PLUS: UNITED STATES MILITARY SECTION

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EXCEPTIONAL PARENT MAGAZINE
MAY 2018
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IMPROVING MOBILITY:
PARTICIPATING in RESEARCH

AN OVERVIEW:
EXTENDED SCHOOL YEAR SERVICES

IN THIS ISSUE: STUDENTS with DISABILITIES BEHIND THE WHEEL

THE ANNUAL ISSUE

MOBILITY

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Sarah Best and her service dog Edison visit the Exceptional Parent Magazine booth at the New York Metro Abilities Expo in May. Sarah faces many mobility challenges, but overcomes them with grit, grace and good humor. Photograph by Faye Simon/Exceptional Parent. *Coverage begins on page 24.*

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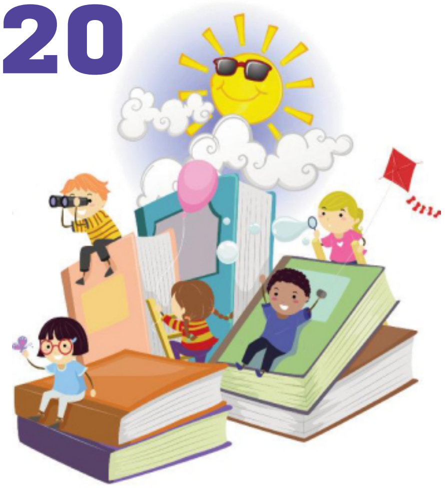

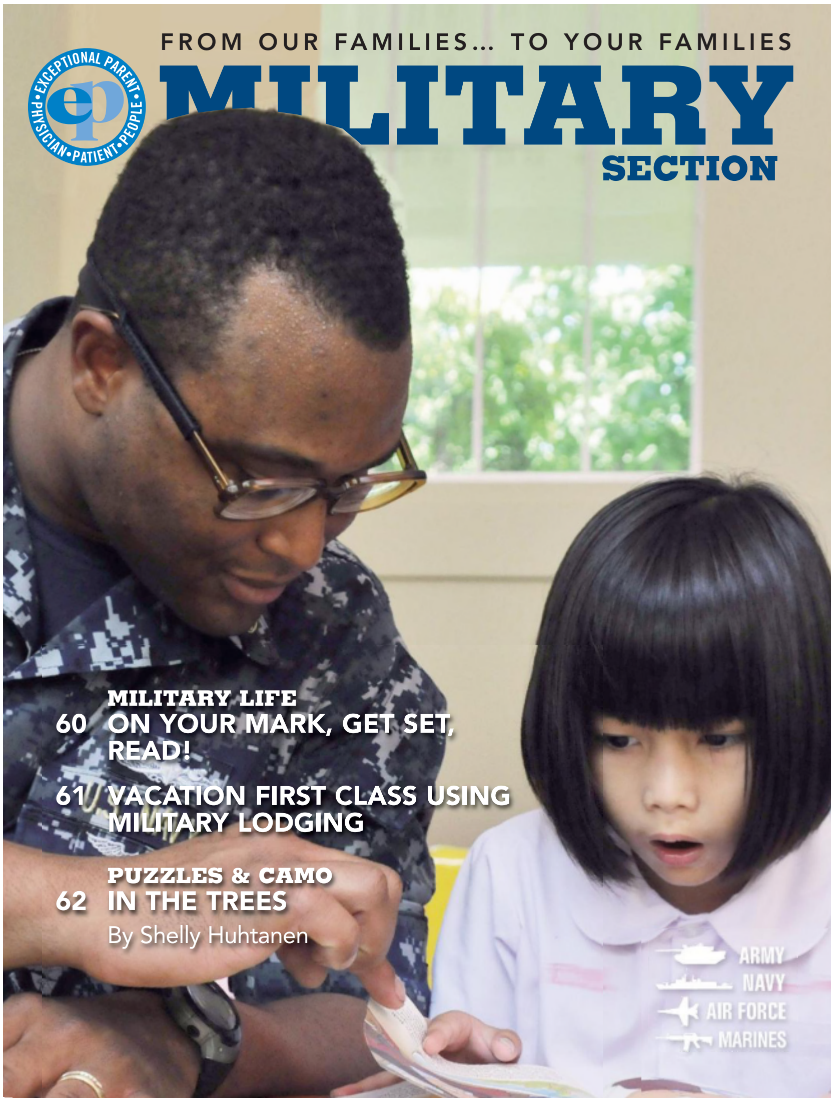

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— Rick Rader, MD

EP magazine neither endorses nor guarantees any of the products or services advertised in the magazine. We strongly recommend that readers thoroughly investigate the companies and products being considered for purchase, and, where appropriate, we encourage them to consult a physician or other credentialed health professional before use and purchase.

ANCORA IMPARO RICK RADER, MD ▪ EDITOR-IN-CHIEF

Black Holes, Wheel Chairs and a Familiar Voice

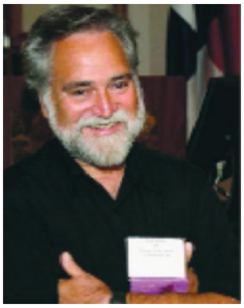
Like Hawking, readers of Exceptional Parent magazine have long fought to have their "voices" heard. They come in numerous accents, decibels and emotions. They are sometimes shouted, sometimes repeated and often done in unison.

In 1988 I was one of several million people worldwide who purchased Stephen Hawking's best seller, "A Brief History of Time". The book was promoted as providing a very simple and understandable explanation of cosmology, space and time, black holes and string theory. The book was an instant best seller, translated into more than 40 languages, and spent more than four years atop the London Sunday Times' best-seller list.

I thought this was my ticket to sounding intelligent at the many Friday night Manhattan parties I wormed my way into during my single days. I was hoping that Professor Hawking would provide me with enough juice to get me through the first five minutes of someone (a blonde, typically) asking me what I thought of gravitational singularity theorems. I blew it. It might have been written in one of the 39 other languages the book was translated into. I read it twice before I gave up on it. Millions of readers applauded it openly but, apparently, they were as clueless as I was. In 2005, Hawking authored the second attempt at explaining the unexplainable and a new version of "A Briefer History of Time" was released. By that time, I knew enough to know enough was enough. To this day the only thing I realize I could have shared about Hawking was the time I spent doing an elective clinical rotation at Addenbrooke's Hospital at the Cambridge University's School of Clinical Medicine. I drew blood from him one evening and thankfully got it on the first stab.

STAR QUALITY: Hawking was a world-famous cosmologist and theoretical physicist, but his "press on regardless" demeanor propelled him to rock stardom.

Hawking, who recently passed away at the age of 76, defied all the predictions of a patient with Lou Gehrig's disease (amyotrophic lateral sclerosis) where the majority of patients die within two years of the diagnosis. It's a cruel disease where the nerves that control your muscles begin to methodically and systematically shut down.



In the great British tradition, Hawking pressed on regardless. Much of his stamina, perseverance and positive outlook came from sharing a hospital room with a patient with leukemia. Hawking thought that his condition was tolerable compared to what the dying boy went through.

In 1985, Hawking, following a tracheotomy, lost his voice forever and required 24 hour nursing care for the rest of his life. The loss of Hawking's voice cast a shadow on his ability to do his work. At this time a California computer programmer was developing a speaking program that could be directed by head or eye movement. The device allowed Hawking to select words on a computer screen that were then passed through a speech synthesizer. This was activated with a handheld clicker until he lost all control of his body. From then on, he activated the program through a cheek muscle attached to a sensor.

In addition to his contribution to theoretical physics he was a promoter and advocate of applying technology to assisting people with disabilities. He worked with software engineers from Intel in developing a program called ACAT and released it as an open-source software program in 2015 so that anyone could access and adapt the program for their own needs. His ability to continue to lecture all over the world provided him with a second chance. In 1993 he shared his appreciation for "speaking."

"Speech has allowed the communication of ideas, enabling human beings to work together to build the impossible. Mankind's greatest achievements have come about by talking, and its greatest failures by not talking. It doesn't have to be like this. Our greatest hopes could become reality in the future. With the technology at our disposal, the possibilities are unbounded. All we need to do is make sure we keep talking."

Over the years Hawking still used the aging program that provided his well-known synthetic voice. Despite newer advances in speech technology he preferred his "old voice," and was reluctant to give it up, despite the fact that he thought it gave him an American accent. Thirty years of use had resulted in the decay of the original software. The original software engineer, Eric Dorsey, worked tirelessly in preserving and upgrading the original program that allowed Hawking to continue to sound like he always had. The poet Longfellow wrote that the human voice is "the organ of the soul," and even if that voice was computer generated, it was important for Hawking's legacy to remain loyal to that early voice.

> "Longfellow said that the human voice is "the organ of the soul," and it was important for Hawking's legacy to remain loyal to that early voice."

Hawking was a world-famous personality as a cosmologist and theoretical physicist, but his disability and his "press on regardless" demeanor propelled him to rock stardom. My favorite Stephen Hawking quote was a reflection of that, "I can disguise myself with a wig and dark glasses – the wheelchair gives me away."

Like Hawking, readers of Exceptional Parent magazine have long fought to have their "voices" heard. They come in numerous accents, decibels and emotions. They are sometimes shouted, sometimes repeated and often done in unison.

One thing remains true for every generation of the exceptional parent movement, and that is the sound of T.S. Eliot in Four Quartets:

"For last year's words belong to last year's language.

And next year's words await another voice. •

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

Introducing Our All-New Website WWW.EP-MAGAZINE.COM

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

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

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

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

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

PLEASE NOTE
that our previous web address, eparent.com, is no longer associated with *Exceptional Parent* Magazine.

EP GOES TO THE ABILITIES EXPO!

CHECK OUT OUR SPECIAL COVERAGE OF THE NY METRO ABILITIES EXPO BEGINNING ON PAGE 30.

Abilities EXPO | The event for the disability community

New York Metro
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New Jersey Convention & Expo Center
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WHAT'S HAPPENING

Promote Positive Mental Health Development in Your Child with 8 Tips from ECC

Learning shapes, numbers and letters, are an important part of preparing a child for school. But supporting positive mental health development is also an important part of school readiness.

"This year's national observance focuses on the importance of an integrated health approach to supporting children, youth, and young adults with serious emotional disturbance who have experienced trauma.," said Dodd White, executive director of ECC. "Society often isolates children with challenges, but we believe every child can achieve and succeed."

The Episcopal Center for Children offers the following tips for parents to assist their child's positive mental health development as part of National Children's Mental Health Day, which was observed nationwide in early May.

Tip #1: Help instill responsibility in your child. Create age-appropriate learning and experiential opportunities that help your child demonstrate responsibility. This can be achieved by assigning chores, providing examples of cause and effect, and establishing routines.

Tip #2: Provide boundaries for your child's behavior. Set consistent limits and follow through with reasonable consequences.

Tip #3: Listen to your child. Create a safe environment within your family where your child can express thoughts and feelings.

Tip #4: Foster independence in your child. Praise your child's efforts and encourage positive risk taking and decision-making.

Tip #6: Provide security. Stress, moves, and change can be disruptive to family life and individuals. Routines, traditions, and time together can help limit the effects stress has on your child and your family. Children who take on responsibilities because the adults in their lives are stressed, may hide their feelings or vulnerabilities. Let your child know that support is always available and you will always take care of him or her.

Tip #7: Build strength. Offer positive feedback and encouragement for your child. Express your confidence in their abilities to manage different situations. Appreciate and acknowledge any help and support they give to you and to others in the family or community.

Tip #8: Seek special services early if your child needs them. If your child is excessively distracted, has frequent angry outbursts, or is unable to concentrate in the classroom, she or he may benefit from evaluations for special services. These evaluations may include psycho-educational, speech and language, and occupational therapy assessments. Early intervention can prevent problems from magnifying over time and assist your child in healthy development.

Parents must identify, address and balance their child's emotional and mental health needs alongside their educational requirements and development.

Children contending with emotional challenges may be withdrawn, over-active, disruptive and challenging to manage behaviorally. They often require additional resources and services to aide them in their educational progress and emotional development. If your child is emotionally challenged and needs help, contact special education services at your local school or within your local school district.

ABOUT THE EPISCOPAL CENTER FOR CHILDREN:

The Episcopal Center for Children is a nonprofit, nondenominational school and treatment program for children contending with emotional challenges from the greater Washington, D.C. metropolitan area. Accredited by the Joint Commission, the Center serves children who are 5-14 years old in grades K-8. The goal of the Center's treatment, therapeutic milieu, and individualized special education program is to empower each child to function productively within his or her family and community. Building on strengths within children, the Center partners with families in treatment and focuses on enabling its students to access and become their best possible selves. More information is available at eccofdc.org and on Twitter and Facebook @ECCofDC #EveryChildCan

WHAT'S HAPPENING

DAYMARK LIVING LAUNCHES INNOVATIVE SUMMER CAMP PROGRAM

GREEN THUMBS: Horticulture is one the four main categories of classes at Daymark Summer Semester, all geared toward supporting students in their quest to gain meaningful employment and foster independence. Fine arts, culinary, and health and wellness will be offered as well.

Daymark Living is launching Texas' first Summer Camp program that simulates and fosters independent living for individuals with intellectual and developmental delays (IDD) aged 16 years and older.

Daymark Living, a residential community dedicated to helping adults age 18+ with IDD live, learn and thrive, is currently pre-leasing for their grand-opening later this summer.

This summer will also kick off the start of Daymark Summer Semester, a day camp where participants will attend a variety of classes, all geared toward supporting students in their quest to gain meaningful employment and foster independence. Sessions are available on a weekly basis, from July 9 through August 17. Courses fall into four main categories: horticulture, fine arts, culinary, and health and wellness. Day camp runs from 8:30 am until 4:00 pm and includes lunch in the community's dining hall. Each weekly session costs $500 to attend.

SUMMER SEMESTER at Daymark

Fun and focused daily activities designed to increase independent living and employment skills on a brand new campus!

Daymark Summer Semester will culminate in a two-day celebration at the end of the program on August 16-17. On Thursday, August 16, attendees will participate in a talent show. On Friday, August 17, there will be a luncheon where campers can connect with potential employers and show off the skills they learned over the summer. "Daymark Living's main mission is to help each of our participants become more independent. We believe in their abilities, have top experts that know how to best reach and teach them, and are excited to help each individual maximize his or her fullest potential," said John Poston, founder and president.

Daymark Living is designed with every aspect of the community intended to foster independence and facilitate friendships in a supportive and supervised environment. Part of the program includes education courses, connections and scheduled transportation to and from employment opportunities.

Daymark is situated just 30 minutes south of downtown Dallas, well-located in an area where adults with IDD face a lack of adequate independent housing options. Presently, just 400 quality beds exist in Texas to service roughly 574,000 adults with IDD in the three major markets (Dallas, Houston and Austin/San Antonio), according to a Texas Workforce Investment Council report - less than one percent of the identified population.

To tackle social integration and interpersonal skills - another big issue facing adults with IDD - Daymark Living has started the Daymark Social Club which hosts at least two events each month throughout DFW for individuals aged 15+. These events offer attendees the opportunity to form friendships and learn new skills.

Daymark Living is a community that was conceived, designed and built for people with intellectual and developmental delays (IDD). It provides housing, recreational, learning and employment opportunities in a 40-acre community in Waxahachie, Texas. Currently under construction and slated to open later this summer, 28 resort-style cottages with 202 beds are designed to facilitate friendships and foster independence in a supportive, safe and supervised environment.

Please visit www.daymarkliving.com or call 972-646-2162 to learn more. For more information about Daymark Summer Semester, please visit: https://daymarkliving.com/summersemester •

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The Vidget 3-in-1 Flexible Seating System™ is a patented 3-in-1 seat that's designed to let kids quietly squirm as they sit. This can be used by fidgeting children or children with autism, Attention Deficit-Hyperactivity Disorder, or sensory processing disorder ages 18 months and up. Even as they move side to side and front to back, the Vidget won't tip over. This active learning seat challenges balance and core strength. It helps young children, students, and adults release energy for improved attention, focus and academic performance. Sensory bumps in the side handles provides additional sensory input for fidgety fingers. The Vidget encourages movement to channel restless energy while providing sensory input for improved focus. Challenges balance and core strength. Stackable and lightweight for easy storage. Embrace fidgeting and wiggling during story-time or circle-time without disrupting others or making noise. Use at home during mealtime or while doing homework to improve focus. The lightweight Vidget even has an easy-to-grasp handle so kids can carry it between activities. Slide a therapy band (sold separately) underneath to allow children to improve motor skills, strengthen muscle tone and release energy.

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Sensory Twists are toys designed for individuals ages 3 and up who are sensory seekers or have fine motor weaknesses. Users can squeeze, twist, and grab. They encourage tactile exploration, strengthen grip, and wake up the hands and forearms before handwriting or other fine motor activities. They can be used for tossing, fidgeting, manipulating, and hand-eye coordination activities. Made of polyvinyl chloride (PVC). Available in red (soft) and yellow (medium). Use with adult supervision. Set of 6.

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ABLEDATA

The ABLEDATA database of assistive technology and rehabilitation equipment contains information on more than 30,000 products for persons of all ages who have a physical, cognitive, or sensory disability. Products are chosen for these pages by the ABLEDATA staff based on their specific applicability to or design for children who have disabilities. ABLEDATA, operated by New Editions Consulting, Inc., is funded by the National Institute on Disability and Rehabilitation Research (NIDRR) under contract number ED-OSE-13-C-0064. For more information on these and other assistive devices, or to submit product information for the database (and possible inclusion on this page), contact: ABLEDATA, 103 W. Broad Street, Suite 400, Falls Church, VA 22046; phone: 1-800-227-0216; TTY – 703-992-8313; website: www.abledata.com; email: abledata@neweditions.net; twitter: https://twitter.com/AT_Info; Facebook: https://www.facebook.com/abledata.

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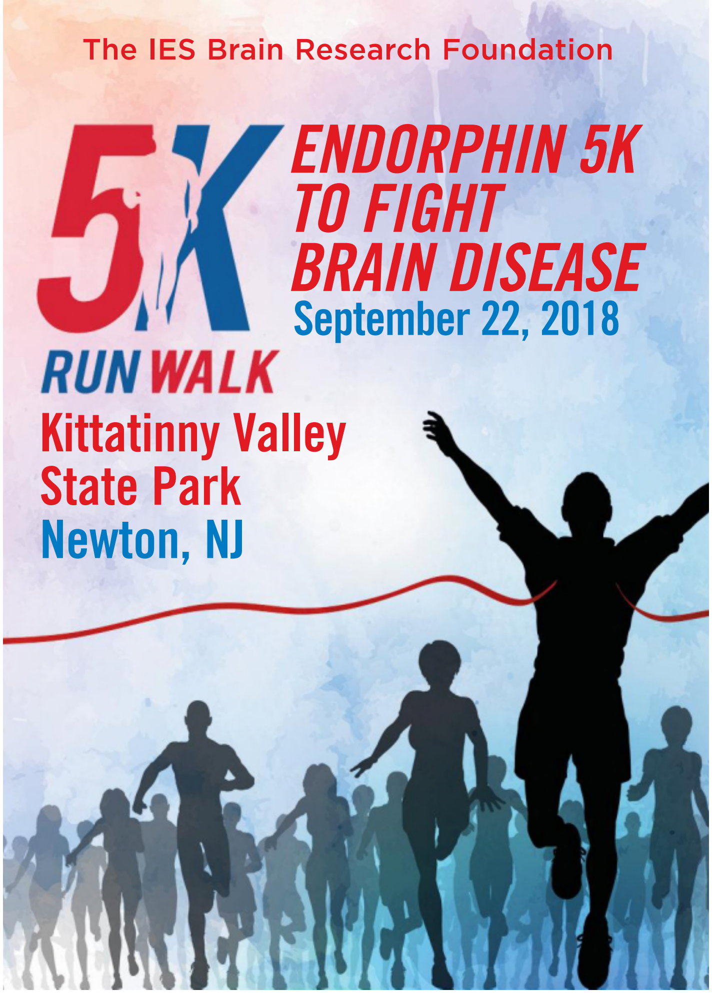

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The Sensory Textured Spoon is a feeding therapy product designed for babies learning to eat and for oral stimulation with feeding. The spoon has a textured bottom that provides increased tactile input during feeding. Parents/therapists can easily hold it with the long handle, and the shallow bowl makes it easy for individuals to remove food with minimal effort. Combine oral-sensory stimulation with feeding. Textured bottoms provide increased oral-sensory stimulation to the tongue. Not recommended for individuals with a bit reflex.

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SEE & SPELL LEARNING TOY

The See & Spell Learning Toy is designed for those with learning disabilities, ages 3 and up, to work on cognitive skills. This wooden puzzle set helps children gain familiarity with the letters of the alphabet and their sounds as they develop a sight-reading vocabulary. They can complete the puzzle to spell a word. The letters are also good for stenciling and lots of learning games. More than 60 colorful wooden letters fit into the eight two-sided cutout boards to spell three- and four-letter words. Carrying case is included.

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Children with Head Injuries: Causes and Care

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"According to statistics on childhood head injuries from the Brain Injury Association of America (BIAA), 564,000 children each year are seen in hospital emergency rooms as the result of these injuries, while as many as 62,000 require hospitalization." [1]

In 2016, 7.0% of children aged 3-17 years have ever had a significant head injury in their lifetime.

- *"In 2016, based on parental report, 8.3% of boys and 5.6% of girls aged 3–17 years have ever had a significant head injury in their lifetime.*
- *As age increased, the percentage of children who have ever had a significant head injury also increased, peaking at 11.7% among children aged 15–17 years.*
- *Non-Hispanic white children were more likely to have ever had a significant head injury compared with non-Hispanic black, Hispanic, and other non-Hispanic children. (Figure 1)*
- *The percentage of children who have ever had a significant head injury was higher among those whose parents had more than a high school education compared with those whose parents had a high school education or less."* [2]

BRAIN INJURY • EP SPECIAL SECTION

Non-Hispanic-white children and children whose parents had more than a high school education had significantly greater proportion of reported head injuries. Why? The National Center for Health Statistics provides no explanation. Similarly, a review of a series of computer search engines offered no information or explanations. Most often, public and social health reports on living status and conditions tend to emphasize lower social conditions and inadequate health services for many minority populations and individuals with limited advanced educations.

A series of discussion sessions with health and social service personnel offered some possible explanations for the unexpected finding that non-Hispanic white child populations and children of parents with advanced education have greater proportions of children with head injuries. The more favorable economic conditions and potential free time

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.

HEAD FIRST: Activities such as swimming, diving, and skateboarding can all result in serious head injuries, both as the result of bumps and blows, as well as due to lack of oxygen resulting in falls.

provide the possibility for greater proportions of children in these families having head injuries that may result from: 1) enrollment of young children in crowded private day care programs for young children (rather than direct supervision by parents), 2) potential dangerous sports activities for children (e.g. skiing, ice skating, football, soccer, backyard swimming pools and hiking in mountainous areas), 3) private car traffic accidents and 4) the availability of other "dangerous toys").

LEADING CAUSES

The Brain Injury Association of America lists the following as among the leading causes of traumatic brain injury among children in the U.S.:

- ***Motor vehicle accidents:*** *While speed is often a factor in car accident-related traumatic brain injuries, even a seemingly minor fender bender can result in serious harm for your child.*
- ***Pedestrian and bicycling accidents:*** *Children need to be particularly careful when riding bikes or walking to and from school and crossing busy streets and intersections, where accidents and injuries are most likely to occur.*
- ***Playground equipment:*** *Falls from swings and climbing equipment as well as being struck by or against objects present serious risks for children in both school and neighborhood parks and playgrounds.*
- ***Recreational activities:*** *Activities such as swimming, diving, and skateboarding can all result in serious head injuries, both as the result of bumps and blows, as well as due to lack of oxygen resulting in falls.*
- ***Sports related trauma:*** *While recreational and school-related sports can teach children valuable lessons about teamwork and physical fitness, they are also one of the leading causes of childhood head injuries. The administrators of youth, high school and college football, lacrosse and ice hockey have shown that dental and facial injuries can be reduced significantly by introducing mandatory protective equipment. Popular sports such as baseball, basketball, soccer, softball, wrestling, volleyball, and gymnastics lag far behind in injury protection for girls and boys.* [3]

"Sports and recreational activities contribute to about 21 percent of all traumatic brain injuries among American children and adolescents. The top 10 sports-related head injury categories (and number of cases) among children ages 14 and younger: (estimated head injuries treated in U.S. hospital emergency rooms in 2009)

- Cycling: 40,272
- Football: 21,878
- Baseball and Softball: 18,246
- Basketball: 14,952
- Skateboards/Scooters: 14,783
- Water Sports: 12,843
- Soccer: 8,392
- Powered Recreational Vehicles: 6,818
- Winter Sports: 6,750
- Trampolines: 5,025

Reported incidence is known to be significantly under-reported (up to 50%), and do not reflect those that are treated by family doctors or other para-medical professionals." [4]

Use of protective helmets: The 2012-

2013 National Ski Areas Association report for the use of helmets was:

- *89% by children 9 years old or younger.*
- *83% by children between the ages of 10 and 14 years.*
- *60% of skiers and snowboarders ages 18-24 years.* [5]

Use of sport mouth guards: The majority of sport-related dental and orofacial injuries affect the upper lip, maxilla, and maxillary incisors, with 50 – 90 percent of dental injuries involving the maxillary incisors. Use of a mouth guard can protect the upper incisors. However, studies have shown that even with a mouth guard in place, up to 25 percent of dentoalveolar injuries still can occur. Children are most susceptible to sports-related oral injury between the ages of seven and 11 years. [6-9]

Physical violence: Head injuries can occur as the result of abuse at the hands of a caregiver, or due to school bullying and violent assaults. [4]

For example, what happens if you shake a baby too hard? Shaking can cause bleeding in the brain (subdural hemorrhages) or bleeding in the retinas (retinal hemorrhages). Additional injury happens when the shaken baby is thrown down onto a surface, resulting in shaken impact syndrome. When a child is shaken, the brain bounces back and forth against the sides of the skull. Babies, newborn to one year (especially babies ages 2 to 4 months), are at the greatest risk of injury from shaking. Often there are no obvious external physical signs, such as bruising or bleeding, to indicate an injury.

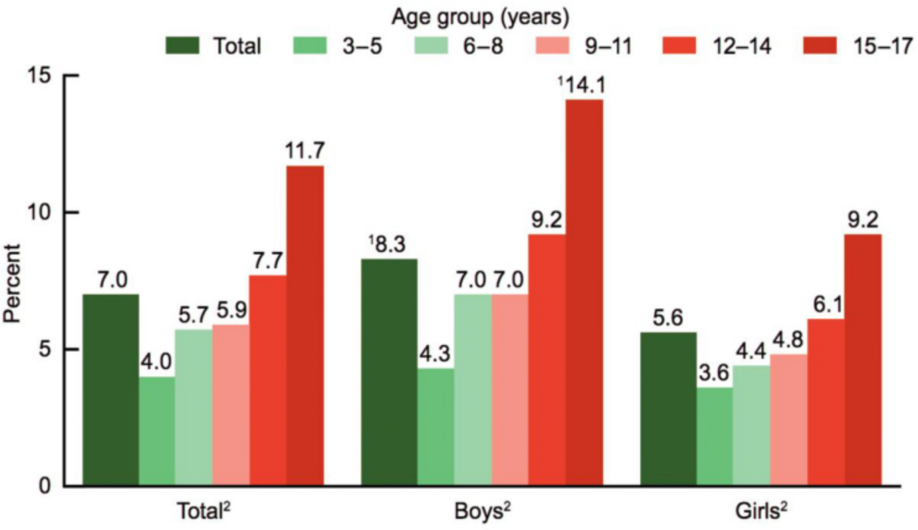
HEAD CASES: Sports and recreational activities contribute to about 21 percent of all traumatic brain injuries among American children and adolescents. There were nearly 15,000 skateboard- or scooter-related head injuries treated in U.S. hospital emergency rooms among children ages 14 and younger in 2009.

The number one reason a child is shaken is because a parent or caregiver becomes so frustrated with a baby's crying that they lose control and just shake them. They are usually average people, who in the heat of their frustration and anger lose control and shake their child. Most people charged with shaking their baby have no previous history of violence and the act is unintended. Other parents with a history substance or alcohol abuse frequently are reported as being involved with baby shaking. [10]

Shaking can cause brain injury, cerebral palsy, blindness, hearing loss, learning and behavior problems, seizures, paralysis, and death. It is estimated that **1,000-3,000 children** in the United States suffer from Shaking Baby Syndrome (SBS) each year, *but it is likely that many cases go unreported or undiagnosed.* One fourth of the victims of SBS die, and 80 percent of survivors suffer from permanent damage. The average charge for each hospital-

PREVENTABLE TRAGEDIES: The number one reason a child is shaken is because a parent or caregiver becomes so frustrated with a baby's crying that they lose control and just shake them. Learn more at: www.americanspcc.org

Figure 1. *Percentage of children aged 3–17 years who have ever had a significant head injury, by race and Hispanic ethnicity and sex: United States, 2016* [1]



[1] Significantly different from girls ($p < 0.05$).
[2] Significant linear trend by age group ($p < 0.05$).
NOTE: Access data table for Figure 1 at: https://www.cdc.gov/nchs/data/databriefs/db302_table.pdf#1.
SOURCE: NCHS, National Health Interview Survey, 2016.

ization is $65,000. In the United States, care for SBS victims and their families can total 1.2 billion to 16 billion dollars each year. [11-14]

NOT ALL HEAD INJURIES ARE THE SAME

Basically, there are two categories of head injuries: 1) external injuries, usually involving the scalp and 2) internal injuries, which may involve the skull, the blood vessels within the skull, or the brain.

"…most childhood falls or blows to the head cause injury to the scalp only. While these can be scary-looking, they usually aren't dangerous. An internal head injury could be more serious because it may cause bleeding or bruising of the brain." [11]

What to look for and what to do

Call your doctor (or use the services of a community urgency center or hospital emergency facility) if your child is an infant; has lost consciousness even briefly; or a child of any age has any of the following symptoms:

- *Won't stop crying*
- *Complains of head and neck pain (younger or nonverbal children may be more fussy)*
- *Vomits several times*
- *Will not awaken easily*
- *Isn't walking or talking normally*
- *If your child is not an infant, has not lost consciousness, and is alert and behaves normally after the fall or blow:*

- Apply an ice pack or instant cold pack to the injured area for 20 minutes every hour for 3 to 4 hours. If you use ice, always wrap it in a washcloth or sock. Ice applied directly to bare skin can injure it.

- Watch your child carefully for the next 24 hours. If you notice any of the signs of internal injury (see above list) seek immediate help.

- If the event happens close to bedtime or naptime and your child falls asleep, let your child sleep (unless advised by the doctor otherwise).

- If you aren't comfortable with your child's appearance, partly awaken your child by sitting him or her up. If he or she still seems drowsy, try to fully awaken your child. If your child can't be awakened or shows signs of internal injury, contact your doctor or call 911 for emergency care. [11]

Whatever the circumstance and explanations, it is critical that all parents must monitor their young and older children's activities to assure the safest environment.•

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Parent Perspectives on the Impact of TRAUMATIC BRAIN INJURY on Academic Success for their College-Aged Children

BY ELAINE SAMPSON, MS, CRC AND AIYANA TAYLOR, BS

INTRODUCTION

According to research, approximately 1.7 million people in the United States have been diagnosed with a traumatic brain injury (TBI). Symptoms related to this injury vary from person to person, but can include:

- *Fatigue*
- *Headaches*
- *Blurry vision*
- *Rapid or extreme mood changes*

These injuries are especially prevalent among transition-aged youth (young people between the ages of 16 and 24). In 2015, the Centers for Disease Control and Prevention reported that the incidence of TBI among people between the ages of 16 and 25 increased 60% from 2001. TBIs sustained by this age group often involve recreational activities such as car accidents and sports-related injuries.

BRAIN INJURY • EP SPECIAL SECTION

The symptoms associated with TBI often create barriers to academic success for young people, whether they are in technical schools, two-year community/junior colleges, or four-year colleges/universities. One study reports that while 80% of students with a TBI state that they struggle with school, fewer than half make use of accessibility services and only about 20% are even aware of other community supports.

Project Career[1] is a multi-site demonstration project funded by the National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR), studying the impact of technology and one-on-one case management on college/university students with TBI. Project Career operates out of three universities – Kent State University, West Virginia University, and Boston University and their surrounding communities. Each university has a Technology and Employment Coordinator (TEC) on staff to coordinate services and support the needs of Project Career students.

Support provided includes:

- *Assessing the challenges and strengths experienced by each student.*
- *Providing iPads to each student and then determining apps and other technology needed to help mitigate these challenges.*
- *Training on apps and technology provided.*
- *Connecting students with services on their campus and in their surrounding community.*
- *Facilitating in initiation of mentor relationships.*
- *Reviewing resumes and cover letters.*
- *Assisting in locating internship and employment post-graduation.*

PROJECT CAREER PARENT EXPERIENCES

Elaine Sampson, the TEC at West Virginia University, met with two parents of Project Career students to obtain their perspectives on the value of Project Career for their children.

The first parent (Parent A) describes her daughter Emily (not

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[1] A comprehensive description of Project Career is given in the November 2017 issue of Exceptional Parents Magazine. http://reader.mediawiremobile.com/epmagazine/issues/202245/viewer?page=52

CATCHING UP: In 2015, the CDC reported that the incidence of TBI among people between the ages of 16 and 25 increased 60% from 2001, and often resulted from recreational activities such as car accidents and sports-related injuries.

her real name) as a student who never gave up despite her challenges. Emily, a 22-year-old nutrition major pursuing a career as a registered dietician, sustained her TBI horseback riding as a high school senior. Since sustaining her TBI, she has struggled with memory issues and has experienced a great deal of frustration adjusting to this challenge as she was an exceptional high school student who took accelerated courses prior to her injury.

Her mother explains "that kid never gave up" as she describes the way Emily tackled her challenges, including referring herself to Project Career after attending a Project Career open house. She explains that Emily would not let her injury "get to her," and that even though she had a hard time with thinking and memory, she was determined to move forward and turn her experience into a positive one.

Emily has been receiving services from Project Career since July 2014, before her sophomore year of college. Her mother sees that her daughter's biggest frustration is that Emily is unable to absorb information the way she was pre-injury. Using the iPad (provided by Project Career) Emily was able to retrain her brain. She had been given memory games as part of her speech therapy, and the iPad and memory apps helped to reinforce these skills.

> "The symptoms associated with TBI often CREATE BARRIERS to academic success for young people."

In terms of challenges, both expected and unexpected, Parent A noted that Emily had to put more time in studying than she had anticipated and that she was not willing to tell her professors about her limitations. Emily ultimately wanted to work through it on her own. Emily would tell her mother "I don't want special treatment. I will just work it." Parent A explained that she had to push Emily to seek accommodations from her school's Accessibility Services. Ultimately, Emily was released from Accessibility Services after her doctor cleared her to return to full activity. Parent A notes that even though Emily was released from Accessibility Services, she still struggled with memory and need extended studying time.

Parent A repeatedly noted Emily's positive attitude and determined nature. Parent A's advice to students with disabilities is "always continue to be yourself. Strive for everything you could do and don't look at it as a disability. Whatever your best is, that's what you should aim for. Don't compare yourself to others, each person has their own strengths." Emily graduated from WVU in 2017 and is currently attending graduate school to attain her goal of becoming a registered dietician.

The second parent (Parent B) describes her 19-year old daughter Sarah (again not her real name), as a positive and happy young woman who has a go-getter spirit. Sarah sustained her TBI in a car accident while she was in high school. She learned about Project Career through her school's Student Accessibility Services and started receiving services in 2015, before she began her freshman year.

Parent B describes fatigue as the biggest challenge that her daughter has faced since sustaining a TBI. "She cannot participate in a lot of activities since she has to go to bed so early." This has caused Sarah some frustration, as many of the activities on her campus are at night. These include both academic supports such as tutoring in the library and study groups, and social activities such as clubs and service organizations. "She is up against kids who don't have concussions and they can stay up late and join sororities and other groups. She just can't do that."

Sarah's mother noted that she still suffers with fatigue and memory loss and that she still has 20 or more headaches a month. All these symptoms impact her ability to go to class, keep up with her classmates and participate in the typical college lifestyle. "It's like an anchor around her neck. As parents we see her struggle and continue to do things that most college students do on their own." Parent B went on to explain that this included laundry, shopping and providing dorm room snacks. Sarah has a special diet because of her concussion. That only compounds the challenges she faces every day. She is unable to go out and eat with friends or just grab a quick bite between classes.

"There are no two
TBI
EXPERIENCES
that are going to be
the same."

Although Sarah has academic accommodations through Student Accessibility Services her mother noted Sarah needed more than what was provided. Parent B felt that the academic accommodations - requiring extra time, a note taker, priority scheduling and preferred seating - did not level the playing field. For example, Sarah was not admitted to an academic program of her choice because she did not have extracurricular activities on her application. According to Parent B, Sarah is competing against "normal" students and she cannot keep up. "When her battery runs down, she is out of energy for the day. There is nothing she can do but sleep."

Once Sarah enrolled in Project Career, Parent B noted "she felt more hopeful," because the full results of the concussion were recognized and not just the physical aspects of the injury. To help Sarah maintain her energy and continue to benefit from Project Career services, her TEC met her at her university's library instead of the Project Career office. The library was significantly closer to the student's dorm, thereby requiring less energy. Additionally, the TEC helped with entering syllabi information into Sarah's organization app, as well as with meal planning and locating restaurants that delivered and had meals she could eat. Her TEC also provided career counseling as Sarah determined a new field of study and ultimately decided to transfer to another university. Despite the transfer, Sarah continues to participate in Project Career, by utilizing the FaceTime option on her iPad to communicate with her TEC.

Parent B's advice to parents of other students with TBI is "When you have a concussion, you just can't do it all. Go to accessibility services and ask for help. Do a lot of praying. It is hard to let a child with a disability go. It is not like the typical student that you can kick out the door and say see you at Christmas. It really presents a challenge." Parent B went on to state that today's technology makes it easier to keep track of your children and to make sure they are getting the help they need. There is a constant connection if the student needs help with something quickly.

CONCLUSION

These two very different experiences highlight the many variables that exist in the impact of TBI and the reaction to TBI. There are no two TBI experiences that are going to be the same. The age at injury, the type of injury, and the severity of injury all impact the manner in which a TBI will affect the individual involved. Parental and societal support, along with the person's attitude and life outlook, will contribute to the full effect of the TBI.

Because of the great disparity in the needs experienced by students who have a TBI the Project Career TECs work with each student on an individual basis, tailoring each person's technology and case management to his or her individual challenges and strengths. The apps provided through Project Career are specifically chosen for each individual based on needs, skills, academic programs and more. The Project Career TECs use the Matching Persons and Technology Assessment Tools to help determine the best cognitive support technology and the best way to introduce this technology to their students. This individualized approach ensures that each student is getting the exact services they need to have the best education and employment outcomes possible.•

ABOUT THE AUTHORS:

Elaine Sampson, M.S., CRC, CBIS, is the Technology and Employment Coordinator for Project Career at West Virginia University. Ms. Sampson joined Project Career in November, 2013. Her primary responsibilities include working with students with traumatic brain injury, determining which cognitive support technologies will best assist these students, providing training on these technologies, supplying training materials in a variety of formats, one-on-one case management to assist with academic and employment goals, mentor matching, internship and employment assistance and post-graduation services.

Aiyana Taylor, B.S., serves as Research Assistant and Communications Coordinator for Project Career out of JBS International in North Bethesda, MD. Ms. Taylor joined Project Career in September 2016. Her primary responsibilities include managing the project's presence on social media, coordinating meetings for Project Career staff and Advisory group, documenting and following up on meeting outcomes, and supporting qualitative data analysis.

Learning Through the Summer

AN OVERVIEW FOR PARENTS OF EXTENDED SCHOOL YEAR SERVICES

BY LILLIAN DUFFIELD

As the school year winds down, many parents are left wondering what they can do so that their child can continue their individualized education plan (IEP) during the summer months. It can be hard to find available resources and decide which one is right for your child. If your child receives special education services under the Individuals with Disabilities Education Act (IDEA), he or she may be eligible for a special education program that goes beyond the school year.

GENETIC ALLIANCE

The world's leading nonprofit health advocacy organization committed to transforming health through genetics and promoting an environment of openness centered on the health of individuals, families, and communities.

WHAT ARE EXTENDED SCHOOL YEAR SERVICES?

Extended School Year services, or ESY, are special education services that help children with disabilities maintain the skills they've developed during the school year.[1] ESY provides extra support for students during summer months so they do not regress or lose what they have learned in school. These services are distinct from day care, summer school, or any other enrichment programs, even they provide some educational benefit. Unlike these other programs, ESY services are a part of the IEP process, must meet the standards of the State Educational Agency (SEA), and are required to ensure the provision of free appropriate public education (FAPE) to a student.

WHO AND WHAT STEPS ARE INVOLVED IN DETERMINING A CHILD'S ELIGIBILITY FOR ESY?

The child's school is the primary decision maker when it comes to qualifications for ESY. As part of the annual review of a child's IEP, the school will consider their need for ESY. The IDEA, the federal special education law, states that all local educational agencies (LEAs) must provide ESY services for students that need them to allow easy access to free, appropriate public education (FAPE). However, it is important to keep in mind that ESY is not guaranteed for all students who have IEPs. IDEA lets each state or school decide its own rules for eligibility, which means that standards will vary from school to school.

The local school district will assist the IEP team to determine the procedures for ESY services. Importantly, the school district is not allowed to postpone the decision regarding ESY services until after the summer in order to determine what would happen if the services are not provided. The IEP team must make a decision regarding ESY services before the end of the school year to ensure that parents can exercise their due process rights if they want to challenge the decision. ESY services cannot be limited to a set number of days or hours. Furthermore, schools are not allowed to restrict the availability of services based on financial resources or administrative convenience. Services can't be denied to students who need them in order to receive FAPE, and the school cannot limit services based on predetermined disability categories or exclude certain students with disabilities. These protections in place for students with IEPs can hopefully provide some peace of mind for families as they look to the school year ahead and the consider how to keep a child cognitively engaged in the intervening summer.

In order to determine if a child needs ESY services, the school's IEP team must decide whether the skills a child gained during the school year will be significantly jeopardized if the child does not receive ESY. To do this, the team reviews data collected throughout the school year, as well as any input from teachers, parents, and other members of the IEP team. Indicators may include progress toward a child's goal on consecutive IEPs, progress reports from teachers and therapists, reports from parents of any changes in adaptive behavior or other skills, observations and opinions by all, and test results from criterion-referenced tests, curriculum-based assessments, or ecological life skills assessments.

> **"With an Extended School Year plan and supports in place, families can finish out the school year with the confidence that their children's learning and skill development don't have to stall once summer begins."**

The IEP team will take into account several factors to determine if a child is eligible for ESY services. Even though a child may be eligible by meeting just one of the criteria, no single factor on its own can be used as a determinant – all must be considered together by the IEP team. One such way is to evaluate if the student is likely to lose critical skills (regression) during a break and, if so, whether the time the student takes to re-learn the lost skills (recoupment), is excessive. The IEP team will also consider the nature and severity of the student's disability, the rate of progress, self-sufficiency and independence, the availability of alternative resources, and the areas of curriculum which need continuous attention. The IEP team with assess and weigh each of these dimensions of a student's developmental profile to reach a decision about ESY eligibility.

Parents may wonder what happens if they find themselves at odds with the IEP team's decision. If the IEP team and the parents can't agree on the eligibility of the child, or on the type or format of ESY services that is most appropriate, the school district will issue a Notice of Recommended Educational Placement/Prior Written Notice (NOREP/PWN) along with the Procedural Safeguards Notice to the parents explaining the IEP team's decision. If the parents still disagree with the decision, they can then respond to the NOREP/PWN with a letter addressing their concerns and requesting another meeting, mediation services, or a due process hearing. While this sounds daunting, there are resources that offer support and guidance for parents along the way (see references and resources at the conclusion of the article).

HOW DO IEP TEAMS CREATE THE RIGHT ESY PLAN FOR A STUDENT?

When determining the correct ESY service for a child, the IEP team will consider what kind of setting and service delivery model is best for them. There are quite a few options when making a decision, and the service will not necessarily be a continuation of the same program and related services that the child receives during the normal school year. ESY options may include parents and teacher working together, home-based programs, group programs, school-based programs, cooperative programs with other agencies, multi-system shared programs, and community-based programs. Qualified ESY service providers will then take the lead on implementing a student's individualized program.

With the school year coming to close, there is still time to prepare for the potential opportunities that ESY can provide. You may find reassurance in talking with your child's teachers now to review which ESY services are right for your child and address any concerns you might have. With an ESY plan and supports in place, families can finish out the school year with the confidence that their children's learning and skill development don't have to stall once summer begins. •

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WHAT CAN PARENTS DO TO FEEL PREPARED TO PREPARE FOR AN ESY PROGRAM?

Parents play a crucial role in deciding whether ESY is necessary for their child. There are a few things they can do to prepare for ESY and ESY meetings. Below are some recommendations from ESY experts:

- It's a good idea to obtain a copy of the ESY determination guidelines issued by your school district or state, familiarize yourself with the guidelines, and ask any questions you might have.
- Collect data that showcases your child's progress throughout the year by keeping a record of their improvement and regression.
- Make a list of factors that you think should be taken into consideration when determining your child's need for ESY services.
- Refer to the criteria on the guidelines sheet and take your list with you when meeting with the IEP team. This will help the IEP team create the best ESY program for your child.
- It is recommended that ESY service providers submit a report regarding the child's progress to their teacher for the upcoming school year. Feel free to speak up and request copies of these reports.
- Don't wait until the last minute to discuss the potential need for ESY services during the break. Meet with your child's teachers and therapists, both in and out of school, in order to gain more feedback and written recommendations from them for ESY services. If necessary, you can request a meeting specifically for the purpose of determining ESY eligibility, or bring it up at your next meeting with the IEP team. The earlier you bring it up, the better prepared you will be.

DON'T GO IT ALONE : EXTENDED SCHOOL YEAR RESOURCES

To help you and your family plan for the transition to adulthood, Christopher Fuller, M.Ed., a special education teacher, has guided us in compiling a list of resources that can help you get started.

PAVE

PAVE

Partnerships for Action, Voices for Empowerment

https://wapave.org/extended-school-year-esy/

autism NOW you, empowered.

SPECIAL EDUCATION GUIDE

www.specialeducationguide.com/blog/what-are-extended-school-year-services-and-who-qualifies/

Understood for learning & attention issues

UNDERSTOOD.ORG

www.understood.org/en/friends-feelings/child-social-situations/summer-camp-summer-school/extended-school-year-services-what-you-need-to-know

IES BRAIN RESEARCH FOUNDATION

MILESTONE:

WE BROKE 100!

This totally volunteer run non-profit, as of this summer, will have given 101 summer fellowships.

CONGRATULATIONS 2018 SUMMER FELLOWS:

1. **Kristin Miner** working with **Rehana Leak, PhD** at **Duquesne University** on **Parkinson's Disease**
2. **Van Truong** working with **Sam Gershman, PhD** at **Harvard University** on **Neuropsychiatric Disorders**
3. **Nyle Almeida** working with **Shawn Hervey-Jumper, MD** at **University of California-SF** on **Glioblastoma**
4. **David Rosenberg** working with **Zhe Chen, PhD** at **New York University** on **Pain**
   2018 IES Brain Research Foundation Rolf Weil Fellowship donated in memory of Rolf Weil by Eric Simon, PhD
5. **Hannah Smith** working with **Brady Maher, PhD** at **John Hopkins University** on **Autism**
6. **Sophie Rogers** working with **Yasmin Hurd, PhD** at **Mount Sinai** on **Addiction**
7. **Ian Cassentino working with Nicholas Stavropoulos, PhD** at **New York University on Sleep**
8. **Malka Svei** working with **Alexander Harris MD, PhD** at **Columbia University** on **Depression**
9. **Adam Lieber** working with **Christopher Kellner, MD** at **Mount Sinai** on **Stroke**
10. **Allison Matous** working with **Heather Wishart, PhD** at **Dartmouth Geisel School of Medicine** on **Multiple Sclerosis**
11. **David Dunn** working with **Elyssa Margolis, PhD, MD** at **University of California-SF** on **Addiction**
12. **Allie Tracey** working with **Ramesh Raghupati, PhD** at **Drexel University** on **Traumatic Brain Injury**
13. **Rebecca Zaritsky** working with **James Clelland, PhD** at **NYU Nathan Kline Institute** on **Schizophrenia**

For a $2500 tax deductible donation, you can attach a name of a person or business to a fellowship and indicate the area/disease to which you prefer the donation to be earmarked.

ALL DONATIONS ARE TAX DEDUCTIBLE

THE FITNESS PRIORITY KRISTIN MCNEALUS, PT, DPT

Improving Mobility by Participating in Research

Get involved and support research studies to help funding continue. Ask how you can help get more funding and awareness to research that would directly benefit the diagnosis that impacts your family.

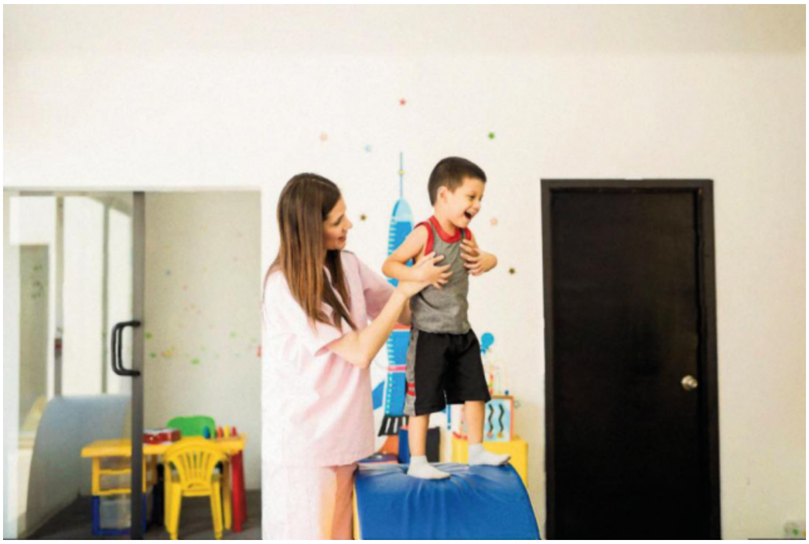
When you or your child has a disability, I am sure that you try to stay up to date with what the latest research is studying – and what results seem promising. Looking into the studies that are starting can allow you to apply to be a participant. It is important to help the research process advance, and there may be great benefit from getting the newest treatment. However, you want to be discerning.

There are studies where the control group gets no treatment, and you are not allowed to explore outside interventions as this could skew the research results. You also want to ask about how participation in one study could impact your ability to participate in later studies.

If your child or you have a disability due to neurological impairment, I am sure that you are waiting for stem cell treatments to advance. It is all very exciting and very promising – but it is not there yet.

There was exciting news about a man who experienced a positive result with olfactory stem cells! I think every step forward makes you evaluate your current lifestyle and what you are doing to keep moving forward. Are you working out? Staying strong? Managing your weight? Research studies want the healthiest subjects to limit the impact of any co-morbidities. It is understandable – they want to maximize the positive results. The best thing you can do, whether or not you are trying to enroll in research studies, is to stay as active and healthy as possible. This will also help you or your child benefit from any new treatment that is developed.

Let's talk about locomotor training, and therapy, geared toward getting walking. There are many studies around this treatment for many diagnoses, and being able to walk is a common goal. There are many benefits to the body-weight-supported treadmill training. Your body is upright and moving. It helps your digestion, it helps spasticity, it could help improve circulation, and decrease pain. The body was built to move and walk, so this therapy makes many people feel better. As far as evidence-based practice goes, we know that the nervous system needs a lot of repetition and intensity to make changes. The treadmill will do this. It can help promote connections and neuroplasticity, which is pretty awesome!



AHEAD OF THE CURVE: The best thing you or your child can do, whether or not you are trying to enroll in research studies, is to stay as active and healthy as possible. This will also help you benefit from any new treatment that is developed.

Walking is the goal for many people who come to physical therapy, and they are disappointed if their physical therapist does not put them on the treadmill. Here's the dirty little secret: if you are receiving your therapy as an insurance benefit, then in order to get payment from the insurance, the therapist has to abide by the guidelines set by the health plan. What they want to see is a measurable improvement in your functional mobility, and more often than not, the treadmill will help your body feel better and move better. But it may not give you the improved scores of standardized tests that insurances recognize. If improvements are not documented over the course of treatment, the clinic may not get reimbursed by the insurance! That's crazy, huh?

Treadmill training is not likely to change how much help you need getting out of bed. So what improves that? Practicing getting out of bed, strengthening innervated muscles, and staying flexible. Boring, I know. It could help increase flexibility and strength that could result in improved bed mobility, but it is difficult to predict.

Additionally, locomotor training on a treadmill requires multiple staff members to work with one patient. It is often very difficult for therapy clinics to afford this with the ever-decreasing reimbursement that insurance is providing.

The options out there are generally cash-pay. And although it's costly, it has many benefits for you. You are now in control of your treatment course instead of an insurance company. You will get more individual time from your therapist. You may not need to work as often with the therapist since you get more time per session. Think about it. And, as previously mentioned, looking for local research studies that are looking at the benefits of treadmill training is another way to get this treatment at no cost.

Before trying any new treatment, you want to consider the risks. As great as treadmill training can be, there are things to be cautious about when getting upright. You have to make sure that your blood pressure cooperates. If you get orthostatic, it'll be difficult to work out. When you do not walk regularly, the bones get weaker. Unfortunately, this will happen even with interventions aimed at maintaining bone density. This puts you at risk for fracturing a bone. You're also at risk for injury of your soft tissues from the new, intense stress that the body is being put under. You may not feel an ankle sprain – or any other injury to an area you do not fully feel – but keep an eye on any swelling. Your therapist may use orthotics to limit the risk of injury to soft tissues and bones, but it is still important to monitor your body following each session. And, most important, WATCH YOUR SKIN! The harness straps could easily cause a sore with all the moving. Check your skin after every session and be sure to add extra padding if you notice any redness. And if you do get a sore, seek medical attention. Also, do not use the harness again until you are healed. Then you will have to ease in slowly with additional padding to make sure the sore does not occur again.

In conclusion, research is always progressing with interventions to help mobility. Get involved and support research studies to help funding continue. Ask how you can help get more funding and awareness to research that would directly benefit the diagnosis that impacts your family. Be discerning about the quality of each study and weigh the pros and cons of participating in any research.•

THE FITNESS PRIORITY

Kristin McNealus, PT, DPT, ATP received her Masters in Physical Therapy from Boston University then went on to earn her Doctorate in Physical Therapy from MGH Institute of Health Professions. She has been a staff physical therapist on inpatient rehabilitation for people with spinal cord injuries at a number of hospitals in Southern California, as well as Director of a community adaptive gym for people with neurological injuries. She is a member of the International Network Spinal Cord Injury Physiotherapists, and has contributed to the APTA Guidelines for Exercising with a SCI. She has completed 3 marathons, and 25 triathlons, including the Ironman! SCI Total Fitness is designed to promote health and wellness for people with physical disabilities.

MOBILITY
THE ANNUAL ISSUE

Independence is an important precursor to driving, so parents who hope to see a son or daughter with disabilities behind the wheel are advised to start fostering independence and decision-making early on.

IN THE DRIVER'S SEAT

STUDENTS WITH DISABILITIES BEHIND THE WHEEL

BY PEGGY CHAPMAN

READY, STEADY, GO: Young adults with invisible processing disorders, including Asperger's sydrome, high functioning autism, attention deficit hyperactivity disorder and learning disabilities, might feel anxious and unprepared once they get on the road.

Many teens count down to their 16th birthday, anxious for the freedom that comes with a driver's license. It is a rite of passage.

But for those with disabilities, the adaptations needed to get behind the wheel – and the decision about whether to drive at all – can be complex.

It may come as a surprise, but the physical challenges related to disability are often the easiest to address because it is possible to fit a car with adaptive tools – buttons, pedals and knobs - to make it physically possible to drive. The biggest obstacle for many teens with disabilities is the visual processing aspect of driving. Many drivers with disabilities may not recognize where they are in space relative to other objects, and the ocular motor skills used to scan and react may be slower or less accurate, so it takes them longer to process the environment.

Consider the complex sequence of steps needed to stop a car at a stop sign:

I see the sign. Where do I put my foot? Where do I need to look? How do I signal my stop? How hard do I press down? How soon do I start the process? When do I need to check the mirror? These are the same steps any new driver must consider, organize and carry out, but for drivers with disabilities, sequence and processing speed can present a problem.

Young adults with invisible processing disorders, including Asperger's sydrome, high functioning autism, attention deficit hyperactivity disorder and learning disabilities, can get pushed through generic driver education programs. They might even get a license, but once they get on the road, they feel anxious and unprepared. Without question, driving is an unpredictable experience filled with unanticipated delays, detours, objects in the road, and yes, flat tires! When a young person does not respond well to the unexpected or a change in routine, driving preparation must address these realities as well.

Then, there is the issue of distraction or failing to identify important variables in the environment. While all drivers - new and experienced - can get distracted, it is a particular problem for novice drivers. About 60% of teen crashes involve driver distraction, and more than 421,000 people were injured in motor vehicle crashes involving a distracted driver in 2012. The National Highway Traffic Safety Administration reported that 'recognition error' – failure to notice a critical element – accounts for more than 40% of all crashes, more than driving under the influence or speeding combined.

These issues are magnified for drivers with disabilities.

HIGH STAKES

According to AAA, nearly 3,000 drivers under age 20 died in motor vehicle accidents in 2012, and those under 20 accounted for 60% of passenger fatalities. National Highway Traffic Safety Administration data show that drivers over the age of 60 have increased rates of fatalities, and suffer more serious injuries in crashes than do younger drivers. And as the number of miles driven increases, so too do fatality rates. It is therefore vital that drivers are ready *before* they get behind the wheel.

Some parents feel fully prepared to teach their teens to drive and are confident that their children are ready to get behind the wheel. Others worry that their own fears and doubts are clouding their judgment and worse, causing their children to share their anxieties. For them, mobility decisions become a source of frustration and concern.

A Certified Driver Rehabilitation Specialist (CDRS) can help. A CDRS has specific training, experience and understanding when it comes to both physical and "invisible" special needs, such as learning disabilities, dyslexia, and high-functioning autism. Some CDRS professionals also hold other credentials, such as Occupational Therapist or Physical Therapist. Driver rehabilitation specialists perform comprehensive evaluations to identify appropriate adaptive equipment. A complete evaluation includes vision screening and, in general, assesses:

* *Muscle strength, flexibility, and range of motion*
* *Coordination and reaction time*
* *Judgment and decision making abilities*
* *Ability to drive with adaptive equipment*

Upon completion of an evaluation, clients receive a report containing specific recommendations on driving requirements or restrictions, and a complete list of recommended vehicle modifications.

A clinical pre-driver evaluation helps identify strengths and weaknesses, and anticipate the types of driving errors the individual is likely to make. The behind-the-wheel evaluation is where we observe actual skills and determine driving potential. Often, a student needs to get into the car several times to tease out what is due to typical novice driver behaviors and what is due to the disability.

Specialized evaluations can be costly, but there is help. Vocational rehabilitation agencies and workers' compensation agencies may assist in the cost of a driver evaluation. In addition, a private health insurance company may pay for part or all of the evaluation. A doctor's prescription or other documentation may be needed to receive such benefits.

LAWS AFFECTING DRIVERS WITH DISABILITIES

The Americans with Disabilities Act (ADA) protects drivers with disabilities in several ways. State offices of motor vehicles are prohibited from denying an individual a license to drive solely because he or she has a disability. In addition, drivers with mobility-limiting disabilities are entitled to pay the self-service price for fuel at a full-service gas station.

States set their own rules for granting licenses to drivers with disabilities, but any driver who can pass the necessary exams with reasonable accommodation is eligible to receive a driver's license. If seeking an accommodation, the driver must disclose his or her disability at the time of application. Depending on the nature of the disability, a state may be entitled to issue a restricted license. State DMV offices also can issue specialty permits and license plates that grant preferred parking.

REINVENTING THE WHEEL: Like all adaptive technology, vehicle modifications can be high tech or low tech. Power steering, which is found in most cars today, can be especially helpful to drivers with a weaker upper body, or someone who uses hand controls.

State and federal law governs the installation of adaptive equipment on passenger vehicles. An approved vendor must perform installation of mobility equipment, especially if the driver is seeking funding from the Department of Vocational Rehabilitation or the Veteran's Administration.

VEHICLE MODIFICATIONS

Like all adaptive and assistive technology, vehicle modifications can be high tech or low tech. Even a generic convenience such as an automatic transmission can be considered an adaptive device, because it eliminates the need for a clutch and manual shift. Similarly, power steering, which is found in most cars today, can be especially helpful to drivers with a weaker upper body, or someone who uses hand controls.

There are more specialized technologies, too. Steering devices, such as steering knobs, cuffs and palm grips can be installed to help drivers who need better grip control for steering. It is even possible to equip a vehicle with floor-mounted steering controls. Other

PHOTO COURTESY ADED

adaptive devices include a raised roof or dropped floor to make room to accommodate a driver seated in a mobility device; a left-foot accelerator; a pedal extender that raises the height of the brake and accelerator, so the driver can control them with his/her hands.

Sometimes, even after the modifications are made and the individual is physically able to carry out the tasks associated with driving – steering, breaking, accelerating – is becomes clear that there are other challenges, often related to visual processing.

The costs for modifying a vehicle can vary. Some adaptive equipment, such as a special seat-back cushion, can provide a better view of the road for as little as $50. More complex equipment, such as hand controls, can be purchased for under $1,000. A new vehicle modified with adaptive equipment will cost anywhere from $20,000 to $80,000.

FULL ACCESS: State offices of motor vehicles are prohibited from denying an individual a license to drive solely because he or she has a disability due to provisions of the ADA.

PREPARING YOUNG PEOPLE FOR DRIVING

Independence is an important precursor to driving, so parents who hope to see a son or daughter with disabilities behind the wheel are advised to start fostering independence and decision-making early on.

Consider the skills that young people need to drive: they have to be able to be alone, follow rules and regulations, solve problems as they happen, understand time to reach a destination promptly, and manage the financial and maintenance responsibilities of a vehicle. As pre-drivers, young people need to master basic self-management skills, and need experience planning and sequencing activities. And they need to do it on their own, without a coach. For example, trusting a teen to operate the dials on a washing machine may seem unrelated to the weighty responsibility of driving a car, but common activities like this will gradually prepare children of all ages to build the foundation skills needed to drive later.

Another strategy that promotes readiness skills, is to start early with "commentary driving" in the car, engaging the student as an active passenger.

Parents can narrate the driving experience, with the student in the passenger sear, teaching them how to scan, think and pay attention like a driver. Riding a bike is also a good prerequisite to driving, and can help with understanding the rules of the road.

At Y.A.L.E. School in Cherry Hill, New Jersey, educators have launched a new program called Mobility Matters® designed to help teach pre-requisite skills through a comprehensive transition curriculum that encompasses decision-making, problem solving, financial literacy, and hands-on learning. The program integrates developmental mobility skills to students as young as 7, designed to promote personal independence. Progressively introducing these skills and building one upon another can help the young person get ready for independent mobility - and perhaps, eventually, a drivers license.

Y.A.L.E. School also offers new pre-driver competency training program for high school students with processing difficulties featuring DriveFit, a state of the art visual scanning app for the iPad as well as a fully-equipped driving simulator, both using virtual driving scenarios, and a progressive mobility curriculum designed by driving rehabilitation specialists and occupational therapists. A collaboration with research partners including Clemson University enables the school to pioneer best practices.

While not all students with Aspergers will be able to drive, this training program can help get them one step closer to being ready.•

HITTING THE ROAD : MOBILITY RESOURCES

ADED
The Association for Driver Rehabilitation Specialists

THE ASSOCIATION FOR DRIVER REHABILITATION SPECIALISTS (ADED)
(866) 672-9466
www.driver-ed.org • www.aded.net

NMEDA
NATIONAL MOBILITY EQUIPMENT DEALERS ASSOCIATION

NATIONAL MOBILITY EQUIPMENT DEALERS ASSOCIATION (NMEDA)
(800) 833-0427
www.nmeda.org

ABOUT THE AUTHOR:

Margaret Chapman B.A., M.J. is the Assistant Director of Y.A.L.E. School in Cherry Hill, NJ. She holds a masters certificate in Transition Special Education from The George Washington University School of Human Development and Education in Washington, D.C. At Y.A.L.E. School, she oversees program development and transition initiatives. Through strategic partnerships and collaboration, she has implemented numerous community-based programs for high school students with disabilities through age 21, spearheading innovative pathways to higher education and employment in natural settings including college campuses, businesses and blended programs with adult agencies.

WHERE ELSE CAN YOU DISCOVER ABILITY-ENHANCING PRODUCTS AND SERVICES, PLAY A FEW ADAPTIVE SPORTS, LEARN NEW DANCE MOVES, ATTEND INFORMATIVE WORKSHOPS AND ONLY SCRATCH THE SURFACE OF WHAT ABILITIES EXPO HAS TO OFFER?

THE EXPO EXPERIENCE

AN ADAPTIVE CLIMBING WALL, THE LATEST DISABILITY PRODUCTS, AND MICAH FOWLER OF ABC'S *SPEECHLESS* FEATURED AT THE NEW YORK METRO ABILITIES EXPO

PHOTOS COURTESY ABILITIES EXPO AND FAYE SIMON/EXCEPTIONAL PARENT MAGAZINE

MAXIMUM EXPOSURE: *(Clockwise from top left)* Micah Fowler, recently named to Forbes' 30 Under 30 – Class of 2018, visits with fans during his Saturday apperance; Jasmine and her mom enjoy one of the hundreds of events and exhibitors; Team Tamelli demonstrate dance moves for an appreciative crowd; Sarah Best's service do Edison takes a well-deserved rest in front of Exceptional Parent Magazine's booth. *(Opposite page)* Adaptive climbing builds confidence, develops goal-setting skills, increases strength and improves flexibility.

People with disabilities, their families, caregivers, seniors, wounded vets and healthcare professionals attended Abilities Expo on May 4-6, 2018 at the New Jersey Convention & Expo Center to discover the latest products, education and fun for all ages. Among the myriad of exciting, inclusive opportunities, attendees were especially excited for the chance to test drive cutting-edge technologies, summit the giant wall with specialized adaptive climbing equipment and meet Micah Fowler.

"The Abilities Expo was such a rewarding, and awesome day! My son, Christian really wanted to go, and encouraged our whole family to go. It was such a memorable, and inspirational day for all of us! We met so many amazing people, met new friends, and even professionals who took the time to mentor, and encourage Christian with his future career ideas, and plans! What an invaluable day!" said attendee Helen Huber. "Thank you to everyone who made this day possible! It was truly a blessing to our family!"

Micah Fowler of ABC's hit sitcom *Speechless* hosted a Q&A, followed by a meet and greet. Fans got to meet the gracious star in person and learn more about his groundbreaking role as JJ DiMeo, and how he refuses to let cerebral palsy define him.

The adaptive climbing wall was also a tremendous hit at the Expo. Regardless of the level of ability, anyone could participate and enjoy the experience of ringing the bell at the top. Instructing would-be climbers was Guinness World Record holder Mark Wellman of No Limits. An avid climber, Wellman was the first paraplegic to summit El Capitan and Half Dome at Yosemite National Park.

Attendees also experienced cutting-edge products and services for people with a wide range of disabilities. They found mobility products, devices for people with developmental disabilities, medical equipment, home accessories, essential services, low-cost daily living aids, products for people with sensory impairments and more. The Assistive Technology Showcase also featured breakthrough AT to empower the community to bridge the gap between ability and disability.

A series of compelling workshops on how research can improve quality of life, travel, therapeutic cannabis, accessible home design, emerging therapies, selecting the right accessible vehicle and more were also offered free-of-charge.

Attendees were able to let loose with daily dance demos focusing on various styles. Sunday's ballroom dancing workshop was led by Cheryl Angelelli and Tamerlan Gadirov, the #1 Para Dance Sport couple in the United States. People also enjoyed service dog demos and play adaptive sports like golf, quad rugby, hockey, basketball, marital arts therapy and racing.

Complimentary loaner scooters, wheelchair repair and sign language interpreters were also available to accommodate attendees. *For more on theAbilities Expo, visit www.abilities.com* •

Having Edison by my side is such a comforting feeling. We go everywhere together.

We often go to New York City, which requires a cab to the train station, a train ride, a bus and then some walking.

Edison does it all with ease and never complains!

PHOTO BY FAYE SIMON/EXCEPTIONAL PARENT MAGAZINE

Have you ever received a gift that changed your life?

That's what it felt like for me when I received my service dog, Edison, from the National Education for Assistance Dog Services (NEADS).

Edison has given me the gift of independence!

I live with cerebral palsy, which is a physical disability that mainly affects my balance and coordination, affecting my ability to walk.

THE GIFT THAT CHANGED MY LIFE

BY SARAH BEST

Having Edison by my side is such a comforting feeling. We go everywhere together. We often go to New York City, which requires a cab to the train station, a train ride, a bus and then some walking. Edison does it all with ease and never complains! Makes me tired just thinking about it! His incredible training helps me more than words can say. The simple act of dropping a pen in the middle of Grand Central Station would send me into a tizzy thinking about having to ask for help and possibly making a big scene. Now with Edison by my side, I don't even think that way. A simple command sends us on our way in less than 30 seconds.

EP GOES TO THE ABILITIES EXPO 2018

This past weekend we traveled to the Abilities Expo, where I served as an Ambassador. Once again, Edison helped me in various ways. We had to take multiple trains and a bus to get there. Quite the journey, but it was made so much easier with my four-legged friend. He was able to press the button to call the elevator for me, pick up my dropped items and press the automatic door buttons. Just a few of the many tasks that he knows that helped me along. Once we got to the Expo, Edison was a great helper while we were interacting with attendees and making sure everyone was finding the booths they were looking for. It was such a great opportunity for me to be immersed in such a large community for this incredible event. There are not too many chances that are available to people with disabilities to be able to be around people that understand what it's like living with a disability.

ON THE GO: Sarah and Edison at the NY Metro Abilities Expo on May 5th."I get things done because I have learned that nothing in life comes easy. Everything requires work. Sometimes the work is very, very hard, like physical therapy. It is difficult for me to walk because of my CP, but I try. I work on my muscles and coordination."

Edison does a lot for me but it took a while for it all to come together. It began with the interview process I went through when I applied to NEADS. I first filled out a short but precise application where I had to answer questions about my daily life and schedule. About a week after I sent the application in, I received a call to head to the NEADS campus for an in-person interview. The interview was an in-depth conversation that elaborated on the questions I previously had answered in the application, and more! Questions like: What time do I wake up in the morning? What time I do I go to sleep? What does a typical day look like? The staff covered all details so they could match me with the dog that would best suit my needs.

Once the interview was done, the waiting began! It was a year later that I got the call that a dog has been matched to my needs. A month later I went to the training facility to learn how to work with my new pal. Now, after a year and a half of our partnership, I can definitely say that Edison is the greatest gift I've ever gotten!

ABOUT THE AUTHOR:

Sarah is a Abilities Expo's NY Metro Ambassador. A native New Yorker with Cerebral Palsy, Sarah resides in Westchester County, just outside of New York City. She is determined and driven to go places and do things that she is passionate about. She currently works in the Marketing Department for Convaid Products, a pediatric mobility equipment manufacturer. She loves to spend time with her family and friends and her service dog, Edison.


INNOVATION AT NEW HEIGHTS
Public safety, government and commercial applications throughout the world


LAW ENFORCEMENT
POLICE


FIRE FIGHTERS
(SEARCH & RESCUE)


U.S. INDUSTRY


U.S. GOVERNMENT

The First Annual Down Syndrome Adult Summit attracted hundreds of self-advocates, along with their families, caregivers and friends, who were welcomed to a conference created to be like no other for adults with Down syndrome.

CATCHING UP: Brad Hennefer *(left)* and Craig Blackburn reconnected at the Summit, which consisted of 26 breakouts and several plenary sessions led by more than 50 speakers who were professionals, family members and self-advocates.

EDUCATE, ADVOCATE AND CELEBRATE

BY JADENE SLOAN RANSDELL, BS AND SARA HART WEIR, MS

PHOTOS PROVIDED BY JADENE S. RANSDELL

“Now at last they were beginning Chapter One of the Great Story which no one on earth has read: which goes on forever: in which every chapter is better than the one before.” ~ C.S. Lewis

And thus began the First Annual Down Syndrome Adult Summit, as hundreds of self-advocates, along with their families, caregivers and friends were welcomed to a conference created to be like no other – an opportunity to educate, advocate and celebrate adults with Down syndrome. The summit was created by Jadene Ransdell, the mother of an adult son with Down syndrome and Sara Weir, president and CEO of the National Down Syndrome Society (NDSS), who are sharing the insights they each gleaned from this outstanding experience.

Jadene Ransdell: The Adult Summit began as a dream after I attended a conference in Orlando, sponsored by the Down Syndrome Association of Central Florida. It had been many years since I participated in a gathering of this type. At the end of the conference, as I drove home to Clearwater, I reflected on the joy and hope seen on the faces of parents with little ones with Down syndrome; I recalled the questions they had about school and medical concerns. Every person in attendance seemed pleased with the information they were gathering to make their child’s early years and school years successful.

As much as I enjoyed the two days I spent with these sweet families, I wanted more! I wanted sessions that could help me and other parents who have older adults with Down syndrome. Our kiddos are young for a very short time. The pediatricians who knew our little ones were suddenly gone from our lives and we were left trying to piece together care for adults with complex medical needs. Federal laws that ensure an appropriate education and related services do not follow our school-age children into adulthood. Rights that we grew accustomed to, disappear. My son, Matt, has been out of public education programs for more than 20 years. He’s been away from his pediatrician for longer than that. As a mom whose career was totally related to disability and family advocacy, I still faced a huge learning curve when Matt became an adult. Reading about Medicaid and how it plays such an enormous part in the lives of people who need services to live in the community was (and continues to be) an unending job. Matt faces multiple health problems, so finding doctors who understand the changes that occur in adults with Down syndrome has not been easy. A few years ago, I began to suspect that Matt was in the early stages of Alzheimer’s

ALL-STAR TEAM: *(Left to Right)* The Summit Team: Jadene Ransdell, Summit Founder, Kandi Pickard, Sr. VP of Philanthropy, Outreach & Events, Sara Hart Weir, President and CEO, and Caleb Herr, Digital Media Technical Specialist

HELLO, MY NAME IS: Kayla McKeon checking the registration table. “My heart filled with joy as I met people who were happy to be there and looking forward to a conference designed for them” said Jadene.

disease. So many unknowns, so much uncertainty, so much isolation – and yet I knew that I couldn’t be the only parent who felt this way.

While I drove across I-4 from Orlando to Tampa, those thoughts started building into a realization. Somehow there had to be a chance for families of adults with Down syndrome to get accurate and timely information about the world they now live in. As I considered the idea, I remembered that before I retired, I had organized many such events. I knew I had the skills, but did I have the energy? I had been a state and national family advocate for too many years to count and had been happily retired for about a dozen more. I loved putting my energy into my family and my hobbies – sewing and writing. For several months, the dream lived inside my head and heart. At times I would get overwhelmed and think it was silly to consider such a huge task. I knew from experience that an event of that type would be years in the making – needing to identify partners, secure funding, select a venue and create an interesting program. Every few weeks the dream resurfaced until I finally shared it with some friends and colleagues who also volunteer with the National Task Group (NTG) on Intellectual Disabilities and Dementia Practices. As I tested the water for this dream, I received confirmation that it was a great idea and I should do whatever was needed to make it happen.

In Houston for the annual American Academy of Developmental Medicine and Dentistry Conference, my friend and colleague, Matt Janicki, Co-Chair of the NTG, suggested I speak with Sara about my vision. On a Saturday morning in early June the dream started to become reality. Sara was immediately on board and offered to add the Adult Summit to the already scheduled 2018 Buddy Walk® on Washington. By lunchtime we had dates and a location. Now we had just ten months to pull together a program that would be of interest to families and self-advocates. In early summer, 2017, the partnership between the NTG and NDSS expanded to include the National Alliance for Caregiving.

Sara Hart Weir: As the President and CEO of the leading human rights organization for all people with Down syndrome, it was an easy decision to host an Adult Summit. When I met Jadene she said she had found no other organizations that were conducting events solely focused on the lives of adults with Down syndrome. We saw this as a way to ensure that our self-advocates and their families knew they were forever part of our “tribe.” It is and has been the intent of NDSS to encourage self-advocates to find their wings, and to support families through the lifetime of their loved ones with Down syndrome. We quickly decided that we would align the Adult Summit program with the NDSS robust and comprehensive programs and pillars, including healthcare and research, inclusive education, community integration, economic self-sufficiency, in addition to employment and the NDSS #DSWORKS® Employment Program. Because the life expectancy for people with Down syndrome is now well into their 60’s we also wanted to include sessions related to older adults and those who are living with Alzheimer’s disease.

Planning officially began in July as a small team discussed what topics might be important to self-advocates, their families and friends. NDSS had used the same hotel in 2017 for another event, so there was already an idea of how many sessions we could run over the day and a half of the Summit. It quickly became evident that this would not be an easy task, as the list of potential topics grew long. Eventually, we had a program we felt would be well rounded and appeal to the audience we targeted.

JR: Fast forward to April 8, 2017 when animated energy began to fill the hotel. I had ventured from my room for a mid-morning Chai tea and found the coffee shop connected to the lobby busy and filled with excited chatter as families had arrived early to take in a day of sightseeing. (Mother Nature had been extremely kind as she provided peak bloom of the Cherry blossoms in Washington, DC that weekend.) My heart filled with joy as I met people who were happy to be there and looking forward to a conference designed for them. My smile should have been a clue; they didn't know who I was or that this had been my dream!

SHW: The Summit consisted of 26 breakouts and several plenary sessions led by more than 50 speakers who were professionals, family members and most importantly, self-advocates. We are proud to have offered sessions that were educational, as well as inspiring, sessions that were stimulating and humorous, along with sessions that may have possibly changed lives.

Neil Romano, Chairman of the National Council on Disability, opened the Summit with thought-provoking words about the employment of people with disabilities who can be paid less than minimum wage because of a depression-era federal law written more than 80 years ago that was to have been eliminated after five years. He said, “If the last car of the train is not moving forward, the train is not moving.” That statement, unfortunately, can be applied to many aspects of the lives of adults with Down syndrome, not just employment. Romano spoke of Dr. Martin Luther King, Jr. being a drum major for justice and called on the self-advocates and other advocates in the room to “Bang your drum loudly!”

It was our great honor to welcome Joe Shapiro and Mary Clayton to lead a conversation about a topic that is often shied away from – sexual assault and misconduct against people with intellectual disabilities. Joe is an investigative correspondent with NPR who recently released a report on this subject. Mary has become an advocate for state and federal reforms after nothing was done to criminalize the assaulter of her daughter who has Down syndrome. One attendee described the session as a “Difficult topic but most informative. I really appreciated the frank conversation.” Another attendee found the most surprising part of this session to be the “extent of sexual assaults aimed at persons with intellectual disabilities.”

> **“If the last car of the train is not moving forward, the train is not moving.” That, unfortunately applies to many aspects of the lives of adults with Down syndrome.**

Self-advocates imparted their life experiences with Summit participants in several sessions. Sharing the stage with other residential options panelists, self-advocate Douglas Rogers, told the audience what it's like to live independently in the home he grew up in. His sister, Margaret, Ph.D., lives several hours away, supports him from a distance, and visits regularly. Another sibling, Embry Burrus, LSLP, spoke about the challenges over the past three years, as she is once again living with her 60-year-old sister, Margaret following the death of their mother. Embry spoke

COMING TOGETHER: Self-advocates listen intently in a breakout session. The program included sessions that were educational, inspiring, stimulating, humorous, along with several that may have possibly changed lives.

CONFRONTING INJUSTICE: *(Left to Right)* Mary Clayton, the mother of a sexual assault victim, Joe Shapiro, an Investigations Correspondent for NPR, and Sara Weir lead a conversation about sexual assault against people with disabilities.

of the importance for parents to make plans for their sons' or daughters' future and to keep siblings apprised of their wishes. Following of the session, one person said, "It was wonderful to hear so many different stories, viewpoints and relationships and learn about how significant the role of siblings is in the lives of individuals with Down syndrome."

Dr. George Capone, Dr. Seth Keller, Kathy Service, RN, and Adel Herge, OTD, were some of the presenters in sessions focused on aging adults with Down syndrome, including common medical conditions, and Alzheimer's disease. Sujata Bardhan, Ph.D., represented the National Institute of Health and spoke about the DS Connect® Registry and research opportunities available for adults with Down syndrome. In an anonymous survey, one Summit attendee described the sessions as "Open, candid discussions in providing feedback. It was good to know that my thoughts did not fall on deaf ears." Another person commented, "All of the sessions that I attended were full of useful & practical information!"

> **"At our first meeting on Capitol Hill, Jenny spoke right up, describing herself and the need for funding and programs to support greater independence and inclusion."**

One of the highlights of the Summit was a networking opportunity for self-advocates only. During this session, members of the NDSS Self-Advocate Advisory Board served as hosts and led a discussion on advocacy in all aspects of life. We received an email from the mother of one of the participants in this breakout session.

"I want to thank you and NDSS. My daughter Jennifer (Jenny) Holden reached out to you before the Adult Conference and Buddy Walk® on Washington. She was interested in the Self-Advocates Speak-Out Lunch. You responded, encouraging her to take part. And she did, attending both the NDSS Adult Conference and the Buddy Walk on Washington. Through these events, Jenny had an opportunity to try out new self-advocacy skills, and I had an opportunity to see what she could do. We both found the experience exhilarating and inspiring.

Jenny hadn't expressed much interest in attending conferences like this since she'd graduated from the GMU Mason LIFE Program. (While a student, she had attended conferences on higher education for students with disabilities.) Her days tend to follow a routine, going to work, playing Special Olympics, acting with ArtStream and visiting with friends. Although she has done some public speaking for the Arc and for Town Hall meetings with state delegates, she had always had a script and read her speeches. While a student, she had interned on Capitol Hill for Rep. Pete Sessions, but she had never gone to Capitol Hill as an advocate. But with the announcement of the NDSS events, Jenny wanted to see her friends Charlotte Woodward and Adrian Forsythe and even David Egan speaking out.

Jenny and I both enjoyed the conference sessions at the hotel, and we learned a lot. (I had not been at this type of conference since she was small.) We prepared for the meetings on Capitol Hill but did not really know what to expect. Our first meeting was at Senator Warner's office. There were about 25 of us representing NDSS including about 10 self-advocates of varied ages. When the senator's staffer decided to start by talking with self-advocates, Jenny spoke right up, describing herself and the need for funding/programs to support greater independence and inclusion. I was very impressed. Similarly, on the House side, when speaking with Representative Barbara Comstock and a special assistant to Representative Gerald Connolly (and the congressman himself, if only briefly), Jenny was relatively outgoing and confident. Jenny also gave each member her bio and her business card. I was surprised and delighted.

Having seen Jenny and the other self-advocates in action, I truly think they made an impact. Thanks for giving my daughter and myself this opportunity.

Sincerely,
Jeanne Holden

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JR: Jeanne was not the only parent to share that she had not recently attended a conference of this type. As Sara, the NDSS staff and I mingled with the crowd at the Summit, we couldn't stop smiling. I shed many tears of joy as I watched and listened in wonder as self-advocates, family members and other advocates spoke so positively about their experience. Several parents expressed their happiness that this was an event that focused on topics important to adults with Down syndrome. Some even shared that when they go to conferences, they spend their time outside the workshops, chatting with other parents of adults, as the session content no longer applies to their son or daughter.

The response to the Summit was tremendously positive, and NDSS is thrilled to announce that it approved funding to support another Adult Summit in 2019.

A couple of weeks after the Summit I received a text from a parent who had attended the Summit. Theresa (Tracy) Godin Morrison had been told that her son, Jonathon, 27, had Alzheimer's disease. As she listened to the medical professionals who spoke at the Summit, she could recognize the losses he has experienced over the past several years. At the same time, she kept hearing them say people as young as Jonathon don't typically have Alzheimer's – even if they are showing regression. Tracy had already done a lot of detective work before the Summit and followed up with one more appointment to unravel the mystery. She was able to share what she learned at the Summit with the new doctor who reviewed more than five years of test results and was able to tell Tracy that Jonathon is not dying. He doesn't have Alzheimer's disease, although he does have memory loss. Tracy told me that attending the Summit changed her life – and Jonathon's life.

NDSS has done a tremendous job speaking for young children and youth with Down syndrome. They believed the Adult Summit was an opportunity to clearly show their continued support for adults and those aging with Down syndrome. The Summit showed the strong commitment NDSS, the NTG and the NAC have made to educate, advocate, and celebrate all adults with Down syndrome.

The response to the Summit has been tremendously positive, and NDSS is thrilled to announce that the Board of Directors, led by Gordon Spoor of St. Petersburg, Florida, approved funding to support another Adult Summit in 2019. The partnership with the NTG and the NAC continues and has expanded to include the Down Syndrome Guild of SE Michigan and all affiliates in Michigan to bring the Second Annual Adult Summit to Detroit, April 25, 26, 27, 2019. Visit https://www.ndss.org/ndss-adult-summit/ at NDSS.org for more information regarding the upcoming 2019 Adult Summit and stay tuned for more updates throughout the year.

In his luncheon address, David Eagan, a self-advocate and Joseph P. Kennedy Jr. Foundation Public Policy Fellow, said it so well, "The things that make us different are the same things that make us awesome!" •

ABOUT THE AUTHORS:

Jadene Sloan Ransdell, BS is the mother of a 43-year-old son with Down
syndrome, autism and Alzheimer's. She has been a family advocate for more than 40 years.
Sara Hart Weir is the President & CEO of the National Down Syndrome Society.

If your lifestyle has become overwhelming while caring for a medically complex child, the idea of being a rare disease advocate can seem daunting. "How do I add advocating for my child's rare disease community when I can barely keep my head above water?" is something I hear all the time.

5 STEPS TO BECOMING A RARE DISEASE PARENT ADVOCATE

BY CARRIE OSTREA

Having "been there" with my daughter Hannah, I remember that feeling quite vividly, so I wanted to put together some simple steps for someone who wants to get involved but is not sure how to start. To advocate for your rare disease community does not mean taking on every aspect of change that needs to be made. Advocating in the rare disease space simply means "putting in the effort to create lasting change."

Every advocacy step you work toward will not only make long-lasting change for your family, but also create hope for others in your rare disease community.

(Originally published on The Mighty website. Reprinted with permission from the author.)

ABOUT THE AUTHOR:

Carrie Ostrea, principal in Ostrea Consulting LLC, is a rare disease advocacy strategist working with nonprofit and industry organizations in the rare disease space. She is also the Executive Director and Co-Founder of the Little Miss Hannah Foundation, a 501(c)3, non-profit organization which was created to honor her three-year-old daughter, Hannah, who lost her battle to Gaucher Type 2/3, an ultra-rare genetic disorder.

1

Take a second to think about this question: What are the top three things would you like to see to help increase your child's quality of life? Would it be related to better healthcare information? Better therapeutic options? More research? Connecting with others who understand what you are going through?

2

Now that you have your top three things, single out your most important one and write it down on a piece of paper. This will become your goal. Take that piece of paper and tape it to the upper corner your computer monitor, or somewhere else you will see it often.

3

Spend 20 minutes expanding your goal, this one topic. Define what actions you would like to see take place. List two or three objectives you feel are doable. For example, if your goal is healthcare provider education, then one of your objectives may be to share your rare disease story with more physicians.

4

Once you have your goal's objectives in place, start to build strategies on how you can accomplish each of the objectives. Using the example above, contacting specialists or genetic counselors at a local teaching hospital would be a great strategy. Ask for help from other parent advocates (like me), regardless of what disease they represent. We are very much a #payitforward community.

5

Create a realistic timeline of what you are able to do, and when, so you can take action on your strategies. You do not need to do everything at once — pace yourself in what needs to get done so you don't get burned out too quickly. Most importantly, you are not alone in your journey. Each parent advocate you see in this community, like myself, has been where you are right now — filled with uncertainty and starting with baby steps and support from others who have walked in my shoes before.•

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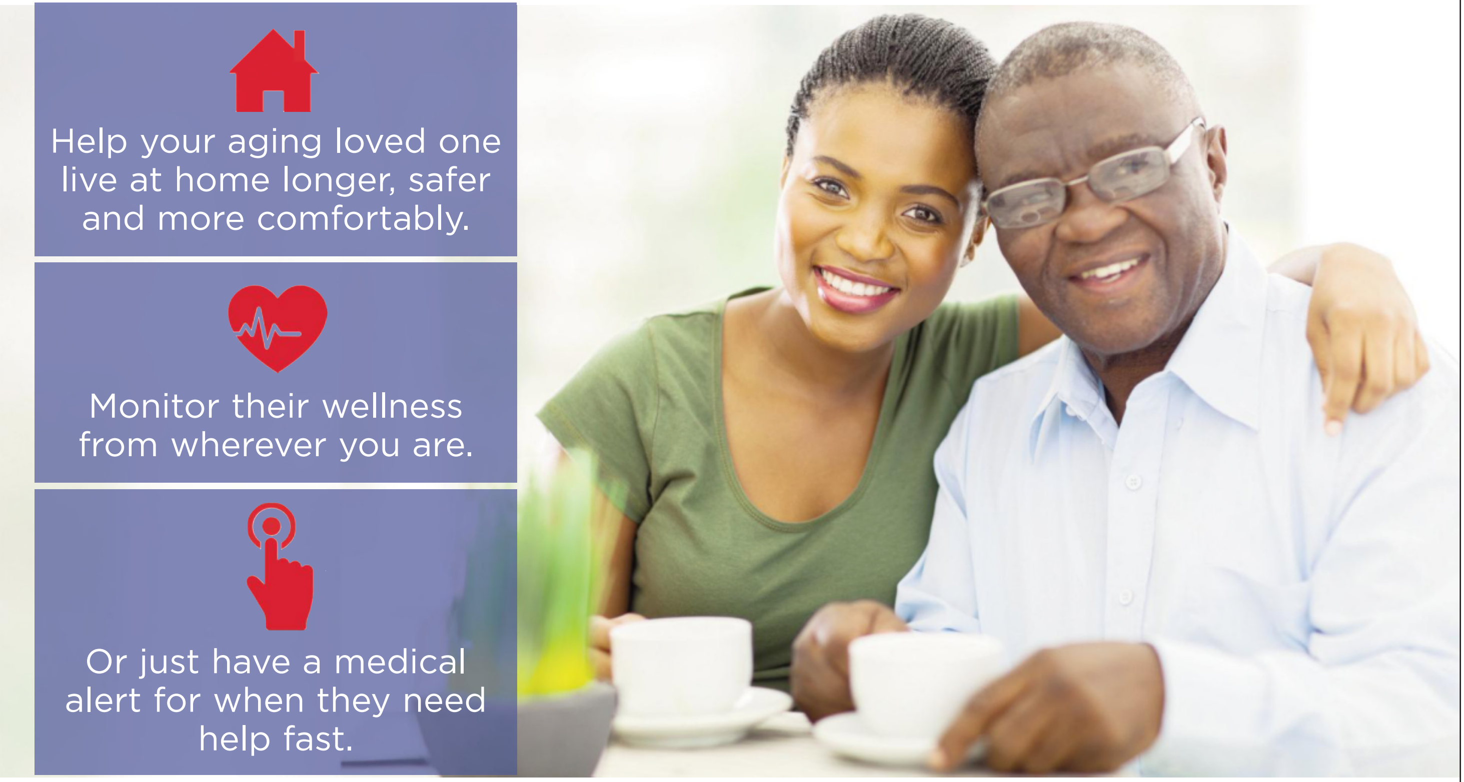

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Talking to Kids About HUNTINGTON'S DISEASE

BY BONNIE L. HENNIG-TRESTMAN

Huntington's disease, known as HD, is a genetic brain disorder affecting one in 10,000 people in the US. Symptoms of HD include mood changes, memory deficits, and involuntary movements. As of now, there is no cure for HD and it is eventually fatal. Families affected by HD have additional stressors when children are involved. Parents and caregivers may feel the best way to protect children is by shielding them from the knowledge that HD is in the family. While many might think this coping style may benefit the family by avoiding distress at that time, it's unfortunately quite detrimental to the child in the long run. Let's discuss why.

Reasons to Talk to Kids about HD

First, a child has the right to know about anything that affects the family. By not sharing this knowledge, children learn there is limited trust in the family. Even if the topic of HD is not discussed children may recognize that there is something wrong. They may even have fears that are far worse than the reality. For example, they might imagine that they did something to cause a family member to become ill. In turn, the child might develop anxiety and guilt. Not talking about HD also gives the message that it is a subject too terrible to discuss.

If HD is not discussed within the immediate family it is almost certain to come up somewhere else. Sooner or later children will find out the truth. HD and other genetic illnesses are

continually highlighted in the media. Genetics is also a topic that comes up more and more in school curriculums.

It takes a lot of energy to “hide the truth”. When you attempt to hide HD you spend more energy trying to remember what you have said. In contrast, when you talk openly about HD it’s easy to be consistent. Furthermore, it is important to know that children who are informed about HD can be a great comfort to you. Remember, children have an amazing ability to deal with difficult situations. Fears are learned. If something is hidden from a child, the message they get is that this is scary. If a child is told what is happening, it becomes part of their normal routine and there is no need for them to be afraid. Instead of pulling away from the person with HD due to fear, children are empowered to continue to show affection and respect towards that person.

Who Might Best Talk to Kids About HD

If you are capable of doing so, you should be the one to tell the children. There may be reasons why this is not possible. If that is the case, then the next option might be a well-informed, family member or friend. The important thing is to insure the child feels comfortable with this person AND that person is well informed about HD.

If neither of these options work then you might decide to have an HD-educated professional healthcare provider help you talk to the child. It can be helpful to first give the child basic information as to why they will be meeting with this person. If the child did not expect to get this information it would be scary for them to meet a new person in a new place and have that person tell them someone in their family is ill.

When Should I Tell the Kids?

Children can be told at any and all ages. Obviously, the younger the child is, the more basic the information should be. The earlier you talk about HD however, the more normal it will be for the child and they will be better able to participate in changes within the family later on.

How Should I tell the Kids?

The way you feel about discussing HD with your children will likely be based on your own experiences of how you learned about HD. Do you feel confident that you can create a positive experience or are you feeling angry and resentful? If you are feeling angry, please consider talking to a professional about this. Working out these feelings before you speak to your children will not only benefit them, it will go a long way to empowering you in the days ahead.

ALWAYS THERE: Tell children they will always be loved and cared for. Besides having children worry about you and other family members, a child is likely worried about what will happen to them if you are not available.

What and How Much Should I Tell the Kids?

Remember that you will eventually need to talk to children of different ages in stages. A good idea is to begin the basic conversation with everyone present. You will be giving the unconscious message that no one in the family is being left out. Provide basic information such as the name of the disease to everyone first. Later you can talk to each age group in more detail. Make sure you think the conversation through in advance. Anticipate the tough questions and practice your answers. Detailed, appropriate information is available at multiple sources, including the Huntington’s Disease Youth Organization (HDYO).

It is important to know that the experience of talking to kids about HD is almost always less distressing than the anticipation leading up to the talk. All the things you are thinking about and all the fear you experience in having this discussion usually go away once you begin to talk to your kids about HD. Realize, however, this is not a one-time discussion. This topic will need to be revisited to make sure everyone in the family has the most up-to-date information and a chance to ask questions.

Tell Children Information They Can Understand

Gradually share bits of information with children. Like feeding a baby, give kids a small amount at a time and observe whether they take it in. Tell children they will always be loved and cared for. Besides having children worry about you and other family members, a child is likely worried about what will happen to them if you are not available. Assure them their needs will be met. Always leave a conversation with a feeling of hope. Now more than ever there is hope that we are getting closer and closer to treatments and a cure. Let children know that scientists are searching for a cure for HD every day.

Listen to Children

If a child asks questions, listen to what the real meaning is behind the question. Answer their questions simply. It is very helpful to ask children what they think HD is once you have explained it to them. One way is to say, "I need to make sure I did a good job of telling you what HD is. Can you tell me what you heard me say to you?" This provides an excellent opportunity for you to correct inaccurate information or impressions.

You may also want to ask kids directly whether they are worried about you or the affected family member. It is important to recognize that children don't want their parents to think they are concerned about them. They think this will over-burden their parents or make their parents feel sad that the child is afraid about the future. If the child says, "No, I'm not worried", you can say something like, "Well, I want to let you know, when I heard about HD I was worried. I found out that it is normal to feel this way. While we can't make the HD go away we can support each other. So, if you ever feel this way, I want you to know you can always talk to me".

Many parents fear they will say too much. That is also a normal feeling. Parents and caregivers know their children best. Once you see the classic "glazed over" look it is a good time to stop and say, "I have gone over a lot of information today. Do you have any questions so far?" If not, tell the child you will check back with them in a few days and continue the conversation.

Things Not To Do

- **Whatever you do, don't lie.** Lying takes a lot of energy. When you are honest you don't need to burden yourself with the added stress of trying to keep track of what you said.
- **Don't overburden children with a lot of medical details.** Give facts but keep them simple. One helpful tip is to say to a child, "Did that answer your question?"
- **Don't trouble children with financial concerns unless it impacts them directly.**
- **Don't make promises you can't keep.** Telling a child that you promise they will not have HD or promise that you will always be able to care for the person with HD can be misleading. This can lead to profound resentment later on. It is much better to say that you will do everything you can to make sure the family member gets the proper care they need.
- **Don't be afraid to say "I don't know."** All that means is you either need to get the answer from someone else or that no one knows what will happen in the future.
- **Don't push kids to talk.** The goal is to provide a safe place for kids to come back and talk when they have questions. Be one step ahead of kids and tell them you understand they might feel more comfortable talking to their friends however if they have questions or concerns about HD you can connect them to people who talk to kids (like HDYO).
- **Don't trust everything on the Internet!** Tell kids to beware of the Internet and social media. There is a lot of information out there about HD and not all of it is correct. Guide them to trustworthy information if they want to explore on their own (www.HDYO.org).

Ways to Talk to Kids About HD

Feel free to use language familiar to you but be cautious that the child doesn't become confused. If you use the word "boo-boo" for a scrape or cut you might not want to use this to describe HD. It can be better to label HD right away so the child knows this is different. You might say, "Daddy has an illness. It is called Huntington's disease, or HD".

Dealing with Changes

It is important to gradually let children know that there will be changes in what the person with HD can do. Work and driving are two such issues. Letting children know about these changes just prior to a parent stopping work or driving is enough time for them. It will be take time to adjust to these changes but you don't need to worry them too far in advance. Again, let them know their needs will be taken care of even if it is not in the usual manner.

It is helpful to be flexible and have back up plans since behaviors due to HD might cause plans to change. The more you are prepared the easier it will be to have the rest of the family work together. Think through all possibilities and plan for changes even though you are hopeful these "emergency plans" will not need to be used. Let children know there might be changes in family plans that are due to HD as an illness, not due to the person with HD.

Discipline

Continue to show kids you love them by continuing to set limits for them. It is normal to see some acting out when there is a crisis in a family. If children are anxious, fearful, or regress in their behavior, it is a good idea to seek out professional support. Take time to share special moments together as a family and to laugh. Besides creating positive memories, you will also be giving your children a gift. You will be teaching them it is okay to find enjoyment even in the midst of sadness. If you take care of yourself you can then take care of your children and you can teach your children to take care of themselves.

A Silver Lining

Children who are aware that HD is a normal part of their lives may become more self-confident and independent. They may become sensitive to the needs of others and become more responsible. It is possible for children to grow in their ability to understand and love another person despite the differences or limitations. Sharing information with all family members, including children, is important and empowering.•

ABOUT THE AUTHOR:

Dr. Bonnie L. Hennig-Trestman has over 30 years of experience as a clinical researcher and therapist. She has a private tele-therapy practice and serves on the Board of Directors for the Huntington's Disease Youth Organization (HDYO). Her book, "Talking to Kids About HD" has been translated into five languages. She has provided educational lectures on talking to kids about HD as well as various HD related topics to national and international audiences. She is a member of the Huntington Study Group and the European HD Network.

Raising a child with special needs is a complex process, and there are no "easy-to-follow instructions." While the CBT framework of feelings, thoughts and behavior – and how they work together – is helpful, parents often have to rely on their own observations, knowledge about their child, and learn to trust their "gut."

STRESSED OUT?

WHAT PARENTS CAN DO TO HELP CHILDREN MANAGE LIFE

BY VIVIANA LITOVSKY, PH.D.

These days, it isn't hard to find someone who feels "stressed out." The pace and volume of stimulation from family, friends, school, electronics, sports, and social media – just to name a few – is enough to overwhelm anyone, including children and teens with disabilities. Given the demands of life in the 21st century, it is often challenging for families to find balance while maintaining a household and supporting a special needs child.

WHAT IS "STRESS?"

Stress is primarily a physical response, but it can be experienced and expressed in many ways. When we feel stressed, the body thinks it is under attack and enters into a 'fight or flight' mode. Hormones (adrenaline, cortisol and norepinephrine) flood into our bloodstream, getting the body ready for physical action. We feel our heart pound, our breathing becomes faster and shallower, blood flow is diverted to muscles, and important bodily functions – like digestion – slow down. We are ready for a fight… or ready to run.

Not all stress is bad. In fact, stress can be helpful because it can give us the energy needed to tackle a new task, improve performance, or get through a challenging deadline. And the body's response is very adaptive if there is a real emergency, such as a fire. But when we experience stress every day, and throughout the day, it can be damaging.

As an educator and psychologist, parents often ask me for advice on ways to slow down the frenetic pace of living, and for strategies to help their child manage stress. Here's some guidance that can help parents balance their children's needs for positive growth and development while creating opportunities to relax, have fun and enjoy life.

In order to help children cope effectively, it is important to first understand and identify how a child is emotionally and mentally processing life. One useful framework that psychologists often use is Cognitive-Behavioral Theory (CBT), which looks at humans' essential functions within three basic domains: thoughts, feelings, and behaviors.

THOUGHTS

Helping our children learn *how* to think about life is essential to helping them manage stress. There is a Chinese proverb that says: *Give a man a fish and you feed him for a day. Teach a man to fish and you feed him for a lifetime.* The same holds true for thinking. We must teach children and adolescents "how to think" about what they experience. For example, we can teach them a framework to make decisions by showing them how to look at the pros and cons of a situation, or how to gather evidence and seek truth. We can guide them as they form opinions by applying reason and logic. By encouraging children's grit, or tenacity, we teach that perseverance is necessary to be successful.

The more often a child practices these "thinking frameworks," the easier it is to use them successfully. Remember, repetition leads to mastery!

SHELTER FROM THE STORM: “We can help children manage their thinking by acknowledging their tension, offering words of encouragement and providing feedback to improve their strategizing around accomplishing tasks.”

Teaching children and teens “how to think” will also help them structure their decision-making and improve their judgment as they learn to manage aspects of their own lives – and reduce stress.

Because some degree of anxiety is actually necessary to enhance performance, we can help children manage their thinking by acknowledging their tension, offering words of encouragement and providing feedback to improve their strategizing around accomplishing tasks. For example, if the thought of having to complete a school project is anxiety-provoking for a child, parents can help the student break the project down into manageable parts by creating an outline first, or suggest working in short time intervals (15-20 minutes and then hit the “pause” button and return to the project later on).

Once a child has the “foundation” for a way of thinking and problem-solving, we can teach our children values such as kindness, empathy, being good towards others, and discipline – an important “layer” on top of the foundation.

FEELINGS

Acknowledging our children’s emotions is fundamental. Initially, children “feel” more than they think. Feelings are visceral and automatic—we don’t plan them. Sometimes, feelings are expressed in exaggerated ways. Who has not witnessed a child meltdown in the supermarket because they cannot have the candy they want?

Most children do not have an “emotional vocabulary,” so parents can help by watching and listening carefully, then “translating” what they see and hear into “feeling words,” such as “sad,” “mad,” “annoyed,” “frustrated,” “disappointed,” “worried,” etc. Once children begin to learn how to label what they are feeling, we can teach them how to put their emotions into a proper perspective. They need to learn that disappointment and frustration are part of normal life. It is helpful to remind children that everyone experiences frustration (the toaster burned the toast; a sibling got the largest pizza slice; someone spoke rudely to us). It can help to provide a “feeling scale” from 1 (minor distress) to 10 (extreme upset), so children can see that all of life’s experiences are not a 10. We have to help our children decipher what’s typical and what’s not. Therefore, we have to listen carefully to what children are telling us. Sometimes, *how* they say something and *what* they really mean can be different.

For example, 7-year-old Marina, who has ADHD screams at her dad that she needs to drink water right now or she’ll DIE! Well, certainly water is an essential life ingredient but unless Marina has been walking in the desert for days, she needs to self-regulate the “need” for water vs. the “wanting” water instantly. We have to teach “emotional balance,” understanding that people cannot live life in a healthy way when most of their emotional responses are at a level 10.

It’s easier for kids to share their feelings when adults express their own feelings in ways that are not overwhelming the child. It is one thing to disclose feeling nervous or angry about something, but it’s quite another to unload on a child how the boss is very intimidating and may fire the parent! Now the child might add worry about loss of household income to his or her own existing worries. Another way of acknowledging emotions is by telling children that we love them. While we may not *like* what they do sometimes, kids need to know that the parent's love is a rock for the child; always there to be counted on. The reassurance is comforting and soothing for the child. It provides emotional safety which can help them feel safer and share their true feelings more easily.

Sharing feelings should be part of the ongoing dialogue with children and adolescents. Riding in the car is a great time to share thoughts and feelings. You have a captive audience without directly looking at the child when sensitive information is being offered. Many kids need to "try on" their feelings, much like trying on clothing in a fitting room, and get feedback from the parent/caregiver. Parents are the "mirrors" for their children's feelings – we can support, honor, dismiss, sort out, discover, empower, etc., whatever a child is feeling. The key is to listen, and not be too harsh with one's feedback unless the content is so dire or extreme that a more dramatic response may be warranted.

PITCHING IN: "Simple chores around the house help children feel productive and become contributing members of the family and their communities. Responsibilities teach discipline and self-reliance. These two dimensions are good antidotes for stress and anxiety, as long as the to-do list is reasonable for the child's age."

Another important aspect of managing feelings is to help kids learn to self-soothe in a constructive way. For example, if a child is bullied and feels sad and nervous about it, a constructive solution is to offer the child empathy by validating that it does hurt to get picked on repeatedly by others, and then helping to come up with solid strategies (Thought and Behavior domains) to address the issue. Figuring out how to stop being bullied (e.g., reporting the bullying to a parent or safe adult, learning prosocial skills, increasing self-confidence, etc.) is far more effective than carrying the burden by oneself, which can increase the likelihood of social isolation and aggravation to the initial stress of being bullied.

BEHAVIORS

It is important to understand your child's developmental level when looking at behavior, because a child's behavior has meaning and purpose at different developmental stages. For example, it is normal for a toddler to express frustration with a tantrum, but less typical for an 8-year-old.

I often tell parents that typically developing children "morph" or change about every three months. Behaviors that seem incredibly annoying today may soon be gone as the child advances to the next stage of growth. If a child is whiny or demanding, that may soon shift to eye-rolling or heavy sighs when frustration or annoyance sets in. Observation is key in gaining insight about how a child is functioning. For example, is he keeping away from others and barely speaking, or is he overly active to the point of distraction? Behaviors should be varied, purposeful, and goal-oriented.

Because "all play and no work," can be just as stressful as "all work and no play," kids need to have responsibilities and high expectations. Simple chores around the house (even a toddler can pull up a blanket and straighten a pillow to make their bed) help children feel productive and help them become contributing members of the family and their communities. Responsibilities teach discipline and self-reliance. These two dimensions are good antidotes for stress and anxiety, as long as the to-do list is reasonable for the child's age.

The key here is balance. Extremes contribute to high levels of stress and anxiety.

Raising a child with special needs is a complex process, and there are no "easy-to-follow instructions." While the CBT framework of feelings, thoughts and behavior – and how they work together – is helpful, parents often have to rely on their own observations, knowledge about their child, and learn to trust their "gut."

While some stress is normal, there are warning signs that a child or teen is significantly stressed and anxious. Take note when the child is uncharacteristically or persistently acting differently than their usual self (a significant personality change with heightened moodiness or tension). If the warning signs persist across several weeks, despite various attempts to work through the anxiety with the child, it may be time to consult with a mental health professional.

WARNING SIGNS OF UNHEALTHY STRESS IN CHILDREN:

- Moody or irritable
- Crying
- Excessive fear
- Acting out
- Increase in behavior problems/self-injury
- Clingy
- Over or under eating
- Social isolation
- Changes in hygiene or self-care
- Changes in sleep (not sleeping or sleeping a lot)
- Withdrawn
- Abandoning friendships
- Feeling "sick" (headache, stomach ache)

Parents must keep in mind that consistency is important, and as the saying goes, "Rome was not built in a day." Armed with a values-driven framework that offers children the reassurance, discipline (doing one's best every day and knowing that tomorrow is another day), warmth and love they need, we accomplish the goal of raising a "quality human being!"•

ABOUT THE AUTHOR:

Dr. Viviana Litovsky is the Executive Director of Westbridge Academy, a private non-profit school in Bloomfield, NJ, serving students with social, emotional and learning disabilities. She has a private practice in Martinsville, NJ.

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CLOSING THE GAP

PUTTING YOUR BEST FOOT FORWARD

BY STEPHANIE CORKETT, JAMIE VALIS, PHD, AND G. COLALUCE, DPM

Liui'a Nikosiaki, a nine-year-old Special Olympics athlete from the village of Mutiatele Aleipata, in Samoa, had his life changed forever when he was struck by a car and had his left leg amputated. He was given crutches to walk, but as he grew older he outgrew them. His family began carrying him around town and to Special Olympics events. At Fit Feet, Liui'a was referred to a local health services provider that did measurements for an artificial leg. They also provided him with new crutches to use until his prosthetic leg was delivered.

Fit Feet offers podiatric screenings to evaluate ankles, feet, lower extremity biomechanics, and proper shoe and sock gear to athletes. Many athletes suffer from foot and ankle pain, or deformities that impair their performance. In fact, up to 50 percent of Special Olympics athletes experience one or more preventable or treatable foot conditions that can affect their sports participation. Often, these individuals are not wearing the most appropriate shoes and socks for their particular sport. To alleviate these problems, volunteer foot specialists work with athletes to evaluate problems of the feet, ankles and lower extremity biomechanics.

The goal of Special Olympics Fit Feet is to improve the quality of life and long-term health of Special Olympics athletes and people with intellectual disabilities. Fit Feet screenings give athletes, coaches and caregivers a better understanding of any existing and previously unknown foot problems. Fit Feet not only increases access to foot care for individuals with Intellectual Disabilities through free podiatric screenings, but also by raising podiatrists' awareness of the foot concerns of the population and training foot care specialists on working with our population.

DID YOU KNOW?

Fit Feet examinations have found that a large percentage of Special Olympics athletes have untreated foot conditions.

- *50% have gait abnormalities*
- *53% have skin and nail problems*
- *21% have bone deformations*
- *41% of Special Olympics athletes in the U.S. are wearing the wrong size shoe*

THE FIRST STEP: An athlete attends a Fit Feet screening at the 2017 World Winter Games.

PHOTOS PROVIDED BY STEPHANIE CORKETT/SPECIAL OLYMPICS

Marc G. Colaluce, DPM has been a Regional Clinical Advisor for Fit Feet for the past 10 years and has seen, evaluated and treated numerous individuals with intellectual disabilities (ID). Special Olympics interviewed Dr. Colaluce to learn more about how parents can be more aware of foot health in their children with ID.

FEET FIRST: *(Above left)* Dr. Marc G. Colaluce is a Regional Clinical Advisor for Special Olympics; *(right)* Liui'a getting fitted for his new prosthetic leg.

Q. What would you recommend for a parent of a child with disability if they are experiencing pain when they walk?

A. Parents of those with disabilities must realize that communication is important and sometimes we must be creative in doing so. We must observe our children and their actions and find ways to provide treatments to relieve them from pain and dysfunction.

Special Olympics
Fit Feet

Fit Feet was developed through Special Olympics' collaboration with the American Academy of Podiatric Sports Medicine. Many Special Olympics athletes suffer from foot and ankle pain or deformities that impair their performance. Also, athletes are not always fitted with the best shoes and socks for their particular sport. During Special Olympics competitions, volunteer health care professionals examine athletes' feet and ankles for deformities, and also check for proper shoes and socks.

In those with ID, we must be aware that there are many situations where they do not respond to pain and do not always tell a parent, caregiver, or physician. We must watch for subtle signs of pain or discomfort. Gait changes, limping, walking slower than usual, not keeping up with others, stumbling and falling without cause, not wanting to keep shoes or socks on, are all examples of how your child could manifest pain.

Once a painful situation is realized then the appropriate care must be arranged. In Florida where I practice, Special Olympics Florida has created a web-based database of clinicians that are available to treat and respond to those with disabilities that we have given specific training and knowledge regarding typical foot issues found with those with disabilities. I have found that by contacting local organizations like Special Olympics, they can assist you in finding the correct avenues for assistance and treatments.

We must understand that there is a typical mindset that those with disabilities are all "children" but we must realize that those with ID are living much longer lives. With all of our population living longer, we may also see abnormalities that are typical within older adults, like arthritis pain.

Q. How often should you visit a podiatrist?

A. If you have poor foot health, visits with your Podiatrist will be needed until resolution or the diagnosis is managed. We must understand that the legs, ankle, and feet could include dermatological, neurological, vascular, muscular, skeletal and bio-mechanical manifestations – and your Podiatrist would be the place to start evaluation and treatment. A Podiatric provider can assist with non-invasive and when needed, invasive treatments, ranging from assistance with new shoes, shoe inserts or bracing. Examples of more involved treatment could include wart, toenail, or bunion surgeries. Patients who have chronic diseases like diabetes need to be seen more often as foot health is adversely affected by diabetes..

FOOT CARE TIPS

To prevent major foot problems, I suggest the following tips:

- *Perform a self or assisted foot examination every day. Look for blisters, redness, and ingrown toenails.*
- *Change and replace your shoes often if the tread/soles wear down. Make sure you wear the correct size and width.*
- *Wash and clean your feet daily, and make sure to thoroughly dry your feet and in between your toes.*
- *Socks made with a blend of cotton and acrylic are the best at keeping moisture under control.*
- *Protect your feet from extreme hot and cold temperatures. Don't walk barefoot.*
- *Trim and file your toenails once a week. Remember to cut straight across the toenail.*
- *Topical medicine should be prescribed and applied as directed.*
- *Moisturize your feet if you have dry skin with creams or lotions.*

We, as parents and caregivers, must listen and observe our children to assure they receive the highest quality of care for all of their physical and psychological needs. By knowing how to check and address any foot issues that may arise, you can ensure your athlete will be able to put their best foot forward in their endeavors.•

EP MAGAZINE EDITORS' NOTE:

Fans, athletes, coaches, families and supporters of Special Olympics can qualify for a free yearly digital subscription to *EP Magazine* by contacting us.

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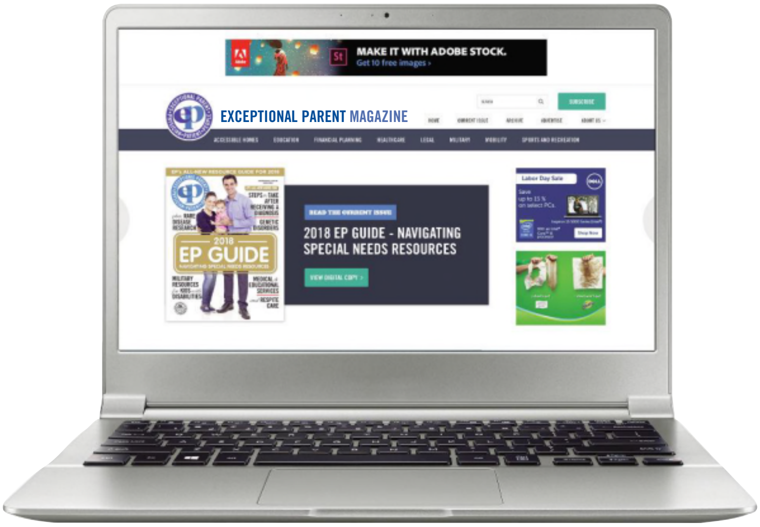


EP's Innovative New Digital Strategy

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

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

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

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

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

ADVERTISERS: *Reach a growing audience on EP's all-new website and strategically target your consumers. Our competitive advertising rates offer top-quality results for an excellent value. Our team of designers and developers are ready to create digital marketing campaigns that effectively communicate your brand's message to our dedicated online audience.*

CONTACT: Faye Simon at fsimon@ep-magazine.com

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

LIVING WITH AN INVISIBLE DISABILITY

BY SHERRI CONNELL

The mission of Invisible Disabilities Association (IDA) is to encourage, educate and connect people and organizations touched by illness, pain and disability around the globe.

Like most little girls, I woke up each day with excitement to see where I could go and what I could do! I loved to ride my bike, roller skate and ride horses. I looked at my life ahead as a blank slate, eager to see who I would be! But I didn't want to wait!

So, at 10, I got my first job as a caretaker for nine horses in a stable, at 13 I worked at a pet store, at 14 I was a cashier for a clothing store and by 18, I was given the keys to manage an upscale children's store downtown.

In high school, I worked, was a cheerleader, pom-pom girl and sang in the choir. I put myself through college studying art and theatre, working multiple jobs, cheerleading and singing and dancing

PHOTOS PROVIDED BY VICTORIA SHOCKLEY

in musicals. My most favorite job ever at was at America West Airlines, where I did ticketing, baggage and even operations for the planes and pilots. I only slept a few hours a night, then I got up to do it all over again.

I also acted in commercials, sang in bands, choirs and modeled in fashion shows. I entered several pageants and modeling contests (winning 16 of them) and I was an Accounts Manager for a job service agency. I also obtained a Bachelor's Degree in Human Management, a Bachelor's Degree in Business and Minor in Liberal Arts. I absolutely loved every moment of my very busy life!

It sounds like an incredible life of adventures, doesn't it? Well, it was! However, what I have not told you yet is that from the time I was 14, I started battling chronic illness.

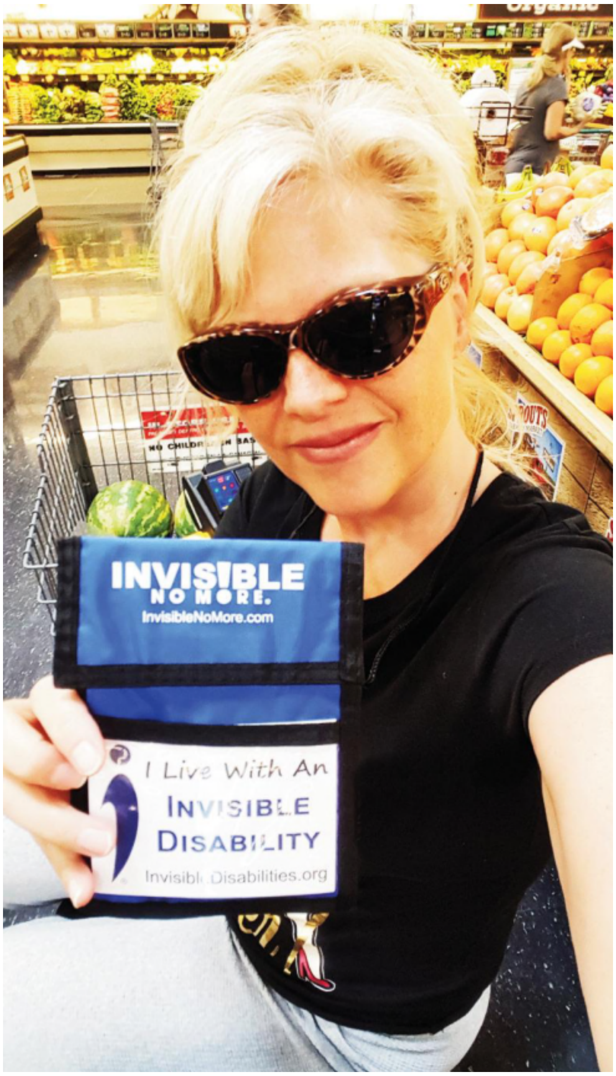
You see, I was on a trip to Arkansas with family. At the time, there was a "Tick Alert" in the news, warning people that cows and horses were dropping over dead from tick bites. Being kids, my brother and I did not let that stop us. He wanted to go fishing and I just wanted to be with my big brother.

When we returned home, I got a horrible fever and hives from head to toe. Nobody knew why, but from that moment on, I started having chronic headaches and infections like strep, flu, bronchitis, pneumonia and by 19, I started having bouts with paralysis.

Yet, I was determined not to let any of it get me down or get in the way of my life! So, I went to work, to school and to the theater, feverish, throwing up, coughing and very ill.

At 27, when I was planning out my Master's Degree and had a great job lined up for a wonderful program, my left leg from the thigh down became paralyzed. I continued to work for months, dragging my leg around and using a stool with wheels to get around. However, the paralysis moved into my right leg and moved up to my ribs on both sides.

I was hospitalized, thinking maybe I had just pinched a nerve in the car accident I had two years earlier where I had a severe head, jaw, neck and back injury. I was in excruciating pain and could no longer get around without a wheelchair. After a week of tests and being on IV steroids, I was diagnosed with Progressive Multiple Sclerosis (MS).



HIGH VISIBILITY: IDA is a beacon that stands for us and brings us together. After all, we could all certainly use a little less judging and a lot more love and compassion in this world!

Honestly, I wasn't too worried. I had fought being sick all my life and figured I would be back to work in a couple of weeks. Yes, they said I would never walk again, but I knew I could still work and sing from the chair. So, what could stop me?

Thankfully, after lots of hard work and physical therapy, I regained feeling in my legs and took my first steps with crutches. I could not walk far or stand for very long, but I believed I was winning this battle and this was literally my first step back into my life!

Nonetheless, no matter how many doctors I went to, or how many medications, therapies, diets and supplements I tried, I still could not budge the disabling, bone-crushing fatigue, horrific pain and unbearable cognitive dysfunctions. Not only could I not return to work, I was now unable to even care for my daily needs. My illness became my new full-time job, filled with tests, treatments, insurance claims and struggling just to get my hair washed or something to eat.

One year later, I was diagnosed with Lyme Disease, which was traced back to tick bites when I was 14. It was brought to my attention when I was in the hospital, the steroids shut down my immune system and the Lyme took over my organs, brain and cells, leaving me literally fighting for my life ever since.

Nevertheless, when people saw that I could move my legs again, they started questioning why I was not back to work. They did not understand that it was not the inability to walk or using a wheelchair that kept me from what I loved. They did not understand the disabling symptoms that came with the MS, Lyme and injuries. Furthermore, they did not understand that I was scurrying to find an answer, because I wanted my life back more than they could possibly imagine!

It was bad enough to lose my career and ability to do the things I loved, but now I also had to contend with people's lack of understanding and disbelief. They would say things such as, "but you look fine," "maybe you should just try harder," or "you could go back to work if you really wanted to."

Who did they think they were talking to? Missing work, riding horses and living my life was devastating every single day! Didn't they know how much I had fought all my life, how I had huge plans for my future and how desperately I was trying to get it back?

Yet, no matter how hard I tried to explain, people left me in agony trying to answer their misgivings and often well-meaning, but extremely hurtful comments. As a result, I began writing in my journal, trying to make sense of how I could explain to people what they could not readily see from the outside.

I grappled with creating a term to use that would encompass what I was living through and be descriptive of the debilitating symptoms that others could not easily see. Then it came to me! I screamed, “I know what to call it! What I have is an ‘invisible disability!” Yes, that was it! I had never heard this before and nobody else was talking about it either! It is a disability that is invisible!

Then, my husband, Wayne, had a great idea! He offered to put some of my writings up on this new thing called the internet. He said when someone questioned me, instead of having to explain, I could just hand them a card and say, “check out the website!” Genius!

We figured we would get a few views here and there from people we gave the cards to, but something else was about to happen! We began getting a flood of emails from patients around the world saying, “Thank you for putting into words exactly what I have been trying to say to my friends and family!”

Many told us stories of spouses, siblings and parents asking for forgiveness for how they had responded to what they were going through. Wow! We had no idea others were dealing with the same hurdles with loved ones! I thought it was just me, and the people in *my* life.

Wayne quickly developed a passion for *all* living with illness, pain and disability. Soon after, he founded the Invisible Disabilities Association (IDA). Their mission is to encourage, educate and connect people and organizations touched by illness, pain and disability around the globe.

Wayne and the IDA Team bring awareness, education and support through the website, pamphlets, articles, radio and television interviews, events, programs, Brain IDEAS Symposiums, Invisible Disabilities Week Online, Invisible Disabilities Community and social media! IDA also honors individuals and organizations making a difference in the lives of people living with disabilities, by presenting their awards at IDA’s Annual Gala. In addition, they produce dozens of YouTube videos featuring personal stories, organizations, special guest speakers, conferences and events!

Wayne also compiled several of my writings into a book called *But You LOOK Good!* The book helps loved ones better understand the nature of invisible disabilities with tips on what to say, what not to say and how to be a source of support. IDA has published the book and has distributed over 33,000 copies around the world, with all proceeds supporting IDA’s ongoing programs.

It is so exciting to see millions, like me, find support through IDA! We are often isolated and feel alone, but IDA is a beacon that stands for us and brings us together. Now people around the world can talk about *their* invisible disabilities, which helps paint a picture for loved ones and society as a whole. What’s more, when we hear about relationships being reunited, we celebrate those who have taken the step to see by listening. After all, let’s face it. We could all certainly use a little less judging and a lot more love and compassion in this world!.•

ABOUT THE AUTHOR:

Sherri Connell was a cheerleader, singer, dancer, actress, model and accounts manager. She obtained two Business Degrees and a minor in Liberal Arts. Sherri was planning out her Master's Degree when she lost her career and ability to care for her own daily needs. Learn how Sherri's story became the inspiration for the Invisible Disabilities Association (IDA), an organization that reaches around the world to millions living with debilitating conditions. Sherri and her husband, Wayne, are co-author’s of the book, “But You LOOK Good!” in which over 33,000 copies have been distributed world-wide. All proceeds go to IDA. www.InvisibleDisabilities.org

Seriously. Who's Already Planning for the Next School Year in May?

BY JACKIE SCHWABE

You might be asking yourself if anyone is seriously planning for the next school year before this year is even over. Maybe you're thinking that any person doing that must be very anal retentive or a have control issues. If you are asking yourself any of these questions when presented with the fact that someone is indeed planning for next school year in May, consider yourself lucky. You are lucky because, chances are, you don't have a child with special needs.

PHOTO PROVIDED BY JACKIE SCHWABE

Please don't get me wrong. My children, all four of them, are pretty darn amazing. Our daughter, who was given an autism diagnosis in 2013, is exceptional in many ways. For example, she cannot tell a lie. I asked her how I looked in a new dress once and she told me my butt looked big. She is also lacking in the ability to judge others on insignificant features. I asked her if she liked "ugly fish" in a game of what do you like the other day; she told me "There are no ugly things!" She apparently does like ugly fish.

I will also admit, full heartedly, I am anal retentive. I remember when all my VHS tapes were in alphabetical order.

We Don't Have the Luxury of Assuming

So why am I planning for next year this year? What things could I possible be planning for? Well, we don't really have the luxury of assuming anything in our family. We cannot assume that our daughter will not have a major meltdown entering the school and finding out she has to go to a new classroom. Nope, we cannot assume that the IEP that was created together with the school will be followed by a new teacher that was not on the team this year. We cannot assume that they will look at or know her goals for the year or the time and setting of her additional resources, like speech or occupational therapy.

Unfortunately, our sweet little angel is scared of everything. She fears change. Change can cause her anxiety, panic, and even a meltdown if we really forget that assuming is not one of our luxuries. But that's okay. Because in our house, fear is just an indication that we don't have a good enough plan yet.

> There is too much going on these days for me to manage it all myself. **I needed a strategy to ensure that I did what I committed to for my daughter, and that her school did what they committed to as well.** So, I started a company and created a software that could help me help myself – and my little girl.

Already Planning for Creative Competence

Yeppers. If she is scared, then we know we need a plan. It is brilliant really. Our bodies and brains, most often regardless of what diagnosis we are given, are amazing at giving us signals that something needs to happen differently. So, when she is scared it is just her body triggering her, and us, to give her a new strategy that allows her to not be afraid.

We plan for creative competence. Essentially that means we do assume she will be able to do it. Yet, we plan for the worst-case scenario, that she won't. That's creative competence. She is afraid of new people, so we will meet her new teacher before the school year ends and introduce them. Yep, before the year ends since summer vacation isn't exactly the optimal time to get ahold of teachers. No, really, try it once.

We can create a school station for her as well. You know, that super special place that has all the backpacks, lunch boxes, and school supplies? If we don't wait to introduce the landing zone until the first day of school, she also knows part of that routine. It is one less thing she doesn't need to be scared of. Well, she will still tell us it is scary, but she won't meltdown - so I'll take what I can get.

Planning for Strategic Compliance

I admit that she isn't the only one that is scared of the new school year. Sometimes all the things that we have to do, advocate for, and remember really get overwhelming. Things like ensuring that her IEP is followed, that everyone knows the goals, and that we she is getting the accommodations that were agreed on can be daunting and exhausting.

Where fear is present, our family plans. In my case, I am an entrepreneur, mother of four, and I help care for my Mom remotely. There is too much going on these days for me to manage it all myself. I needed a strategy to ensure that I did what I committed to for my daughter, and that her school did what they committed to as well. Solutions to manage my complex family caregiving situation didn't exist. So, I started a company named MindLight, LLC and created a software that could help me help myself – and my little girl.

Executing Strategic Plans

I didn't realize that parenting was going to need the same type of effort that was required to run a company. Yet, it is in our family. So, we needed our family to be a team. We needed to have a plan, tasks, and calendar that we could all use and see. We needed to be able to exchange information quickly, and in the case of personal medical information, safely. The app by MindLight, LLC does just that. I never wanted anyone to feel as helpless as I felt when I started our journey. I figured this was at least a start.

Seriously Planning for the Next School Year

So yes, we are seriously planning for the next school year, in May of this school year. We put all our tasks in the family calendar. We assign tasks to each other. Since we have done it before we don't forget anything now. We can exchange therapy notes or teacher notes without too much work. It does gives us a tad bit more control.

Frankly, at the end of the day, or the beginning of the next school day, we feel like we made every effort to help our little girl feel less afraid and more in control too.•

ABOUT THE AUTHOR:

Jackie Schwabe is CEO of Mindlight, LLC and Vice President of Leadership Research at North of Center. She is a certified Caregiving Presenter, Certified Caregiving Consultant, and Certified Caregiving Educator. She received her BA in Management Computer Systems from the University of Wisconsin – Whitewater and her MBA in Technology Project Management from the University of Phoenix. She has been active in the area of healthcare integration, healthcare IT, telemedicine, product development, and product management for over 20 years. A mother of four children, one with autism, she co-founded MindLight, LLC as a way to technologically help caregivers. She joined North of Center because she saw a way to use the Communication-Based Leadership framework to help others.

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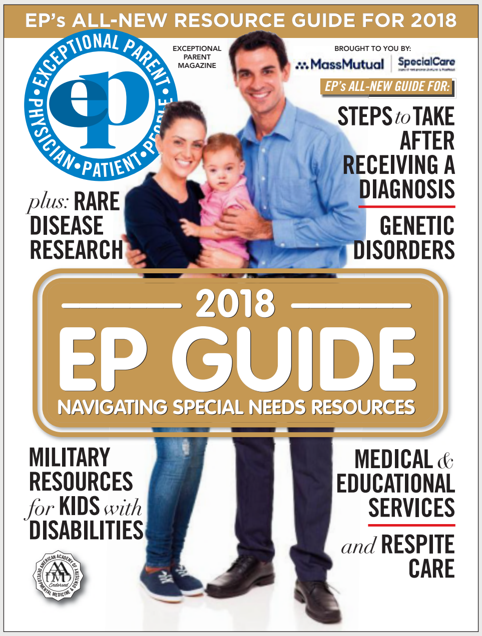

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FROM OUR FAMILIES... TO YOUR FAMILIES

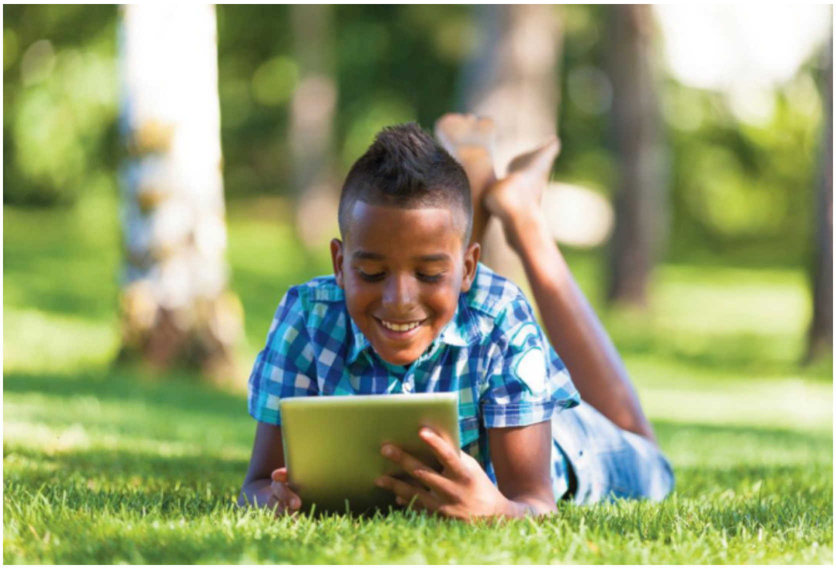
MILITARY SECTION

ARMY
NAVY
AIR FORCE
MARINES

MILITARY LIFE

ON YOUR MARK, GET SET, READ!

Morale, Welfare and Recreation develops all kinds of enrichment programs to support force readiness and military community. One such program is the Department of Defense-MWR Summer Reading Program (**www.ila.org/dodsumread**). The program's theme this year is "Reading Takes You Everywhere." Reading fosters the imagination and can open a window to the world. New and exciting activities include crafts, STEM events, recommended reading lists, incentives, films and more for children, teens and parents. Enroll in this year's summer reading program and help your child explore, discover and experience new people, places and things.



ENCOURAGE SUMMER READING

The mission of the Department of Defense-MWR summer reading program, through a contract with the Illinois Library Association iREAD Reading Programs, is to provide the resources and experiences to bridge the summer gap, while inspiring literacy and life-long learning. The benefits of summer reading are clear:

- *National research finds that students who participate in the library summer reading programs scored higher on reading achievements tests at the beginning of the next school year than those who did not participate.*
- *Avid readers of all backgrounds are higher achievers than students who seldom read.*
- *Skillful, critical and prolific reading is one of the most important personal habits that leads to a successful academic career and happy, productive life.*

Plus, reading is fun for the whole family. Reading can lead to priceless conversations, spur a child's imagination and inspire young readers to explore creativity and design new worlds. Sign up for the Summer Reading Program: contact your local Morale, Welfare and Recreation (**www.militaryinstallations.dod.mil/MOS/f?p=MI:ENTRY:0**) installation library.

EXPLORE YOUR INSTALLATION LIBRARY

The Department of Defense and MWR oversees the management of 207 libraries (**www.militaryonesource.mil/-/explore-the-library**) on military installations, which provide much more than aisles of books. Check your installation library to see what events are offered. These could include activities, graphics, crafts, reading lists, incentives, films, and more for children, teens and parents. Discover what's in your installation library.

TAP INTO THE MWR DIGITAL LIBRARY

If you're a member of the National Guard or reserve or don't have access to a local installation library, you can still participate in the Summer Reading Program virtually. Learn more at **https://dodvirtualsrp.beanstack.org/reader365**. The MWR Digital Library (**www.militaryonesource.mil/-/morale-welfare-and-recreation-digital-libra-1**) can help you support your summer reading goals, giving service members and families access to eBooks, audio books, digital magazines, genealogy resources, digital newspapers, journals, tutoring services and more. The digital library service is a particularly helpful benefit for those military families who may not have access to installation libraries.The digital library service is available through your service branch:

- *Army digital library (A library account is required to access digital resources.)* **http://mwrlibrary.armybiznet.com**
- *Marine Corps digital library* **http://mccs.ent.sirsi.net/client/en_US/default**
- *Navy digital library* **https://www.navymwr.org/libraries**
- *Air Force digital library* **http://www.myairforcelife.com/libraries**

LEARN MORE

Visit the following links to learn more about the MWR Digital Library and other library and reading resources:

- *Department of Defense - MWR Summer Reading Program* **www.ila.org/dodsumread**
- *Morale, Welfare and Recreation Digital Library* **www.militaryonesource.mil/-/morale-welfare-and-recreation-digital-libra**
- *DoD MWR Library Resources* **www.militaryonesourceconnect.org/achievesolutions/en/militaryonesource/Content.do?contentId=27777**
- *From Audiobooks to Academic Research, the Digital Library Has It* **www.militaryonesource.mil/-/from-audiobooks-to-academic-research-the-digital-library-has-it**
- *Explore the Library* **www.militaryonesource.mil/-/explore-the-library**
- *Libraries – the Essentials* **www.militaryonesource.mil/-/libraries-the-essentials**

– Military One Source

VACATION FIRST CLASS USING MILITARY LODGING

You've worked hard and it's time to enjoy a little R&R. Military families are eligible to use military lodging around the world, ranging from cottages on the beach to world-class resorts or recreational lodging facilities. You have many options and destinations include popular resort towns, big cities, oceanfront getaways, mountain top retreats and overseas locales.

WHERE CAN I GO?

No matter where the military sends you, a military lodging facility can help you vacation in style. Sometimes the toughest part of planning a vacation is deciding where to go. If you want some inspiration, here's just a sampling of what you can find around the world.

EASTERN UNITED STATES

- **Shades of Green Resort**, located at Disney World in Orlando, Florida, and operated by the Army, offers all the perks of a Disney resort. Purchase your Disney tickets, and then book your Shades of Green room by calling 888-593-2242. www.shadesofgreen.org
- **Fort Fisher Air Force Recreation Area** near Cape Fear, North Carolina, offers beach cottages and a lodge. Call 910-458-6549 for details. http://ftfishermilrec.com
- **The Coast Guard** maintains coastal cabins across the country. Enjoy a summer stay on Cape Cod or one of many other options. Cabins are available to all active-duty service members, their families, reservists and retirees. Learn more at www.dcms.uscg.mil/Our-Organization/Assistant-Commandant-for-Human-Resources-CG-1/Community-Services-Command-CSC/MWR/Coast-Guard-Lodging/

WESTERN UNITED STATES

- **Seward Resort** in Alaska is open year-round to military families. Call 800-770-1858 to make a reservation. www.sewardresort.com
- **The Marine Corps' Big Bear Recreation Facility** is near ski resorts in Big Bear, California. In the off-season, it offers mountain biking, hiking and fishing. Call 858-577-4126 or visit www.mccsmiramar.com/big-bear-cabins
- Waikiki Beach in Hawaii is home to the **Hale Koa Hotel**, operated by the Army. Reservations may be made up to a year in advance. Call 800-367-6027. www.halekoa.com
- **Kilauea Military Camp** is a joint services recreation center in the Hawaii Volcanoes National Park. It offers mountain cottages and scenic tours. Call 808-967-7315. http://kilaueamilitarycamp.com

CENTRAL UNITED STATES

- The **Army's Lake of the Ozarks Recreation Area** in Missouri features lakefront cabins and motel rooms with boat and Jet Ski rentals. Call 573-346-5640 to reserve your space. https://leonardwood.armymwr.com/us/leonardwood/programs/lake-ozarks-recreation-area-lora

ASIA

- In Japan, the **Okinawa Okuma Joint Services Recreation Center** offers log cabins, hotel rooms, campgrounds and a number of activities. www.kadenafss.com/okuma
- The **Dragon Hill Lodge** is a first-class hotel in Seoul, South Korea, with resort amenities and shopping nearby. Visit Dragon Hill Lodge for more information. www.dragonhilllodge
- The **New Sanno Hotel** is a joint services facility operated by the Navy in the heart of Tokyo. Visit New Sanno Hotel for more details. www.thenewsanno.com

WHO IS ELIGIBLE

- Active-duty service members
- Military family members
- Military retirees
- National Guard and reserve members
- Department of Defense civilians

WHAT DO I NEED TO KNOW?

- Some military lodging properties fill up fast, so do your research and make reservations as early as you can. Reservation requirements vary by facility and duty status.
- Some military lodging facilities give priority to active-duty military members on orders, but not to leisure travelers. Rules vary by service branch and lodging facility.
- Pet policies may vary. If you plan to travel with your pets, make sure furry guests are welcome before you book.
- Mailing addresses are sometimes listed on military lodging websites or brochures. Request a GPS-friendly address when you make your reservation to help you reach your destination.

HOW DO I PLAN MY GETAWAY?

- Do your research first. Make sure your destination is available.
- Take a look at all of your exciting options. Visit Army Morale, Welfare and Recreation (www.armymwr.com), Marine Corps Community Services (www.usmc-mccs.org/services/lodging/recreation-lodging/), Navy Gateway Inns & Suites (http://ngis.dodlodging.net) and Air Force Services (http://af.dodlodging.net).
- Book as early as you can – especially if you want to vacation during peak travel times – to make sure popular destinations have openings. Keep in mind some facilities prioritize reservations by branch of service, duty station or status.

Eligibility and reservation requirements vary from one facility to the next. Call Military OneSource at 800-342-9647 to learn more about your destination of choice. You can also use your Morale, Welfare and Recreation and installation resources to plan your getaway. Visit your Information, Tickets and Travel (www.militaryonesource.mil/-/information-tickets-and-travel-your-key-to-fun) office to learn where you can enjoy military discounts and entertainment.

– Military One Source

In the Trees

I'm learning that sometimes we need to be reminded that if we protect our children too much and we hold on too tight, we hinder their progress. I'm grateful that James convinced Mark and me to let Broden go.

"Broden, take a step when you're ready." While hooked on to a line in the trees, Broden took his first step on the obstacle course while grabbing a hold of the support lines next to him. He continued to take another step, then another. Broden did not hesitate. He had been watching from the ground for three years and he was ready, even though we, his parents, were questioning if we were pushing him too far and setting him up for failure.

Last month was Broden's twelfth birthday. Since we have been at Fort Benning, we've taken the boys to Callaway Gardens to hike and to visit the Butterfly Pavilion. Broden's favorite part of Callaway is Treetop Adventures, a series of obstacles in the trees laced with opportunities to zip line. Broden enjoys walking along the path in the woods while stopping to watch people meander above him as they work their way through each obstacle and then zip lining to the adja-

PHOTOS PROVIDED BY SHELLY HUHTANEN

cent tree. Most of the time, our family is prodding Broden to keep up the pace during a walk, but walking under the Treetop Adventures, we are usually trying to keep up with him.

With this being our last year at Fort Benning, Mark and I decided to see if Broden could give it a try. We called ahead to see if there were opportunities to modify the course due to his severity on the spectrum. The staff told us to bring him to Treetop Adventures to see what he can do. My parents were here visiting for his birthday and they could tell Mark and I were uneasy that morning. We were taking a leap of faith, faith in the staff at Callaway Gardens and also faith that Broden would be fearless.

> Before I could weigh the pros and cons of whether to let him try the big course, Mark looked over at me and said, “We’re going.” My mom and I looked at each other and gasped, “He’s doing it. He’s really doing it.”

Once we arrived, the staff was reminded of our phone call the day before and that Broden would need quite a bit of assistance. Mark, Hayden, and my father decided to do the adventure with Broden in the hopes of encouraging him through it. My father said, “I don’t feel right about encouraging the boys to do this, unless I do it too.” My mother and I decided to stay on the ground to document with video and pictures and quietly agreed to one another that it was better they go, than us. The closer we got to the obstacles, the more intimidating the obstacles became.

The briefing started after they were given their harnesses and gear. While explaining to the group how to zip line and use their gear, the briefer said, “Everyone should go through each obstacle individually.” Mark looked back at me and shook his head while I shook my head back at him. We decided at that moment we were pushing Broden too far. When the briefing was over and the group did a test run through the zip line, Mark went over to the supervisor, James, and explained to him that this was probably not a good fit for Broden.

After the rest of the group climbed into the trees to start the obstacles, James encouraged Mark to let Broden try the “test zip line” on his own. Once Broden was hooked in and told to let his body relax in the harness, he started to scream. His scream caused the rest of the staff to run towards the test line. A staff member approached me and said, “I’m the one who you spoke with yesterday.” She could tell I was nervous as I tried to convince her that this was not going to work. She said, “Ma’am, James knows what to do. Don’t worry.”

After Mark spoke with James, he ran over to me and said, “James assured me he’s going to get Broden through this course.” I was skeptical until I watched James and how calm he was with Broden. James pulled out some more equipment and hooked it up to the line. He asked, “Broden can you sit on my knee?” Broden complied and sat on his knee while James zip lined with him to the other tree.” Broden had his arms out stimming while he squealed with delight.

Before I could weigh the pros and cons of whether to let him try the big course, Mark looked over at me and said, “We’re going.” My mom and I looked at each other and then stared at them as they climbed up the ladder into the tree. My mom opened her mouth and gasped, “He’s doing it. He’s really doing it.” For each obstacle, James would start with asking Broden, “Are you ready?” and then Broden would stretch his foot out ready to be challenged once again.

I’m learning that sometimes we need to be reminded that if we protect our children too much and we hold on too tight, we hinder their progress. I’m grateful that James convinced Mark and me to let Broden go. Our fear of him not making it through was causing us to hold on too tight because we want to keep him safe and for him to not experience fear. Maybe that is what is so difficult for parents. We want our kids to succeed and know they can do whatever they set their mind to, but we also don’t want our children to experience fear and hardship. That day, we let go and Broden did it. Instead of walking under the tree tops that day, he was the one in the trees, looking down on everyone else. •

PUZZLES & CAMO

Shelley Huhtanen is an Army wife with two children, one with autism, whose husband is currently stationed at Fort Benning, GA. She is an autism advocate and currently the parent liaison for the Academy for Exceptional Learners.

PRODUCTS AND SERVICES

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Wade Spann
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