation (P305L) in the KIF1A gene. KIF1A is responsible for

making a protein which is vital for brain function. Our daughter's genetic anomaly triggers a constellation of medical complexities: movement disorder, cortical vision impairment, spasticity, brain atrophy, and epilepsy. At the age of two, she was diagnosed with a very rare form of epilepsy called Electrical Status Epilepticus in Sleep, or ESES. The severity of ESES is measured by percentage of seizure activity, or continuous electrical discharges in the brain captured only by EEG during sleep. At last count, 100% of Susannah's sleep was filled with epileptic discharges. She has different types of seizures during the day, but this nocturnal epilepsy prevents Susannah from ever reaching the most crucial stage of sleep: REM.

Susannah's epileptic encephalopathy is kindling to a potential forest fire in her brain. We watch her sleep, waiting for that match to strike and ignite a blaze. She twitches, and sweats like a marathoner throughout the night. Susannah's breathing slows. Sometimes I wake her just to make sure those breaths have not slowed to a stop. Still, the most damaging outcome of these epileptic spikes in her brain is a complete lack restorative sleep. REM sleep is vital for brain development. It is that deep, wonderful sleep which yields recovery and alertness. REM is the stage of sleep when critical areas of the brain are stimulated. This sleep is responsible for skills like learning, memory, movement, energy and cognition. The REM stage of sleep is when we dream. Susannah never gets there.

KIF1A steals away steps, words and vision. These are measurable deficits, painful reminders that her disease is progressive— but tangible. We can count words and steps. We know when Susannah's

sight fails. Dreams, however, are magical and intangible events; intimate worlds far too complex to capture or describe in detail. Dreams are deliciously ambiguous, private secrets that inspire action. Is Susannah's disease so ruthless that it robs children of the ability to dream too?

It is hard to describe the flood of panic when a doctor explained possible consequences associated with ESES, and lack of REM sleep: deteriorating neurons, dementia, loss of motor skills and speech. But Sally and I have heard it before. These outcomes are similar to the implications associated with her genetic condition. To fathom this future for any child is impossible, but the epilepsy part of her decline can be prevented if we dampen the fire inside Susannah's sleeping brain.

Is it possible to address the severity of KIF1A Associated Neurological Disorder if we control the catastrophic seizure activity

ing from those buildings to save people. It is so beautiful to hear him unpack those dreams. When I ask Susannah what she dreamed about last night, we have a fleeting moment of hope, a sliver of hope that today she will rattle off whatever dreams may have come

**“When I ask Susannah what she dreamed about last night, we have a fleeting moment of hope that today she will rattle off whatever dreams may have come the night before. Instead, she looks at me with glassy round eyes and smiles.”**

the night before. Instead, she looks at me with glassy round eyes and smiles. A pause before she works hard to find words; words that once were easier for her to recall. I hug her tight.

If there was one magic pill, a pill that could cure only one of the myriad challenges our sweet girl lives with, what would it be? If only *one* part of her devastating disease could be treated, what would I choose? I would not choose a pill to help her walk or see. If there was only one part

of this damn disease that we could cure, I would choose a magic pill that gives Susannah the chance to dream. I would do anything for our girl to describe vivid dreams with enigmatic endings. Tales of



**TO SLEEP...:** “The most damaging outcome of these epileptic spikes in Susannah’s brain is a complete lack restorative sleep. REM sleep is responsible for skills like learning, memory, movement, energy and cognition. Susannah never gets there.”

in Susannah's sleep? If we race to find an effective medicine for her epilepsy, maybe we can slow the clock – a bandaid to buy her more time. Epilepsy is just one piece of her rare genetic disease. The seizure symptom of KIF1A compounds everything, and makes life so hard. Every hour of every day Susannah's brain and body run on fumes because her nights are filled with epileptic firestorms. The tank empties more with every dreamless night, and fatigue triggers severity in every aspect of her health: balance, vision, focus, speech, energy, spasticity, more seizures. All parts of KIF1A made worse by ESES. In the morning, after her marathon of spikes and waves, acute battle fatigue sets in, and it is our job to activate the neurons in Susannah's brain and get her body moving.

Like most parents, if I had one wish, it would be for my children's dreams to come true. When my son wakes up, I ask him what he dreamed about. Some mornings it was playing second base in the big leagues, and other mornings he describes buildings he designed, and his dream to be an architect – or a superhero jump-

running through castles and losing herself during a night of perfect sleep. I would be so lucky to appear as a character holding Susannah's hand in the dreams she decides to share with us. Soon.

**W**e work with doctors to find the right combination of medications, hoping for a temporary fix. With every EEG comes a new drug. A medicated roller-coaster of side effects in a monogenetic nightmare where clarity was fleeting long before we titrated up on the last benzodiazepine. We need new treatments today. Not tomorrow, not in one year or ten years. If we wait any longer nothing will come in time to help Susannah and kids like her. We are trying. It is a costly, life-altering burden to drive rare disease research — research which might go away if the lemonade stands stop and the funds run out. We need help to develop treatment before the damage is beyond repair. We need treatment that slows degeneration and makes Susannah's life less severe.



Last night I was home alone with the kids for the first time in months. Sally was returning well after bedtime, so it was my night to sleep with Susannah. Nat asked if he could sleep in his sister's bed, and Susannah sharply replied with a yell "slumber party!" The three of us climbed in, watched a movie and they fell asleep. Bliss. I slipped out of bed and went into the kitchen to begin tomorrow's prep. Sally walked through the door a few hours later, and we found ourselves in the rarest of moments. It was nighttime. We were alone. Together. Rare because one of us always sleeps with Susannah while the other prepares for the chaos of tomorrow's remote learning, therapies and work. It felt strange to be alone with my wife, but we took advantage of the moment and sat down to talk. We spoke like two people who had not talked in years, even though we are together more these days than ever before.

*Innocent sleep. Sleep that soothes away all our worries. Sleep that puts each day to rest. Sleep that relieves the weary laborer and heals hurt minds. Sleep, the main course in life's feast, and the most nourishing.*

**"We need new treatments today. Not tomorrow, not in one year or ten years. If we wait any longer nothing will come in time to help Susannah and kids like her. We are trying. It is a costly, life-altering burden to drive rare disease research."**

In that moment, four years after her diagnosis, I understood Electric Status Epilepticus in Sleep. The impact of Susannah's epilepsy was clear to me. As described by Shakespeare, Susannah's rare epilepsy prevents sleep from healing her hurt mind; a mind hurt with atrophy caused by a rare and toxic genetic mutation in KIF1A.

No doctor explained ESES in this logical way. No medical journal educated me about Susannah's specific form of epilepsy.

Lying in bed, reading Macbeth to Nat in a funny voice, I finally understood our daughter's epilepsy. Shakespeare explains the mechanism of Susannah's disease with far more clarity than any



**...PERCHANCE TO DREAM:** "If there was one magic pill that could cure only one of the myriad challenges our sweet girl lives with, what would it be? I would choose a magic pill that gives Susannah the chance to dream."

During the last ten months we rarely see each other after the kids' bedtime. Even with this tiny escape from routine, something felt off. We sat on the couch eating ice cream when Nat's terrified voice called from the bedroom, "Dad get in here! Somethings wrong with Sus!" Snap back to reality. Sprint into the room.

Susannah was lying asleep covered in her own vomit and gurgling. Without hesitation, Sally picked her up, cleared the vomit from her mouth and Susannah woke up. She was in a midnight haze, weary from her march through the battlefield of seizure-filled sleep. Thanks to Nat's slumber party and awareness, his sister did not aspirate or stop breathing last night.

Some nights Nat and I read Shakespeare after Susannah and Sally are in bed. I use funny voices, and he asks to hear the battle scenes again. Last week we read Macbeth. I thought of Susannah downstairs fighting an invisible enemy in her dreamless sleep. I read Macbeth's lines:

neurologist. I read the lines again, *Sleep that relieves the weary laborer and heals hurt minds. Sleep, the main course in life's feast, and the most nourishing.*

I looked at Nat, smiled and turned off the light. I was covered with a rare blanket of comfort, an overwhelming feeling that tonight Susannah will win the battle. Tonight Susannah will dream, and tomorrow she will tell me all about it. In her own way. •  
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**ABOUT THE AUTHOR:**

Luke Rosen and Sally Jackson founded KIF1A.ORG in 2016 following their daughter Susannah's KIF1A diagnosis. In 2017 Luke left his career in film and television to jumpstart discovery of treatment for Susannah and children like her. His mission is to accelerate biotech innovation and forge efficient collaborations to rapidly discover treatment for KIF1A Associated Neurological Disorder.

# CHOOSE TO GET VACCINATED

PROTECT yourself, your family, your community, and help end the pandemic.



1. The vaccine will offer additional protection from COVID-19.
2. When entire communities get vaccinated, wear masks, social distance, avoid large gatherings, and wash their hands we'll have the best chance of ending the pandemic.
3. Initial vaccine quantities will be limited. Talk with your healthcare provider or local Medical Treatment Facility for more details about when vaccine will become available.

The vaccines available for COVID-19 have been proven safe and effective, are authorized by the U.S. Food and Drug Administration, and are being manufactured and distributed safely and securely.

For more information:



<https://phc.amedd.army.mil/topics/campaigns/covid19/Pages/vaccine.aspx>



**COVID**  
CORONAVIRUS  
DISEASE  
**19**

**For current COVID-19 information:**

<https://phc.amedd.army.mil/covid19>

<https://www.coronavirus.gov/>

**The Military Health System Nurse Advice Line is available 24/7:**

Call 1-800-874-2273 option #1

or visit <https://www.health.mil/I-Am-A/Media/Media-Center/NAL-Day-at-a-glance>

**Emergency Kit Checklist for Families:**

<https://www.cdc.gov/childrenindisasters/checklists/kids-and-families.html>



**Public Health**  
Prevent. Promote. Protect.

Army Public Health

**The Army COVID-19 Information Hotline:**

1-800-984-8523

Overseas DSN 312-421-370

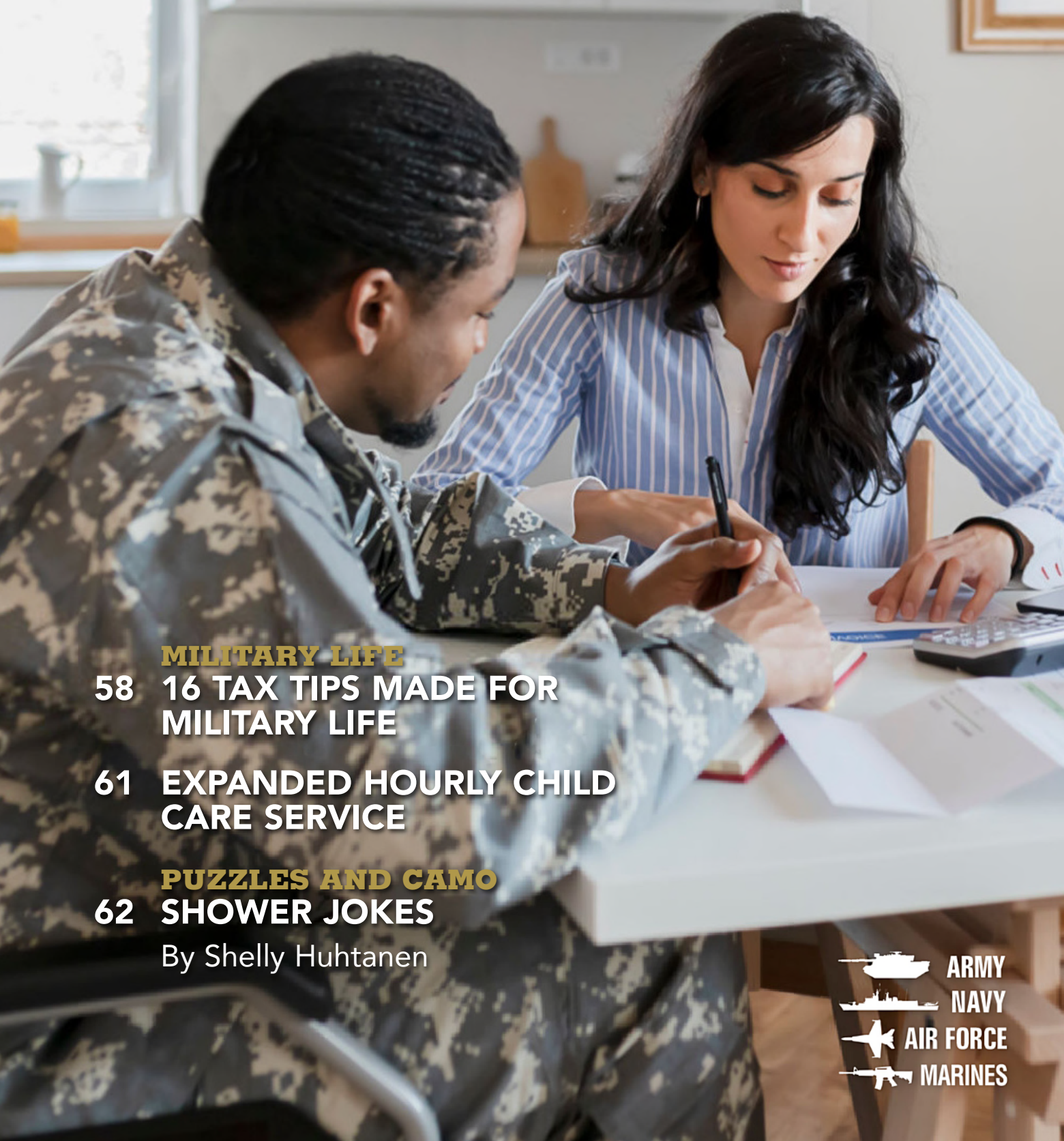
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FROM OUR FAMILIES... TO YOUR FAMILIES

# MILITARY

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By Shelly Huhtanen





# MILITARY LIFE

# 16 TAX TIPS MADE FOR MILITARY LIFE

*As a service member, the tax implications of combat pay, deployment or multiple moves can be daunting. This tax season you may also have questions related to the COVID-19 pandemic and federal relief efforts. Military OneSource MilTax services – designed specifically for the MilLife – can make tax time easier – and help maximize your tax refund.*

**W**ith MilTax ([www.militaryonesource.mil/financial-legal/tax-resource-center/miltax-military-tax-services](http://www.militaryonesource.mil/financial-legal/tax-resource-center/miltax-military-tax-services)), service members have quick access to tax consultants who can answer your questions about the tax code and how it applies to military life, as well as easy, free and secure preparation and tax filing software ([www.militaryonesource.mil/miltax-software](http://www.militaryonesource.mil/miltax-software)). All MilTax services are 100% free with no hidden surprises, so take advantage of MilTax to save money and time this tax season.

## TAX TIP 1: GATHER TAX DOCUMENTS FIRST

Before filing, organize paperwork and establish a specific place for all incoming tax documents ([www.militaryonesource.mil/financial-legal/tax-resource-center/preparing-filing-and-refunds/making-tax-filing-simple](http://www.militaryonesource.mil/financial-legal/tax-resource-center/preparing-filing-and-refunds/making-tax-filing-simple)), like W-2 forms, as they arrive in the new year. You may need to track down others. You'll also need Social Security numbers, birth dates and other information for everyone included in the return.

Take another look at that Leave and Earnings Statement ([www.militaryonesource.mil/military-life-cycle/new-to-the-military/getting-settled/your-leave-and-earnings-statement](http://www.militaryonesource.mil/military-life-cycle/new-to-the-military/getting-settled/your-leave-and-earnings-statement)) withholding. Taxpayers will want to check to see if their 2020 federal income tax withholding will unexpectedly fall short of their tax liability for the year. They can check this by using the Tax Withholding Estimator on IRS.gov ([www.irs.gov/individuals/tax-withholding-estimator](http://www.irs.gov/individuals/tax-withholding-estimator)).

Not sure of all the documentation you'll need? Contact a MilTax consultant ([www.militaryonesource.mil/financial-legal/tax-resource-center/miltax-military-tax-services](http://www.militaryonesource.mil/financial-legal/tax-resource-center/miltax-military-tax-services)) for free help on which documents you'll need to file for your specific situation

## TAX TIP 2: CONFIRM THAT YOU RECEIVED YOUR COVID-19 ECONOMIC IMPACT PAYMENT

If eligible, you should have received \$1,200 (\$2,400 if you are married) and \$500 for each qualifying child under the 2020 Coronavirus Aid, Relief and Economic Security Act. If you did not, you may claim the Recovery Rebate Credit ([www.irs.gov/newsroom/recovery-rebate-credit](http://www.irs.gov/newsroom/recovery-rebate-credit)) on your federal tax return.

## TAX TIP 3: REPORT ANY UNEMPLOYMENT BENEFITS AS INCOME

If you or your spouse were among the millions of workers who received unemployment compensation in 2020, you must report it as income on your tax return. You will receive a 1099-G ([www.irs.gov/pub/irs-pdf/f1099g.pdf](http://www.irs.gov/pub/irs-pdf/f1099g.pdf)) in the mail that states your total received, including special unemployment compensation under the CARES Act.

## TAX TIP 4: DEDUCT YOUR CHARITABLE DONATIONS

The CARES Act allows taxpayers to deduct up to \$300 in cash donations to eligible charities without itemizing the contributions. Go to the IRS's Tax Exempt Organization Search ([www.irs.gov/charities-non-profits/tax-exempt-organization-search](http://www.irs.gov/charities-non-profits/tax-exempt-organization-search)) to find out whether the charities you gave to in 2020 qualify.

## TAX TIP 5: CONTACT MILTAX WITH YOUR TAX QUESTIONS.

Stuck? Questions? Unsure of the next step? Let MilTax take the stress out of tax season ([www.militaryonesource.mil/financial-legal/tax-resource-center/miltax-military-tax-services](http://www.militaryonesource.mil/financial-legal/tax-resource-center/miltax-military-tax-services)). Military OneSource's tax consultants can answer your questions, and our free tax preparation and e-filing software makes filing your returns fast and simple. Call 800-342-9647 or live chat (<https://livechat.militaryonesourceconnect.org/chat>) 24/7 to schedule an appointment with a MilTax consultant to get answers to your tax questions.

## TAX TIP 6: DETERMINE IF TAKING THE STANDARD DEDUCTION IS A BETTER DEAL FOR YOU

The standard deduction for married filing jointly is \$24,800 for tax year 2020. For single taxpayers and married individuals filing separately, the standard deduction is \$12,400 for 2020, and for heads of households, the standard deduction is \$18,650 in 2020.



**TAX TIME TIPS:** Military OneSource's tax consultants can answer your questions, and our free tax preparation and e-filing software makes filing your returns fast and simple.

### TAX TIP 7: GET TAX CREDITS, DEDUCTIONS AND EXCLUSIONS FOR YOUR CLASSES AND MUCH MORE

The IRS allows you to take certain tax credits on your tax returns, including:

- *The Lifetime Learning Credit ([www.irs.gov/credits-deductions/individuals/llc](http://www.irs.gov/credits-deductions/individuals/llc)) is for qualified tuition and related expenses paid for eligible students enrolled in an eligible educational institution. The LLC can help pay for undergraduate, graduate and professional degree courses – including courses to acquire or improve job skills. There is no limit on the number of years you can claim the credit. It is worth up to \$2,000 per tax return and applies to 20% of the first \$10,000 of a taxpayer's out-of-pocket expenses.*
- *The Earned Income Credit ([www.irs.gov/credits-deductions/individuals/earned-income-tax-credit/earned-income-tax-credit-income-limits-and-maximum-credit-amounts](http://www.irs.gov/credits-deductions/individuals/earned-income-tax-credit/earned-income-tax-credit-income-limits-and-maximum-credit-amounts)) up to \$6,660 for taxpayers filing jointly who have three or more qualifying children; check out income and credit amounts.*
- *The Child Tax Credit ([www.irs.gov/publications/p972](http://www.irs.gov/publications/p972)) maximum amount of credit is \$2,000 per qualifying child and is refundable up to \$1,400, subject to phase outs. The bill also includes a temporary \$500 nonrefundable credit for other qualifying dependents ([www.irs.gov/publications/p972#en\\_US\\_2018\\_publink10002676](http://www.irs.gov/publications/p972#en_US_2018_publink10002676)).*
- *The maximum credit allowed for adoptions is the amount of qualified adoption expenses up to \$14,300 in 2020. This credit is nonrefundable, which means it's limited to your tax liability for the year. However, any credit in excess of your tax liability may be carried forward for up to five years.*

While the IRS allows taxpayers who itemize to deduct a range of expenses, alimony payments were no longer deductible starting in tax year 2019; the recipient does not have to report alimony as income any more either.

Meanwhile, one exclusion common among military families is the foreign earned income exclusion, which is up to \$107,600 for tax year 2020.

For more information about these or other credits, deductions or exclusions, contact a MilTax consultant ([www.militaryonesource.mil/financial-legal/tax-resource-center/miltax-military-tax-services](http://www.militaryonesource.mil/financial-legal/tax-resource-center/miltax-military-tax-services)) about your specific situation.

### TAX TIP 8: TAKE ADVANTAGE OF THE MILITARY SPOUSE RESIDENCY RELIEF ACT.

Active-duty service members have always been able to keep one state as their state of legal residency for tax purposes – typically their home of record – even when they move frequently on military orders. A state of legal residence is also considered their “domicile” or “resident” state.

Since 2009, when the Military Spouse Residency Relief act was signed, military spouses may keep their state of residency to that of the service member, regardless of which state they currently reside.

### TAX TIP 9: GET AUTOMATIC TAX EXTENSIONS WHEN YOU'RE DEPLOYED

When you're deployed, your service wants you to focus on your mission, not your tax forms. The IRS automatically extends tax deadlines for U.S. Armed Forces personnel deployed to a combat zone ([www.militaryonesource.mil/financial-legal/tax-resource-center/special-tax-considerations/ins-and-outs-of-filing-military-taxes-when-you-are-deployed](http://www.militaryonesource.mil/financial-legal/tax-resource-center/special-tax-considerations/ins-and-outs-of-filing-military-taxes-when-you-are-deployed)) or in support of operations in a qualified hazardous duty area.

The deadline for filing returns, making payments or taking any other action with the IRS is also extended for at least 180 days after the last day of qualifying combat zone service or the last day of any continuous qualified hospitalization for injury from service in the combat zone.

## U.S. MILITARY ★

### TAX TIP 10: EXCLUDE HOME SALE PROFITS FROM YOUR TAXES

Many military families buy a home knowing they may have to sell it when their next PCS comes around. It's important to know about capital gains tax ahead of time.

If you make a profit from the sale of your main home, you may qualify to exclude up to \$250,000 of that gain from your income, or up to \$500,000 of that gain if you file a joint return with your spouse. This is called the Sale of Primary Home Capital Gain Exclusion.

To be eligible for this exclusion, most people must have owned the home for at least two years and lived in that home for at least two of the last five years. However, service members who have moved due to PCS before being able to meet these requirements, may still qualify for an exclusion ([www.irs.gov/publications/p523](http://www.irs.gov/publications/p523)). In those cases, they may not be taxed with the total capital gain for the sale of the home.

### TAX TIP 11: DON'T WORRY ABOUT THE PENALTY FOR NOT MAINTAINING MINIMUM ESSENTIAL HEALTH COVERAGE.

The individual mandate in the Affordable Care Act was lifted last year. This means that you will not pay a penalty if you did not have health insurance in 2020.

### TAX TIP 12: REPORT AND CLAIM CASUALTY LOSSES FROM DISASTERS

If you have property in an area determined by the president to be eligible for federal assistance – such as a region devastated by a hurricane or forest fire eligible for assistance from FEMA – you can claim unreimbursed expenses from casualty losses on your federal tax return.

If you are eligible to claim a loss on your tax filing, use IRS Form 4684, "Casualties and Thefts" ([www.irs.gov/forms-pubs/about-form-4684](http://www.irs.gov/forms-pubs/about-form-4684)). Refer to IRS Publication 547 ("Casualties, Disasters, and Thefts" [www.irs.gov/forms-pubs/about-publication-547](http://www.irs.gov/forms-pubs/about-publication-547)) and Publication 584 ("Casualty, Disaster, and Theft Loss Workbook" [www.irs.gov/forms-pubs/about-publication-584](http://www.irs.gov/forms-pubs/about-publication-584)) for more detailed information.

Additional resources ([www.irs.gov/businesses/small-businesses-self-employed/disaster-assistance-and-emergency-relief-for-individuals-and-businesses](http://www.irs.gov/businesses/small-businesses-self-employed/disaster-assistance-and-emergency-relief-for-individuals-and-businesses)) can be found on the IRS website, and MilTax consultants can help you sort out your specific tax situation for free ([www.militaryonesource.mil/financial-legal/tax-resource-center/miltax-military-tax-services](http://www.militaryonesource.mil/financial-legal/tax-resource-center/miltax-military-tax-services)).

### TAX TIP 13: DON'T IGNORE A CORRECTED W-2 FORM

If you receive a corrected W-2, or W-2C, and have filed a tax return for the year covered by the form, then file an amended tax return for the year the corrected W-2 covers. If you have not yet filed a return for the year covered by the W-2C, use the W-2C when filing your initial return.

### TAX TIP 14: REACH OUT IF YOU SPOT AN ISSUE

If something doesn't look right on your W-2:

- Call the Military Pay customer care center at 888-332-7411 to request a corrected W-2.

- Use AskDFAS; clickable icons are located on the myPay and Defense Finance Accounting Services homepages. FAQs are available for information and the application allows members to submit a secure message to the appropriate DFAS military pay office.

### TAX TIP 15: KNOW ABOUT TAX DEDUCTIONS FOR RESERVISTS

Reservists whose reserve-related duties take them more than 100 miles away from home each way, can deduct their unreimbursed travel expenses on Form 2106, even if they do not itemize their deductions. They can also deduct the purchase and upkeep costs of certain uniforms that they can't wear while off duty, minus any allowance they receive for these costs.

Taxpayers can request a free transcript of tax returns covering the past three years. The Get Transcript tool ([www.irs.gov/individuals/get-transcript](http://www.irs.gov/individuals/get-transcript)) on IRS.gov is the fastest way to get a transcript.

If you have any questions about special tax situations for National Guard or reservists, contact a MilTax consultant for a free consultation ([www.militaryonesource.mil/financial-legal/tax-resource-center/miltax-military-tax-services](http://www.militaryonesource.mil/financial-legal/tax-resource-center/miltax-military-tax-services)).

### TAX TIP 16: REMEMBER YOUR RETIREMENT PLAN CONTRIBUTIONS

An IRA or 401(k)-type plan might mean saving for retirement and cutting taxes at the same time. Service members who contribute to a plan, such as the Thrift Savings Plan ([www.militaryonesource.mil/military-life-cycle/new-to-the-military/getting-connected/thrift-savings-plan-options-making-your-retirement-dollars-work-for-you](http://www.militaryonesource.mil/military-life-cycle/new-to-the-military/getting-connected/thrift-savings-plan-options-making-your-retirement-dollars-work-for-you)), may also be able to claim the Retirement Savings Contributions Credit, or Saver's Credit.

IRAs are different from 401(k)s and TSPs. By the end of the year, a single person can make an IRA contribution of \$6,000, or \$7,000 if you are age 50 or older, or your taxable compensation for the year was less than this dollar limit. If you file a joint return and have taxable compensation, you and your spouse can both contribute to your own separate IRAs. You can contribute up to \$6,000 to a spousal IRA in 2020 or \$7,000 if you are 50 or older.

In a 401(k) or TSP, you can contribute the maximum of \$19,500. If you are 50 or older, you can make an additional catch-up contribution for as much as \$6,500, for a total of up to \$25,000.

There are two kinds of IRAs – traditional and Roth. The Roth is pre-taxed and can be withdrawn after the age of 59½ without penalty. The traditional is taxed at the time of withdrawal and will be penalized if you are not 59½. You can deduct your contributions if you qualify with a traditional IRA, but Roth IRA contributions are not deductible.

Taxes are complicated. Remember that our 100% free MilTax services – both our expert military tax consultants and e-filing tax preparation software – stand ready to make tax season easy for you. Call 800-342-9647 for 24/7 help. Learn more about MilTax at [www.militaryonesource.mil/financial-legal/tax-resource-center/miltax-military-tax-services](http://www.militaryonesource.mil/financial-legal/tax-resource-center/miltax-military-tax-services)

– Military OneSource

# EXPANDED HOURLY CHILD CARE SERVICE

To help meet the growing and diverse needs of military parents, the Department of Defense is proud to offer an expanded child care service for members and their families.

Through Military OneSource, military families now have free access to a national database of more than a million caregivers so they can find hourly, flexible and on-demand child care.

## BACKGROUND FOR EXPANDED HOURLY CHILD CARE SERVICE

Child care is a workforce issue that directly impacts the readiness and retention of the total force. Lack of child care options has been connected to challenges for spouse employment and increased stress. Some evidence suggests it also impacts retention decisions.

## THE DEPARTMENT OF DEFENSE OFFERS MORE OPTIONS TO SUPPORT THE NEED FOR HOURLY CHILD CARE

As part of its ongoing commitment to help military families thrive, The Department of Defense is introducing a new way for military families to find child care for hourly, flexible and on-demand needs.

By expanding child care options, the Department of Defense helps:

- Support the growing and diverse needs of military families
- Increase the number of military families who receive support
- Ensure force readiness and lethality

## BENEFITS OF THE EXPANDED HOURLY CHILD CARE SERVICE

The nationally recognized online subscription service is:

- Easy to access
  - Fee-free through Military OneSource for anyone eligible for Military OneSource services (visit [MilitaryOneSource.mil](http://MilitaryOneSource.mil) to learn more at [www.militaryonesource.mil/confidential-help/non-medical-counseling/military-onesource/eligibility-for-confidential-non-medical-support-services](http://www.militaryonesource.mil/confidential-help/non-medical-counseling/military-onesource/eligibility-for-confidential-non-medical-support-services))
  - Convenient and flexible
- Parents can:
- Access a database of more than a million care providers
  - Search at their convenience for care that meets their own needs and criteria
  - Find potential care providers
  - Check references
  - Review background checks
  - Interview, hire and pay providers on their terms

## HOW CAN PARENTS ACCESS THE EXPANDED HOURLY CHILD CARE SERVICE?

The new caregiver search service is available 24/7/365 through Military OneSource. Parents can visit the Expanded Hourly Child Care Options page ([www.militaryonesource.mil/family-relationships/parenting-and-children/military-childcare-services](http://www.militaryonesource.mil/family-relationships/parenting-and-children/military-childcare-services)) and click "Log in to access." If they already have a Military OneSource account, they can log in. If not, they will need to create one. From there, they will be directed to Military OneSource Member Connect, where they will receive a unique member code and a link to the child care service site. Parents can then create their login and begin searching for child care. In the future, they can return directly to the child care service's homepage to access care and search for providers.

## EXPANDED HOURLY CHILD CARE SERVICE COMPLEMENTS EXISTING PROGRAMS

This online service is available in addition to existing child care options such as:

- Finding full-time, on-installation care through [MilitaryChildCare.com](http://MilitaryChildCare.com) (<https://public.militarychildcare.csd.disa.mil/mccu/ui>)
- Receiving child care fee assistance for off-installation care through Child Care Aware of America ([www.childcareaware.org](http://www.childcareaware.org))
- Checking with their local installation child development center (<https://installations.militaryonesource.mil/?looking-for-a=program/program-service=29/focus=program>) about child care options, or speaking with a Military OneSource consultant who can provide options based on specific child care needs (Consultants are available 24/7/365 by calling 800-342-9647. OCONUS dialing options and live chat are also available.)

For more information about military child care programs, parents can visit the Military OneSource Military Child Care Programs page at [www.militaryonesource.mil/family-relationships/parenting-and-children/childcare/military-child-care-programs](http://www.militaryonesource.mil/family-relationships/parenting-and-children/childcare/military-child-care-programs).

– Military OneSource





## Shower Jokes

I told Broden's BCBA the story and she started to tear up, "That is the best story I have heard all day. Thank you for sharing that with me." The next day, I told my hiking partner about it and she giggled. "Shelly, it's the little things these days that get you through. Thanks for making me laugh."

### After watching the news

for the last week or so, I've been searching even harder for things to be grateful for and experiences in my life to make me smile. I realized I didn't have to look that far this past week to get a giggle, and what was special about that moment was that I was able to share it with others to make them smile. I've learned that those moments are the best because they are a gift that keeps giving, a gift of spreading laughter and joy out into the world, something we need more of these days.

The other day, Broden's BCBA brought up the fact that he'll be 15 years old this March. Obviously, I'm aware that every year he'll get older but, for some reason, saying he will be 15 years old seemed a lot older than 14 years old. I'm not sure

why. I kept saying it over and over again. Fifteen years old? Already? Don't even talk to me about teaching him how to shave. I'm definitely not there yet. In my world, I'm perfectly content picturing him running around in his Minion pajama pants and sequined slippers. I'll tackle the concept of shaving another time, thank you very much.

As I'm reminded of the days that go by, as his mom, I understand how important it is to continue working with him on life skills. As always with Broden, there is a little clock that continues to tick in my head. As he gets older, I'm getting older too. I won't be around forever to care for him, so we need to



keep pushing to make sure he is as independent as possible. Broden being capable of showering himself is very important to me and it's something we continue to work on in the morning.

A few days ago, just like any other morning, I was working with Broden on his showering skills. As I was standing in the shower in my workout clothes, I turned around to grab the bottle of shampoo. My other son, Hayden, and Broden use the same shampoo. As I grabbed the bottle, I started to wonder how much shampoo his big brother was using every morning. There was barely any in the bottle, but I thought



if I squeeze it over and over again, I would be able to get just enough for Broden's hair that morning.

I turned around and explained to Broden our dilemma and proceeded to squeeze the bottle over and over again. As shampoo started to pour into my hand, the bottle started to make a funny sound, like when you try to get the last bit of ketchup out of the bottle. Broden started to laugh. He laughed like I'd never heard him laugh before. I kept squeezing the bottle to make the sound, and then he yelled out, "Ewww!" Through my laughter I said, "Does that sound like a fart noise?" He kept giggling and said, "Ewww!" each time I did it. At this point, I had about 10 times too much shampoo in my hand.

Once he was out of the shower and in

his robe, I started to make "fart" noises to make him giggle. I grabbed his "fart book" from the bedroom and we took turns pushing buttons to emulate the sound that we heard in the shower. His giggle was so infectious and genuine. I

couldn't get enough of it. What was so special about that moment was that he laughed at something that anyone else would think was funny. It didn't matter how infantile the joke was at the time. It was a joke and it was funny!

I told his BCBA the story and she started to tear up, "That is the best story I have heard all day. Thank you for sharing that with me." The next day, I told my hiking partner about it and she giggled. "Shelly, it's the little things these days that get you through. Thanks for making me laugh."

**"Life is heavy these days. Our nation seems more divided than ever. Maybe we should take some advice from Broden and find some joy in the world by laughing."**

I keep his "fart book" nearby and when I need to laugh, or want to hear Broden's giggle, I'll push a few buttons on the book. Laughing about something as trivial as hearing a fart noise is what we need right now. Life is heavy these days. Our nation seems more divided than ever. Maybe we should take some advice from Broden and find some joy in the world by laughing. No one can deny the power of a good belly laugh. •

#### **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.



Naomi Mathis

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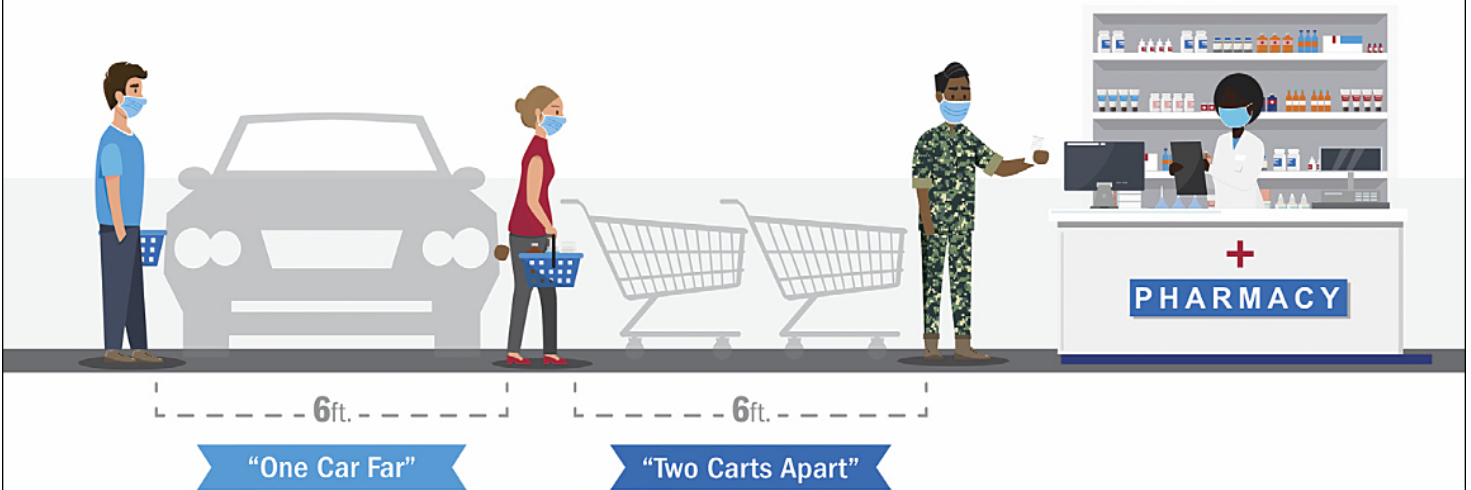
Coronavirus Disease 2019

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To learn more about TRICARE and COVID-19, visit:  
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# Special needs require *Special Care.*

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