PLUS: UNITED STATES MILITARY SECTION

EXCEPTIONAL PARENT
MAGAZINE
MARCH 2025
$14.95

VISION, HEARING & SPEECH ISSUE:

THE IMPACT *of* SINGLE-SIDED HEARING LOSS

INSIDE • A CLEARER VIEW:

KERATOCONUS *and* DOWN SYNDROME

SPEECH THERAPY:

LITTLE VOICES, BIG POTENTIAL

PLUS:

ADVANCING HOME HEALTH CARE

DEAF & HARD OF HEARING TEENS:

GROWING SELF-DETERMINATION AND SELF-ADVOCACY SKILLS

U.S. ASSOCIATION OF BLIND ATHLETES SOCCER:

BLINDNESS IS NOT THE OBSTACLE

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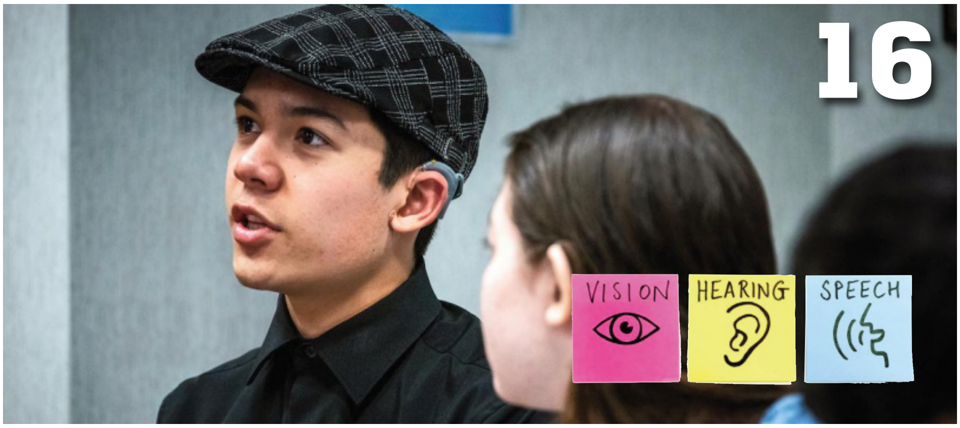
MARCH 2025 VOLUME 55 ISSUE 3



VISION, HEARING AND SPEECH

FEATURES

ON OUR COVER

Deaf teenager Tenzin Lang participates in a group discussion during a student program offered by the Alexander Graham Bell Association for the Deaf and Hard of Hearing. Children who have vision, hearing and/or speech disabilities must identify and develop strategies that will help them face and overcome their individual challenges, including becoming stronger self-advocates. *Coverage begins on page 13.*

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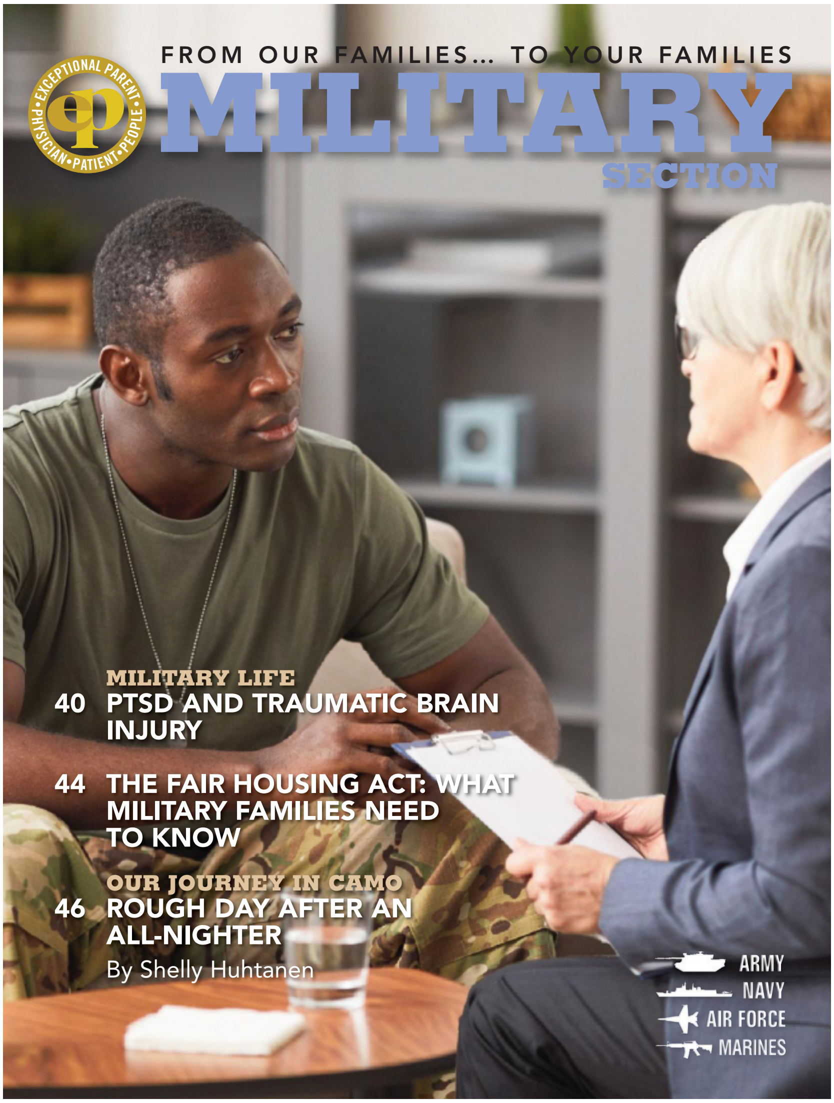

ARTICLES ON DISABILITIES AND SPECIAL HEALTHCARE NEEDS SPANNING ALL AGES

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Exceptional Parent Magazine is a print and digital magazine that provides information, resources and inspiring stories on disabilities and special health care needs for all ages, from infancy to elderly.

Exceptional Parent Magazine's audience and contributors consist of individuals with disabilities, parents, caregivers, families, education, medical, legal and financial professionals.

Each issue includes a special Military Section that addresses the unique challenges of military families caring for a family member with a disability.

The digital version is free to all. Sign-up is easy by clicking on **EP for Free** at **www.epmagazine.com**

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Loud and Clear

Developing strategies that will help overcome vision, hearing and speech challenges can lead to rich and fulfilling lives.

Parents as well as education and healthcare specialists play an important role in assisting children with vision, hearing and/or speech disabilities. Helping the children develop strategies to deal with their individual challenges can allow them to live fulfilling and productive lives.

In her article, Christina Kreml, special education teacher and mother of a special needs daughter writes, "Speech therapy is hugely important in the lives of children who need it, and parent involvement can truly enhance progress in this area." Athlete and advocate Oseas De Leon says in his article, "From an early age, my parents instilled in me the importance of learning and self-reliance. They ensured that I had access to a quality education, not just academically, but also in navigating the world as a blind person."

> Parents who are strong advocates for their children with disabilities can have a significant impact on their lives.

Parents who are strong advocates can have a significant impact on their children's lives. In the story of her journey, we learn that Sinclair Darr, a young woman with Down syndrome, underwent a special procedure for keratoconus. Her vision problems have markedly improved due to the diligence of her mother Kimberly and the compassionate care of vision specialists.

In our cover story, "Growing Self-Determination and Self-Advocacy Skills in Teens with Hearing Loss," the authors emphasize how essential it is for children with disabilities to voice their own needs and wishes. "While developing good advocacy skills is important for all children, it is a critical skill for children with hearing or vision loss." Their voices need to be heard loud and clear!

Feature articles this month include an excerpt of an upcoming book by Jordan Jankus, an informative article on early childhood developmental milestones, and a piece on home health care for children with complex medical needs.

The positive feedback about the "outstanding" quality and helpfulness of *EP Magazine* reinforces the time and love we put into it. Thank you to the readers who have taken the time to email their kind words.

You can always contact me at **epmagazinevp@gmail.com** or **fsimon@epmagazine.com**. Follow us on **facebook.com/exceptionalparentmag**, Instagram **@epmzine** and **x.com/epmzine** and share our posts. It's easy to subscribe and get "EP for Free." Just visit our homepage **www.epmagazine.com** and click EP for Free Sign Up!

Faye Simon

Editor In Chief

THE EDITOR IN CHIEF'S DESK

Faye Simon is a certified pre-K–8 teacher with a wide range of educational experience. She has worked in deaf/blind and infant stimulation programs, taught K–2 in public schools, and was a Head Teacher and Parent Coordinator for Head Start. She is Founder and President of the volunteer-run IES Brain Research Foundation. Faye has been interviewed about *EP Magazine* and IES Brain Research Foundation multiple times including on: Mrs. D's Corner, SFN Dad to Dad Podcast, Oscar Mike Radio, Wreaths Across America Radio, Shana Siegel's Aging Answers, and Able Today Show.

Information and Support for the Special Needs Community

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WHAT'S HAPPENING

MARCH IS DEVELOPMENTAL DISABILITIES AWARENESS MONTH, HIGHLIGHTING ACHIEVEMENTS AND INCLUSION

Developmental Disabilities Awareness Month takes place throughout the month of March. It is a time for individuals, organizations, and communities to come together to educate, advocate, and celebrate diversity and inclusion.

The month kicks off on Saturday, March 1, and concludes on Monday, March 31. Developmental Disabilities Awareness Month began with President Ronald Reagan's Proclamation in 1987, which sought to bring attention to the contributions of individuals with developmental disabilities and the challenges they face. This effort built upon decades of advocacy by disability rights organizations and individuals, including pivotal moments like the passage of the Americans with Disabilities Act (ADA) in 1990. Since its inception, Developmental Disabilities Awareness Month has grown into a nationwide campaign encouraging communities to promote understanding, remove stigmas, and foster accessibility and equity for all.

CLASS ACT: Teachers can help create inclusive communities by encouraging students of all abilities to play together and participate in daily life.

Developmental disabilities are a diverse group of conditions that may affect physical, cognitive, or social development. These can include (but are not limited to):

- *Autism Spectrum Disorder (ASD)*
- *Attention-Deficit/Hyperactivity Disorder (ADHD)*
- *Intellectual Disabilities*
- *Learning Disabilities*
- *Cerebral Palsy*
- *Down Syndrome*
- *Epilepsy*
- *Language Disorders*
- *Sensory Disabilities (such as hearing loss and vision impairment)*

Teaching children about developmental disabilities during this month can foster empathy, understanding, and an appreciation for diversity. Here are some tips to help:

- **Highlight role models:** Introduce kids to influential figures with developmental disabilities, such as artist Judith Scott or self-advocate and public speaker Lydia X. Z. Brown.
- **Advocate for equal opportunities:** Teachers can advocate for equal opportunities for students with developmental disabilities to live full lives.
- **Engage in inclusive activities:** Plan classroom or family activities that emphasize teamwork and inclusion, such as collaborative art projects or inclusive sports.
- **Explore books and media:** Read stories and watch films that include characters with developmental disabilities, helping kids understand diverse perspectives.
- **Host a classroom discussion:** Facilitate a conversation about respect, acceptance, and the ways we can make our communities more inclusive for everyone.
- **Create an "Inclusion Board:"** Have kids brainstorm ways to support inclusion and display their ideas at school or home.

PHOTO COURTESY REUTERS/SEBIN CHOI

EPILEPSY ORGANIZATIONS APPLAUD THE INTRODUCTION OF THE NATIONAL PLAN FOR EPILEPSY ACT

The National Plan aims to support the 3.4 million people living with epilepsy in the United States through a unified approach, calling for bipartisan support.

Epilepsy Caucus Co-chairs, U.S. Senators Eric Schmitt (R-MO) and Amy Klobuchar (D-MN), along with U.S. Representatives Jim Costa (D-CA-21) and Greg Murphy, MD (R-NC-03) reintroduced the National Plan for Epilepsy Act (S. 494/H.R. 1189), which supports the development of a comprehensive strategy to prevent, diagnose, treat, and cure epilepsy and improve the well-being of people with epilepsy and their families. Over 120 epilepsy-related organizations joined together to celebrate these efforts and urge members of Congress to co-sponsor and pass the bill. Epilepsy is the fourth most common neurological condition in the United States. The monumental legislation would bring more attention, support, and resources to the nearly 3.4 million Americans living with the epilepsies and other seizure disorders.

ACT NATIONALLY: The National Plan for Epilepsy would enable federal coordination to facilitate better outcomes for people with epilepsy and prioritize development of more effective treatments.

"I understand the unique challenges the epilepsy community faces," said Tony Coelho, former member of Congress (CA), primary sponsor of the Americans with Disabilities Act (ADA), and person living with epilepsy and having seizures for 64 years. "While we have made a lot of progress over the years, there is still work to be done. The National Plan for Epilepsy will propel us forward by fostering understanding among policymakers and driving innovation."

ABOUT THE EPILEPSY FOUNDATION:

EPILEPSY FOUNDATION

The Epilepsy Foundation is a national nonprofit organization dedicated to improving the lives of people affected by epilepsy through education, advocacy, research, and connection. For more than five decades, the Epilepsy Foundation has shone a light on epilepsy to promote awareness and understanding, and to advocate for laws that matter to people with epilepsy, while also funding epilepsy research and supporting epilepsy investigators and specialists in their early careers. In partnership with the CDC, the Epilepsy Foundation has helped to improve access to care for people with epilepsy and trained more than 600,000 people in seizure recognition and first aid. The Epilepsy Foundation continues to focus on serving the epilepsy community through advocacy, education, direct services, and research for new therapies. To learn more visit **epilepsy.com** or call 1.800.332.1000.

If passed by Congress and signed into law by the President, this bill will direct the federal government to develop a National Plan for Epilepsy. This plan will enable the federal coordination necessary to ensure better outcomes for people with epilepsy and prioritize the development of more effective epilepsy treatments.

"The Epilepsy Foundation of America is extremely excited that the National Plan for Epilepsy has been reintroduced with such far-reaching organizational support," said Bernice Martin Lee, Chief Executive Officer of the Epilepsy Foundation of America. "A National Plan will empower the entire epilepsy community to come together while bringing hope to millions of families across the United States. We are incredibly grateful to the Epilepsy Caucus co-chairs for championing this critical legislation and look forward to working with them to make this bill a reality."

In addition to various assessments and reports conducted by the Secretary of the U.S. Department of Health and Human Services, the National Plan for Epilepsy Act will create an Advisory Council of relevant federal government and community representatives to advise the Secretary on epilepsy-related issues. It will also provide a report on recommended priority actions. The Advisory Council will focus on areas including improving health outcomes and quality of life; fostering research and innovation for more treatments and cures; strengthening data and information systems; increasing public awareness about epilepsy and reducing stigma; reducing Sudden Unexpected Death in Epilepsy (SUDEP) and other epilepsy-related mortalities; and increasing access to specialized epilepsy care.

"The loss of my four-year-old son Henry to SUDEP was devastating. Deaths for people with epilepsy are two to three times higher than the average population," said Gardiner Lapham, Co-Director, Partners Against Mortality in Epilepsy. "A National Plan will increase research into cures and prevention so no other families experience this unimaginable loss from SUDEP or other causes of premature mortality."

"Thanks to Senators Schmitt and Klobuchar and Representatives Costa and Murphy, we are taking a transformative step forward for the millions of families impacted by epilepsy," said Dr. Dan Lowenstein. "Now is the moment for true collaboration between the public and private sectors to drive groundbreaking research, provide comprehensive and holistic support for patients, improve outcomes, and, at long last, work toward a cure."

To take action and learn more about supporting efforts to pass the National Plan for Epilepsy Act, visit **www.epilepsy-national-plan.org**

WHAT'S HAPPENING

CONVO ACCESS ALLOWS DEAF AND HARD-OF-HEARING MTA RIDERS TO CONNECT WITH LIVE ASL INTERPRETER

New York's Metropolitan Transportation Authority (MTA) has announced a pilot program to connect people who are Deaf or hard-of-hearing with an instant and on-demand American Sign Language (ASL) interpreter while using the transit system.

Convo Access is a mobile smartphone and web-based application that allows users to scan a QR code, connect with a live interpreter and chat with an MTA employee about service changes, payment, or anything regarding their journey.

The pilot, which is free to use for all customers, was initially deployed at Penn Station, Times Square, and Port Authority. Those locations achieved a 94% activation rate, with users reporting enhanced personal connections and more natural interactions with transit staff. The deployment follows a successful initial Transit Tech Lab proof of concept. The Transit Tech Lab is a public-private initiative created by the MTA and the Partnership Fund for New York City to make New York transit more accessible, responsive, and efficient.

RAIL TALK: New York's MTA has launched their Convo Access Pilot, which will allow those with a hearing disability to have an easier time navigating the city's public transportation system through an app that connects them with a live interpreter.

"Delivering a solution for customers who are Deaf or hard-of-hearing to have direct communications with MTA employees is a great enhancement to the customer experience," said MTA Chief Accessibility Officer Quemuel Arroyo. "This Pilot is going to redefine how we engage with our customers and allow us to explore new best practices ensuring equal access for all our customers throughout the MTA."

"Convo Access is more than a tool – employees and riders will be able to greet each other and have conversations beyond directions and train times," said Convo CEO Jarrod Musano. "Together with our partners at MTA, we're creating a transit system where everyone feels empowered and welcomed."

"This pilot with the MTA, along with the broader testing of the service across the region with the Port Authority and New Jersey Transit, is an exciting step towards improving service for Deaf and hard-of-hearing transit riders," said Senior Vice President of Innovation at the Partnership for New York City Stacey Matlen. "This work is yet another example of how we can use technology to provide New Yorkers with essential government services more effectively and efficiently. We are proud of how Convo and the other companies from last year's Transit Tech Lab's Customer Experience challenge are creating a better and more communicative transit system."

In 2023, the MTA and the Transit Tech Lab introduced NaviLens and NaviLens GO, free smartphone apps that translate visual information into accessible formats. When users scan a NaviLens code in a subway station or at a bus stop, the app will read out information like train or bus arrival times, real-time elevator status, and information about in-station features to transform how blind and low-vision riders use the transit system.

"For the Deaf and hard-of-hearing community, real-time access to information is critical for a seamless and independent transit experience. The MTA's Convo Access pilot is a groundbreaking step toward ensuring that all riders have equal access to transit services," said NYC Mayor's Office for People with Disabilities Commissioner Christina Curry. "NYC MOPD commends the MTA and its partners for leveraging innovative technology to enhance accessibility, and we look forward to seeing the positive impact this initiative will have on the daily lives of New Yorkers."

"I'm thrilled that Deaf and hard-of-hearing MTA riders will now be able to get live American Sign Language translation for customer support services through this pilot, said Manhattan Borough President Mark Levine. "After the successful launch at Penn Station, Times Square, and Port Authority, I'm confident that riders who use ASL to communicate will take advantage of this expanded program."

"As an ACTA committee member focusing on Deaf and hard of hearing, I am so pleased MTA took up an innovative approach to provide on-the-go accessible communication tool using American Sign Language between Deaf/hard-of-hearing customers and MTA customer service staff," said MTA Advisory Committee for Transit Accessibility Member Rachel Frumin. "Partnering with Convo, this innovative solution can become a mainstay for accessible communication for a better transit experience and access to information for the Deaf and hard-of-hearing community."

The Convo Access Pilot will run through at least November 2025. Users can submit questions or feedback through the Customer Feedback Form or email **accessibility@mtahq.org**.

PHOTO COURTESY MTA

WHAT'S HAPPENING

AS MEASLES OUTBREAKS MOUNT IN THE U.S, HERE'S HOW TO PROTECT YOUR FAMILY

BY RO WHITE

The South Plains region of Texas is facing a measles outbreak. As of February 25, there are 124 people infected (most of them children), according to the state health department. On February 26, health officials also reported that one unvaccinated child died due to the ongoing outbreak. Additionally, in neighboring New Mexico, nine cases have been reported as of February 20.

Measles is a highly contagious and potentially fatal disease caused by a virus. The measles, mumps, and rubella (MMR) vaccine prevents measles, so unvaccinated people put themselves and others at risk, including infants who are too young to receive the vaccine. Learn more about measles: what it is, how to stay protected and what to do in case of an outbreak near you.

WHAT ARE THE SYMPTOMS OF MEASLES?

Measles symptoms usually begin 10 to 14 days after exposure. The illness begins with a fever followed by a cough, runny nose, and red eyes, and then causes a rash of small red spots on the face and body. Measles can affect anyone, but it is most severe in children younger than 5 years old, immunocompromised people, and people who are pregnant, who may give birth prematurely or whose babies may have low birth weight as a result of a measles infection.

Measles isn't just a rash; the disease can cause serious health problems and even death. About one in five unvaccinated people in the U.S. who get measles will be hospitalized with pneumonia, dehydration, or brain swelling. If you get measles, it can also damage your immune system and make you more vulnerable to other diseases.

HOW IS MEASLES SPREAD?

Measles is transmitted through the air when an infected person coughs or sneezes. It is so contagious that unvaccinated people have a 90 percent chance of becoming infected if exposed. An infected person can spread measles to others before showing symptoms.

WHY ARE THERE MEASLES OUTBREAKS NOW?

The pandemic resulted in many children missing out on routine vaccinations , including the MMR vaccine. This decline in childhood vaccination coverage coincided with lower confidence in vaccine safety and increasing resistance to vaccination requirements. Skepticism about the safety and effectiveness of COVID-19 vaccines has led some people to question or oppose other routine vaccinations.

CAUSE FOR CONCERN: An unvaccinated school-aged child in Texas has died of measles in what the CDC says is the first fatality of the disease in the U.S. in a decade.

HOW DO I PROTECT MYSELF AND MY FAMILY FROM MEASLES?

Getting the MMR vaccine is the best way to avoid getting sick with measles or spreading it to others. CDC recommends that children get the MMR vaccine between 12 and 15 months of age, and again between 4 and 6 years of age, before starting kindergarten.

One dose of the MMR vaccine provides 93 percent protection and two doses provide 97 percent protection against all strains of measles. Because some children are too young to be vaccinated, it is important that those around them are vaccinated to protect them.

IS THE MMR VACCINE SAFE?

The MMR vaccine has been rigorously tested and monitored for over 50 years and has been found to be safe. Adverse reactions to the vaccine are extremely rare. Getting the MMR vaccine is much safer than getting measles .

WHAT DO I DO IF THERE IS A MEASLES OUTBREAK IN MY COMMUNITY?

Anyone who is not fully vaccinated against measles should receive the measles vaccine as soon as possible. Measles vaccines given within 72 hours of exposure can prevent or reduce the severity of the disease. Young children up to 6 months old can receive the measles vaccine if they are at risk during an outbreak. Talk to your pediatrician if your child is not fully vaccinated with two doses of the MMR vaccine, or three doses if your child received their first dose before their first birthday .

Unvaccinated people who have been exposed to the virus should stay home from work, school, daycare, or other activities for 21 days to prevent the spread of the disease.

For more information, talk to your health care provider.

ABOUT THE AUTHOR:

Ro White is a Health & Science Reporter for PGN Network. She is a writer with more than a decade of professional experience crafting health-focused, compelling content across formats. Before coming to PGN, Ro covered reproductive health and mental health for countless online and print publications. Ro holds a B.A. from the University of Chicago.

ILLUSTRATION COURTESY PNG

WHAT'S NEW

A SPRING IN OUR STEP

JUMPING JACK

Spin the spinner to see how many carrots to pull from the bunny hill. One carrot will make Jack jump, but which carrot is it? Jumping Jack is an exciting game that keeps children engaged because every player gets a chance to catch Jack to win! Kids will jump for joy when they play with Jumping Jack, the world's cutest bunny! If he jumps on your turn, catch him to win, or additional gameplay lets every player try to catch Jack when he jumps. If no one catches Jack, then the player with the most carrots wins. This is a delightful preschool game of mounting excitement that teaches quick reflexes, hand-eye coordination, taking turns and quick reactions. Simple rules make it accessible for young players and enjoyable for the whole family. For 2-4 players, ages 4 and up - tested for safety and quality.

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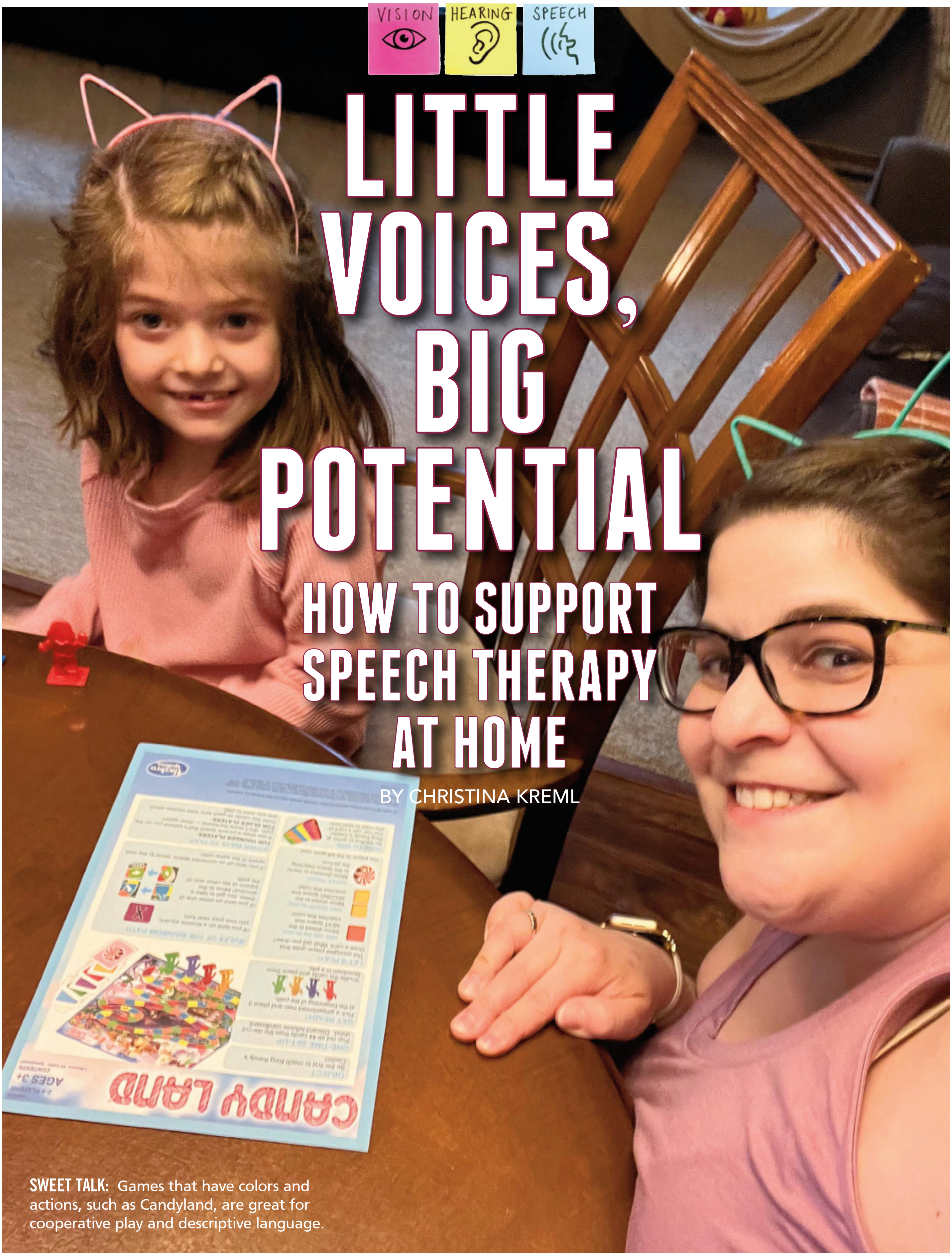
LITTLE VOICES, BIG POTENTIAL

HOW TO SUPPORT SPEECH THERAPY AT HOME

BY CHRISTINA KREML



SWEET TALK: Games that have colors and actions, such as Candyland, are great for cooperative play and descriptive language.

PHOTOS PROVIDED BY CHRISTINA KREML

Speech therapy is a common related service for children to have. It is hugely important in the lives of children who need it, and parent involvement can truly enhance progress in this area. As a parent of a child on the Autism spectrum, I have seen this firsthand.

Although my child is different from so many others, strategies can be tailored to the specific needs of the child. Small, consistent effort at home and in the community can make a big difference. Here are some strategies for parents to help ensure a language-rich environment for their child.

COLLABORATE WITH THERAPISTS

The child's speech therapist is the expert on expressive and receptive language (what the child says and understands). It is important to understand the child's specific speech and language goals. Regular meetings for parents to discuss data with the speech therapist are always encouraged to see how their child has been growing and what skills have been mastered. During these meetings, the parents should review their child's goals, see if the speech therapist can recommend exercises at home, and ask for feedback. With parents and the therapists both using the same concepts and language in different settings, the child will learn to generalize and retain information to keep with them in their daily life. If the therapist does provide specific examples, parents should make times each day to practice.

BOOK AN APPOINTMENT: During the day, parents finding time to read a book with their children, especially interactive books, can be a fun way to incorporate language.

CREATE A SUPPORTIVE AND LOW-PRESSURE ENVIRONMENT

As parents go about their day, they should narrate their activities. That actually tells the children about the home and routines, helping the children label words and activities in their life. During the day, parents finding time to read a book with their children, especially interactive books, can be a fun way to incorporate language. Parents should ask questions while reading, point out colors, shapes, and animals, while reading with their children. When out in the community, if the child says "dog," the parents should use some adjectives to describe the dog, like, "Yes, look at that big, brown, furry dog!" This not only acknowledges the child's speech, but adds on some more descriptive language to learn. It is important to encourage communication without forcing speech, because pressure can increase anxiety and resistance. Responding positively to any communication attempt, even if it is not perfect, is important.

MAKE SPEECH PRACTICE FUN

Families should find some games that encourage speech, like "I Spy," "Spot It," a rhyming game, or storytelling game. Games that have colors and actions are great for cooperative play and descriptive language. Having toys on hand that promote language is also beneficial. Dolls can be great for imaginative play, modeling social interactions, and cooperative play. Toy kitchens are great for learning how to use household tools and independent skills. Songs at home and in the car are beneficial ways to continue speech. Singing songs and nursery rhymes are strong ways to help with a child's rhythm and articulation.

FOCUS ON THE CHILD'S PREFERRED COMMUNICATION METHODS

Communication is extremely important. For some children with limited speech, it takes a different way to listen to determine what these children have to say. Facial expressions and gestures can be helpful when speech is limited. If verbal communication is difficult for the child, alternative methods like sign language, picture exchange methods (PECS) or AAC devices can be helpful. No matter how the child communicates, all forms of communication: verbal words, gestures, pointing, or assistive technology use should be celebrated and encouraged.

INCORPORATE SPEECH INTO DAILY LIFE

Each part of the day is a new opportunity to practice speech language skills. During mealtime, talk about what is on the plate. Talk about colors, textures, smells and tastes. During playtime, use pretend play to encourage conversations. During an evening bath, name body parts, sing bath time songs, and give simple directions. Using favorite toys and activities can also encourage speech. For example, when blowing bubbles (say "pop," "blow," etc.) or when doing puzzles (request pieces).

A FINAL REMINDER

Speech development can be slower for children with special needs, and that is okay. Any and every attempt at communication (whether it be a sound, a gesture, a word, or the use of an AAC device) is worthy of praise. It is also important to remember to keep expectations realistic rather than focusing on perfect speech. Parents are their child's most important speech partner, but it can be daunting to do this alone. Parents should reach out to their child's speech therapist, a support group, or another special needs parent to see what has worked for them. Speech is not a one-size-fits-all therapy. Progress may look different, but each step forward on the path to language learning is cause for celebration. •

ABOUT THE AUTHOR:

Christina Kreml is a dedicated special education teacher with two advanced degrees and a passion for supporting children with disabilities. As a parent to a special needs daughter, Christina brings both professional expertise and personal experience into her advocacy work. She is committed to empowering families, championing the rights of children with disabilities, and helping parents navigate the journey of raising exceptional children.

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COVER STORY

WITH THE RIGHT GUIDANCE AND SUPPORT, CHILDREN WITH DISABILITIES CAN LEARN TO BUILD THE LIFE THEY WANT, LIVING LIVES THAT FULFILL THEIR HOPES AND DREAMS.

GROWING SELF-DETERMINATION AND SELF-ADVOCACY SKILLS IN TEENS WITH HEARING LOSS

BY MELODY BERTRAND, JANE MADELL AND GAYLA GUIGNARD

All caregivers want to help their children become successful. There are many ages and stages a child progresses through, adapting and growing into independent adults who are capable of creating the life they want. This ability to create success is rooted in self-determination and self-advocacy skills.

PHOTOS PROVIDED BY MELODY BERTRAND/AG BELL

HAVING HIS SAY: Tenzin Lang participates in a group discussion during the AG Bell Leadership Opportunities for Teens (LOFT) program. While developing good advocacy skills is important for all children, it is a critical skill for children with hearing or vision loss.

While children with disabilities can be faced with bigger obstacles, the fact remains that they can learn to advocate for themselves and to voice their own wishes, wants, and needs. While developing good advocacy skills is important for all children, it is a critical skill for children with hearing loss.

Signs of independence emerge in the first year of life. Think of the baby who goes from being fed to feeding oneself or from asking for a toy to going to get it themselves. For all children, including those with a disability, it is important to be particularly intentional about transferring responsibility for tasks and decision-making to the child.

For example, young children should be answering questions on their own when someone asks, and not rely on caregivers to answer for them. By the time children with hearing loss are in the middle school years, they should be attending and participating actively (to the degree possible) in their own Individualized Education Program (IEP) meetings at school. They know what their needs are and should be encouraged to discuss them with the team.

From ages 11-14, most children should be increasing the ability to begin advocating for themselves. Advocacy does not happen on its own. It has to be encouraged by caregivers and by school staff. Caregivers play an important role and can support their children in developing independence. If a young child wants an ice cream, the child should order it at the store. The child should be encouraged to make choices about clothes, books, games etc. School staff also have a responsibility to build advocacy skills. Teachers should ask children to report when they are not hearing or understanding, and their behavior should be rewarded when they do.

WHAT IS SELF-DETERMINATION?

Self-determination is the ability to make choices, take action, and believe that one can achieve goals. It's an extremely important skill for teens with hearing loss to develop. It can help them be successful in school and in their careers. If teens have positive self-determination, they can confidently say, "I have the ability to determine what I want to do with my life and make it happen."

Here are four ways that caregivers can help their children begin developing these skills.

1. Set high expectations: Encourage your teens to set their own goals and support them as they work towards them. Give them ownership of their disability, and help them learn scripts to express what they need to help them communicate and participate. Encourage your teens to report when they do not hear or understand something.

By the time children reach middle school, they should be responsible for setting an alarm and getting up on their own, checking technology daily, and actively participating in IEP meetings. For children who are deaf or hard of hearing, that means they understand their hearing loss, what accommodations they need, and can communicate those needs clearly to the people around them.

2. Guide them towards independence: Independent teens understand their disabilities and are able to manage them without grown-up intervention, or they know how to ask for assistance when needed. A way to ensure this is to practice choice making and problem solving early, and to continue through the teen years.

There are many ways to begin building independence. Start early and small. For example, elementary-aged children who wear hearing aids should be able to change their own hearing aid battery without supervision. By the time they are in middle school, they should be completely responsible for their technology and advocating for themselves in the classroom. In high school, students should be comfortable discussing the effects of their hearing loss with their friends.

Another way of teaching teens with hearing loss to take responsibility for their technology is to allow them more control on how they use hearing assistive technology. For example, if a teen chooses not to use a FM/DM/RM systems* at school (which is a fairly

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* FM (frequency modulation), DM (digital modulation) and RM (remote microphone) systems help users hear a teacher or other speaker better, and reduce background noise for the listener. The speaker wears a microphone and the listener wears a receiver that brings speech close to or directly to the ear. In the case of those who use cochlear implants and hearing aids, the hearing devices themselves act as receivers so they can hear the words directly from the speaker.

TEAM PLAYERS: Alessandro Florit works collaboratively on a group project during AG Bell's LOFT program.Teens benefit from having group discussions with other children their age who also have a hearing loss.

typical issue), they can be asked to collect data on their academic performance while using the systems versus not wearing the systems. If their performance declines without the system, they may realize that their FM/DM system helps them with academic performance.

3. Encourage self-advocacy: Self-advocacy is the ability to speak up about one's needs and wants. Self-advocacy skills are critical in helping children develop self-determination skills. Children should learn early what it means to speak up for one's own needs and interests. Building the confidence to speak up can start early. It will benefit the children greatly into their high school years and beyond.

One way to build advocacy skills is to practice responses that the children can use during specific scenarios. The parents can have the teens imagine going out to eat at a restaurant. The parents can prompt them to think about what could go wrong during the meal. "The food is undercooked, there is too much noise, and I can't hear anyone talk. The waiter got my order wrong. It's too busy and loud." The parents can ask what part of those situations the teens can fix and how they would fix them. "Wave to the waiter and ask for new, cooked food. Ask to move to a quieter part of the restaurant. Ask the waiter to bring the right food." The parents can then ask what the teens can't fix, and how they might respond to those things. "Go to a quieter restaurant; come back later when it's not so busy."

In every single aspect of the children's life, they will have to learn to speak up for themselves and learn to ask for supports when it's needed and available. Teaching them to build these skills is critical to them leveraging their disability to their advantage.

SPEAKING UP : RESOURCES FOR DEVELOPING SELF-DETERMINATION SKILLS

For children with hearing loss, there are many organizations and resources available to help guide caregivers in each age and stage of self-determination development.

Supporting Success
for Children with Hearing Loss

SUPPORTING SUCCESS FOR CHILDREN WITH HEARING LOSS

Offers a guide for developing self-determination skills by age, from preschool through high school.

https://successforkidswithhearingloss.com/self-determination

ThinkCollege
CHANGING EXPECTATIONS. INCREASING OPPORTUNITIES.

THINKCOLLEGE

A group that provides research and resources to ensure an inclusive higher learning environment for students with intellectual disabilities, including children with dual diagnoses (such as hearing loss).

https://thinkcollege.net

a.g.bell
Association for the Deaf & Hard of Hearing

THE ALEXANDER GRAHAM BELL (AG BELL) ASSOCIATION FOR THE DEAF AND HARD OF HEARING

Offers several programs for middle school through high school-aged students to actively grow self-advocacy and self-determination skills. These programs are guided by professionals and involve peer-to-peer engagement and growth.

https://agbell.org/student-programs

Preparing for College Handbook:
Also offers a checklist of tips, tricks, and advice for students transitioning from high school to college.

https://agbell.org/2024/04/29/college-handbook

4. Talk about identity: Discuss with your teens how their hearing loss fits into their identity, and how they can disclose it in different situations. One easy way to approach this is to ask the teens to draw a picture of themselves. They may or may not choose to draw their technology. Either way is fine. You can talk about why they did not, if they didn't. For older children, it may be good to have a group discussion with other children their age who also have a hearing loss. They should think about and discuss who they are and what they are interested in. Once teens fully understand who they are, they can look around to see what supports they need, who they can turn to for support, and why they trust that person.

SELF-DETERMINATION IS A JOURNEY

Guiding children into adulthood is a journey on which all caregivers embark. Some children need more direction than others. Starting early and continuing to work on advocacy and other developmental skills will make it easier.

With the right guidance and support, children with disabilities can learn to build the life they want, living lives that fulfill their hopes and dreams. With some guidance and support to help them build self-determination and self-advocacy skills, these children can live a life full of adventure and success.•

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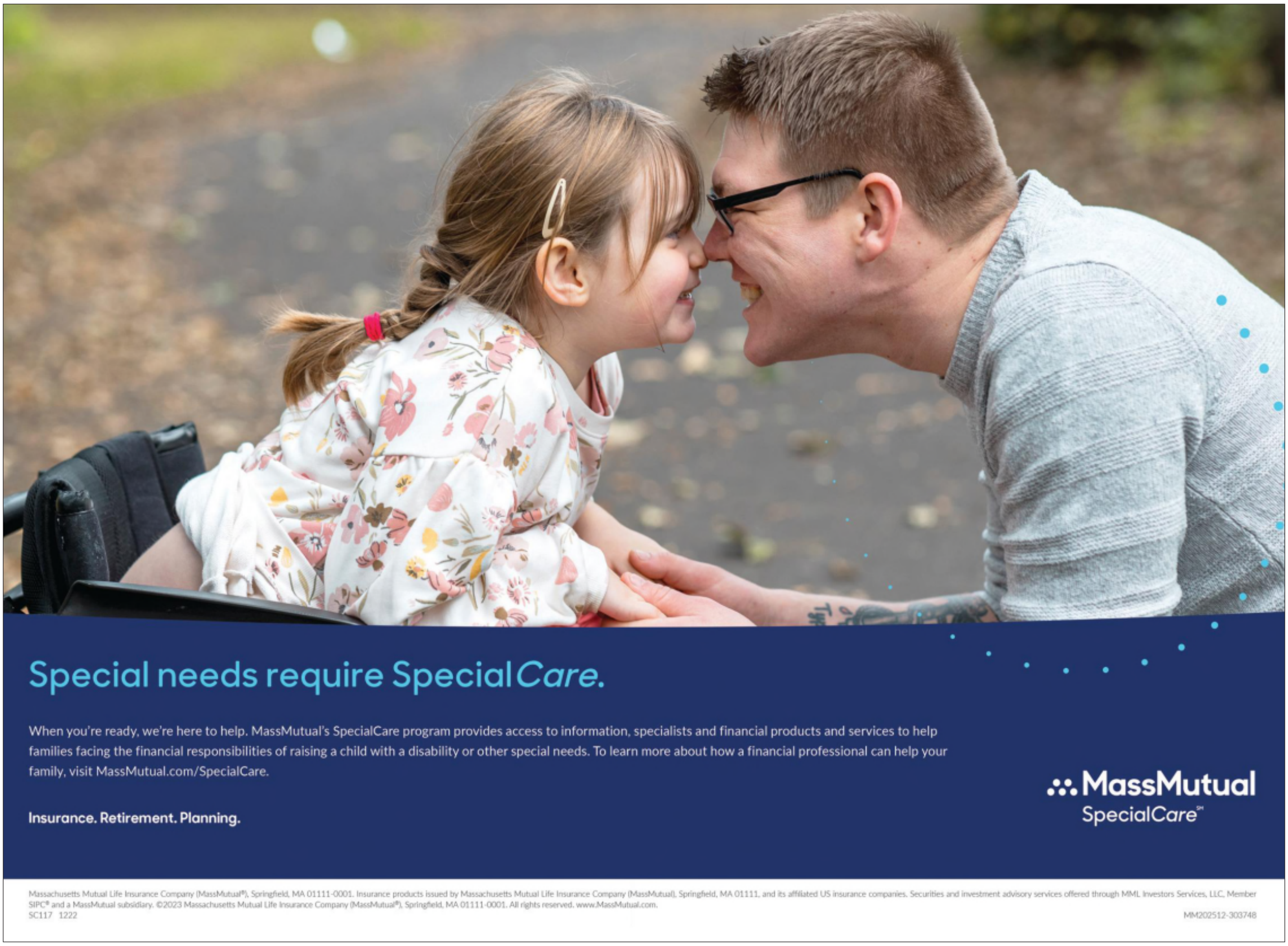
Jane Madell, PhD, CCC A/SLP, LSLS Cert. AVT has been a pediatric audiologist in clinical settings for almost 60 years. She has written seven textbooks and multiple articles. She presents nationally and internationally.

Gayla Guignard, M.A., CCC-A/SLP, LSLS Cert. AVT, is AG Bell's Chief Strategy & Programs Officer. Certified as an audiologist (CCC-A), speech-language pathologist (CCC-SLP) and Listening and Spoken Language Specialist (LSLS Cert. AVT), she has both clinical and programmatic experience with individuals with hearing loss across the lifespan.



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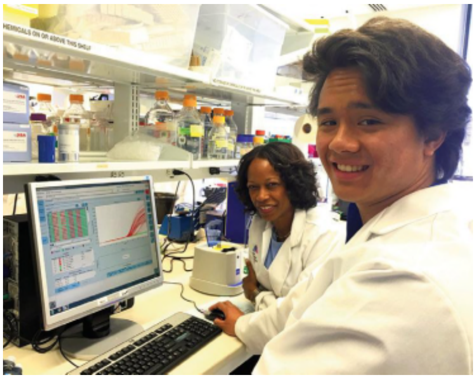

> "THE MESSAGE TO PARENTS IS CLEAR: PRIORITIZE REGULAR EYE EXAMS, BE AWARE OF THE INCREASED RISK OF KERATOCONUS, AND SEEK OUT SPECIALISTS EXPERIENCED IN WORKING WITH INDIVIDUALS WITH INTELLECTUAL DISABILITIES."

A CLEARER VIEW:

SINCLAIR'S JOURNEY THROUGH KERATOCONUS WITH DOWN SYNDROME

COURTESY OF GLAUKOS

Sinclair Darr and her mother, Kimberly, spent decades attending routine medical appointments. Sinclair was a very healthy young woman, but as an individual with Down Syndrome, she and her mom knew the many comorbidities that could emerge, and they did their best to stay on top of them.

PHOTOS PROVIDED BY KIMBERLY DARR

Their vigilance was the reason that Sinclair's eyesight had never been a cause for concern. She enjoyed 20/20 vision throughout her childhood, a fact that brought relief to her parents, both of whom wore glasses. Annual trips to a pediatric ophthalmologist, a two-and-a-half-hour drive each way, consistently yielded positive results. However, as Sinclair got older, a seemingly minor comment from a college instructor set them on an unexpected journey that highlighted the importance of vigilance and specialized care for people with Down syndrome.

"One day, Sinclair really wasn't seeing the board well," Kimberly recalls. Initially, this had been thought of as a simple misunderstanding. After all, a routine eye appointment just six months prior had revealed no issues. It wasn't until three years later that the diagnosis finally came: keratoconus.

A keratoconus diagnosis presented an entirely new set of challenges for Kimberly and Sinclair. Keratoconus, often abbreviated to "KC", is a non-inflammatory eye condition in which the normally round dome-shaped cornea progressively thins causing a cone-like bulge to develop. This results in significant visual impairment.[1]

The cornea is the clear window of the eye and is responsible for refracting most of the light coming into the eye. Therefore, abnormalities of the cornea severely affect the way we see the world making simple tasks, like driving, watching TV or reading a book difficult. In its earliest stages, keratoconus causes slight blurring and distortion of vision and increased sensitivity to light. These symptoms usually first appear in the late teens and early twenties. Keratoconus may progress for 10-20 years and then slow or stabilize. Each eye may be affected differently.[2]

In addition, an estimated 5%-30% of people with Down syndrome are affected by keratoconus. That's why it's extremely important to raise awareness of keratoconus in this community and to be aware of the potential signs and symptoms.[3]

"Of course, the prospect of losing your vision would be horrible for anyone," Kimberly notes. "But for those with intellectual disabilities, each and every one of your senses is like a lifeline. I couldn't risk her losing that."

LOOKING TOWARD THE FUTURE: Sinclair undergoes an eye exam; Since her procedures, she has seen a significant improvement in her quality of life and is back to doing the things she loves.

The initial news was crushing and didn't reveal a lot of obvious solutions. The ophthalmologist mentioned the need to "train" Sinclair not to blink in order to be eligible for a future procedure that would halt the progression of her keratoconus. This would be a significant challenge, as individuals with Down syndrome often have different blink rates. "I left that appointment feeling devastated," Kimberly says. "The timing couldn't have been worse. It was 2020 and the world was becoming significantly less responsive as it began to grapple with the onset of the COVID-19 pandemic".

Finding care became an uphill battle. Stanford, where Sinclair received other medical care was an option, but they didn't offer corneal cross-linking under anesthesia, a crucial consideration for Sinclair. Cross-linking is a minimally invasive procedure that strengthens the cornea and slows or halts the progression of keratoconus. For many people, it's performed while they are awake, but for those with intellectual disabilities, anesthesia is often necessary for an effective and comfortable approach. Corneal crosslinking (CXL), also known as corneal collagen cross-linking (CCL, or C3R), is a minimally invasive procedure that strengthens the cornea. Corneal crosslinking has been used to prevent the progression of corneal ectasia, such as keratoconus and post-LASIK ectasia.[4]

Corneal Cross-Linking is a non-invasive treatment therapy for Keratoconus. It involves the placement of specially formulated riboflavin drops that are then activated with UVA light. An exam under anesthesia was scheduled if data points from these exams/procedures were unreliable or unable to be obtained in the clinic. Most patients tolerated CXL well without significant postoperative complications, and no eye that underwent CXL progressed to hydrops.[5]

Kimberly and Sinclair persevered, contacting UCSF and UC Davis. With the pandemic-induced slowdown making it nearly impossible to get timely responses, Kimberly resorted to some creative methods of outreach including sending faxes with pictures of Sinclair to the hospitals, determined to get her daughter the care she needed. Finally, after six long months, Dr. Indaaram at UCSF responded, marking a turning point in Sinclair's keratoconus journey.

Dr. Indaaram not only provided expert care, but also offered crucial information that other professionals had overlooked. She explained that if keratoconus was present in one eye, it was highly likely to present in the other. This proactive approach allowed them to schedule procedures for both of Sinclair's eyes, streamlining the process and ensuring medical coverage.

Sinclair's procedures were just a few months apart and the results were remarkable. Not only did the progression of keratoconus halt, but Sinclair and Kimberly both felt her vision had even improved slightly. Improvement is not always the direct goal of cross-linking which primarily aims to stabilize the cornea, but it can occur when the procedure helps to flatten the cornea.

Overall, CXL has demonstrated to halt the progression of the disease clinically and in keratometry readings and improve the quality of life for patients.[6] CXL halts KC progression by strengthening and stabilizing the collagen lamellae, resulting in corneal mechanical stiffening. This can reduce the irregular astigmatism caused by corneal chemical instability and therefore improve refractive errors while also avoiding further corneal steepening.[7] Keratometry readings demonstrate a flattening in Kmax as well as improvement in ocular aberrations after crosslinking.[8, 9]

Sinclair, now 27, wears glasses for a slight vision correction in her right eye, but the cross-linking has stabilized her vision significantly. The need for further interventions, such as corneal transplants, which can be complex and challenging to access, seems unlikely.

Since her procedures, Sinclair has seen a significant improvement in her quality of life and is back to doing the things she loves. She works at a bridal shop, where she can now clearly see the beautiful dresses she's helping brides pick out every day. She also takes part in a lot of public speaking, especially to school classrooms.

"I like to bring marshmallows to the class so that the audience can put them in their mouths and try to talk. That's what talking with Down syndrome feels like," Sinclair says. "I want to be able to show them how different my life is than theirs, but at the end of the day, I want them to see that I still love being me."

Community is a huge part of Sinclair's life. In 2015, she and her mom founded a local yogurt shop that only employed people with intellectual disabilities. It was a wonderful place for these people to come learn marketable skills and work together to create a warm environment that the neighborhood loved.

On top of working directly in her neighborhood, Sinclair is also very active in the Down syndrome advocacy community, regularly attending conferences and events like the National Down Syndrome Congress. Since her keratoconus diagnosis, Sinclair and her mom say that the resources made available to them through the connected Down syndrome community allowed them to find the treatment they needed, but there is always room to speak up. "I wish I had known how prevalent of an issue this could be for Sinclair," said Kimberly. "Sinclair and I tell everyone we can about her diagnosis and journey through treatment. I hope we can encourage even one person to learn more about it and take proactive steps toward early diagnosis."

Sinclair's story underscores the importance of proactive eye care, especially for individuals with Down syndrome and other intellectual disabilities. Kimberly now actively shares her experience in Down syndrome support groups and online forums, emphasizing the need for early detection and intervention. She encourages parents to be vigilant and informed, highlighting the increased risk of keratoconus in this population.

"I feel a little guilty that we didn't catch it sooner," Kimberly admits. However, her advocacy is now preventing other families from experiencing similar delays. She praises the Adult Resource Center on Facebook and the National Down Syndrome Congress for raising awareness within the community.

The experience also highlighted the importance of finding a specialist experienced in working with individuals with intellectual disabilities. Dr. Indaaram's approach, including offering anesthesia for the cross-linking procedure and communicating directly with Sinclair, made a significant difference.

Sinclair's experience has not stopped her from living a full and active life. She attended community college, participates in public speaking engagements, and works at a bridal shop. Her ability to see clearly is crucial for her daily activities, especially her love for writing and using her iPad.

This experience has transformed Kimberly into a passionate advocate for eye health within the Down syndrome community. Her message to other parents is clear: prioritize regular eye exams, be aware of the increased risk of keratoconus, and seek out specialists experienced in working with individuals with intellectual disabilities. Early detection and intervention, as Sinclair's story demonstrates, can make a world of difference.

Sinclair's story is a testament to the power of early intervention and the importance of advocating for your child's health. By raising awareness about keratoconus and its prevalence in the Down syndrome community, Kimberly hopes to empower other families to ensure their children receive the timely care they need to maintain clear vision and live full, vibrant lives.•

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Courtesy of Glaukos, focused on eye health and treatment.

A SPEECH

BY KAREN WARFLE

Effective and accessible communication is considered a human right by many. Organizations supporting this include the American Speech, Language and Hearing Association; the International Society for Augmentative and Alternative Communication; and the North American Alliance for Communication Access.

As Care Managers and others serving and supporting individuals with disabilities strive to improve the health care and mental health care of those they serve, one consideration that sometimes is overlooked is the communication and social-emotional needs of those with limited speaking ability, or more commonly referred to as "non-verbal." I prefer the term "limited speaking ability" because language or verbal expression can include vocalizations, body language, gestures, signs, symbols, or other forms of Augmentative and Alternative Communication (AAC).

It is difficult for a person with limited or no speech to communicate their needs, feelings, location and level of physical pain or discomfort, or the fact that they're struggling.

One solution is to employ a Speech-Language Pathologist or a collegiate speech clinic that has faculty and graduate students who have experience with Augmentative and Alternative Communication. They are able to do assessments and help people learn how to use, or increase their effectiveness in using AAC. Another possibility is providing access to communication boards or devices. They can be helpful when taking individuals with limited or no speech to medical appointments. If a hospital stay is necessary, requesting the assistance of an on-staff Speech-Language Pathologist is important, just like an interpreter for someone who uses American Sign Language or speaks a language other than English.

For mental health, finding counselors, psychologists or psychiatrists who have experience in communicating with and counseling people that have limited speech or use AAC is important. If it proves to be challenging to find, search for a provider who is willing to consult with a Speech Language Pathologist experienced in working with people with complex communication needs.

IT IS DIFFICULT FOR A PERSON WITH LIMITED OR NO SPEECH TO COMMUNICATE THEIR NEEDS, FEELINGS, AND LEVEL OF DISCOMFORT.

~

ONE SOLUTION IS TO EMPLOY A SPEECH-LANGUAGE PATHOLOGIST OR CLINICIAN THAT HAS EXPERIENCE WITH AUGMENTATIVE AND ALTERNATIVE COMMUNICATION.

Those who work daily with people who have limited speech need to know how to be effective communication partners and understand the technological supports their clients utilize. To assist staff in learning how to be effective communication partners, agencies could provide person-specific training for their direct support professionals and other staff. Family members often can provide this training for those that work with their family member. But for those who don't have family involved or perhaps have new guardians who have limited or no experience with how the person communicates, then the need is even greater to provide this support.

The consideration of communication needs, access to AAC, and ongoing training for proficiency continues to be an important consideration for young adults. It is important as they transition out of school and to the next stage of life, whether it be work, day programs, or community integration. It is especially important for those with the concurrent diagnosis of intellectual or developmental disability as they face new challenges with new or reduced supports, along with the social-emotional changes that are a natural part of this season of life. Care Managers can work with the young adult, parents, and the circle of care team, including a Speech-Language Pathologist to ensure that the communication needs of the young adult continue to be met in all aspects of life. •

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The North American Alliance for Communication Access (NAACA) is a collaborative working group comprised of members from Communication Disabilities Access Canada (CDAC), ISAAC Canada, Mexico and The United States ISAAC Chapter (USSAAC)

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ABOUT THE AUTHOR:

Karen Warfle has had several careers in her lifetime. She enjoyed her tenure as a homeschool mom most, learning alongside her son who has multiple disabilities but a love for learning too. Karen has co-presented at American Speech-Language-Hearing Association (ASHA) conventions, colleges, and women's conferences.Today she and her husband, Mark, continue to help their son move toward independence. Karen writes and publishes in service to parents, especially those who have children with special needs. Contact Karen or learn more at **Karenwarfle.com**

> **“My parents gave me the tools to navigate life on my own terms, and today, I pay that forward by ensuring others have the same opportunities.”**

BLINDNESS IS NOT THE OBSTACLE

BY OSEAS DE LEON

Growing up as a blind child could have been a limitation, but thanks to my parents, it became an opportunity. I lost my sight at the age of three due to measles, a reality that might have shaped a life of dependence. However, my parents refused to let blindness define my future. They gave me the most invaluable gifts: education, independence, and a love for life.

PHOTO PROVIDED BY OSEAS DE LEON

BEST FOOT FORWARD: Oseas drills with other USABA soccer players. Blind soccer players use echolocation to navigate the field and track the ball. The ball produces sound when it moves, allowing players to determine its location through auditory cues.

From an early age, my parents instilled in me the importance of learning and self-reliance. They ensured that I had access to a quality education, not just academically, but also in navigating the world as a blind person. They introduced me to Braille, assistive technology, and problem-solving skills that empowered me to thrive in a sighted world. Their vision for me went beyond academics. They also believed that a fulfilling childhood included play, fun, and adventure. That is how I was introduced to soccer.

Soccer became more than just a game. It became a passion and a way for me to develop confidence, teamwork, and resilience. My parents encouraged me to participate, fostering my love for the sport, while helping me refine my orientation and mobility skills by relying on my senses and echo localization.

Blind soccer players use echolocation to navigate the field and track the ball. The ball contains items inside, like ball bearings, that produce sound when it moves, allowing players to determine its location through auditory cues. Additionally, players rely on verbal guidance from coaches and teammates to orient themselves and strategize their movements. These heightened senses enable them to play effectively without relying on sight. It was through soccer that I learned that blindness was not a barrier to movement, competition, or joy. Today, I proudly wear jersey number 11 as part of the U.S. Men's Blind Soccer Team, and aspire to compete with them in the 2028 Paralympics in Los Angeles.

As I grew older, these foundational experiences shaped me into the person I am today. I pursued higher education, earning a master's degree in U.S. History, and I have dedicated 18 years of my career to teaching assistive technology at the Miami Lighthouse for the Blind and Visually Impaired. This field allows me to empower others with visual disabilities, showing them that independence is not just possible, it is a right.

Beyond my professional life, I am also a father to two beautiful children. Parenthood has given me a new perspective on the values my parents instilled in me. Just as they nurtured my potential despite the odds, I strive to provide my children with the same love, encouragement, and belief that they can achieve anything.

I'm also proud to be part of an interdisciplinary team at the Miami Lighthouse teaching soccer to blind children, helping them develop strategies emphasizing cognitive awareness paired with physical activity, and the critical importance of communication with teammates and coaches. Developing these skills at a young age provides a foundation, as they learn life skills such as camaraderie, teamwork, and sportsmanship.

This comprehensive program is the first of its kind to offer programming starting at age one, and I'm thrilled to help introduce the sport to the next generation of blind children ages one to 22 years old. My journey from a blind child to a father, educator, and advocate would not have been possible without the unwavering support of my parents. They gave me the tools to navigate life on my own terms, and today, I pay that forward by ensuring others have the same opportunities.

Growing in momentum, blind soccer offers the blind and low-vision community the opportunity to get involved in a fast-paced, physical, and technical game. The growing popularity of blind soccer is seen through its inclusion in the Paralympics and, most recently this past November, the International Blind Sports Federation's 2024 USA Blind Soccer International Championship Game.

Blindness was never the obstacle. Limiting expectations were. •

ABOUT THE AUTHOR:

Blinded at the age of three. 21, Oseas moved to the United States without knowing English. He embraced the tools available to learn the language, complete his college education, and ultimately earn a master's degree in U.S. History. He is a Senior Assistive Technology Specialist at the Miami Lighthouse for the Blind where he helps individuals with visual disabilities navigate technology and achieve greater independence. He is a dedicated athlete and a member of the U.S. Association of Blind Athletes soccer team. He works with the Comprehensive Soccer Initiative as part of an interdisciplinary team teaching children ages 1-22 who are blind to play soccer. Through this initiative, he helps create opportunities for young athletes to develop their skills, confidence, and love for the game. Committed to breaking barriers in accessibility and inclusion, he continues to advocate for equal opportunities in education, sports, and technology. •

UNDERSTANDING THE IMPACT OF SINGLE SIDED HEARING LOSS

BY ROBIN BLIVEN

Old theories led us to believe that strong speech/language development and consequently academic success could be achieved with one typical-hearing ear.

Research compiled over the last 15 years has radically changed the profession's viewpoint on Unilateral Hearing Loss (UHL) or Single Sided Deafness (SSD). Many of these old beliefs are still being adhered to in both the medical and educational settings. It is vital to the success of children with unilateral hearing loss that we update our way of thinking and practice, in order to improve outcomes and long term success.

DON'T BELIEVE EVERYTHING YOU HEAR : DISPELLING UNILATERAL HEARING LOSS MYTHS

It is vital to the success of children with unilateral hearing loss that we update our way of thinking and practice in order to improve outcomes. Understanding how the research has changed will assist you in advocating for your child's needs as they grow.

MYTH #1

IT'S JUST ONE EAR.

FACT

It's a very common misconception that one normal hearing ear is "good enough." Due to this belief, many unilateral hearing loss cases have gone untreated and without assistance in schools. With the most recent research however, we now know that having a hearing loss in one ear has significant impacts on the brain itself! After a prolonged period of time with no hearing on one side, pathways in the brain are altered, and other senses begin to use those pathways instead. This is called cortical reorganization. This phenomenon can sometimes be reversed if the hearing loss can be caught early, and if it can be treated through amplification (hearing aids, cochlear implants, etc).

MYTH #2

UNILATERAL HEARING LOSS DOES NOT IMPACT LANGUAGE AND VOCABULARY.

FACT

It was previously thought that students with Unilateral Hearing Loss did not experience language delays in the same way as children with bilateral losses. Newer research shows, that is not the case. In a study completed in 2010 (Lieu, Tye-Murray, Karzon, & Piccirillo, 2010), sibling pairs were administered the OWLS (Oral and Written Language Scales). The sibling with the UHL consistently scored lower than the sibling with normal hearing. This is a very significant finding! Many students with unilateral hearing loss are not being evaluated for language and vocabulary growth. This is an area of concern that should be addressed, evaluated, and monitored for students with UHL.

MYTH #3

UNILATERAL HEARING LOSS DOES NOT HAVE EDUCATIONAL IMPACT.

FACT

Students with a unilateral hearing loss are TEN TIMES more likely to fail a grade level than their hearing peers. That is an astounding statistic! The educational impacts of the UHL are far reaching. Generally, phonemic awareness will be the most commonly impacted area for school age children. Phonemic awareness is the ability to identify and manipulate individual sounds (phonemes), and to know how the sounds work in spoken and written words. However, deficits are also seen across academic subjects, due to reading, language, and vocabulary delays. Educational settings are also more difficult for the student with UHL, due to difficulty hearing when there is background noise, working memory issues, and inattentive behaviors from not being able to access the information in the classroom through hearing alone.

MYTH #4

UNILATERAL HEARING LOSS DOES NOT NEED AMPLIFICATION.

FACT

In conjunction with the belief that one ear is "good enough," it has long been believed that amplification was not necessary or beneficial for the UHL. However, new technologies and research have opened many avenues for treatment! Hearing aids, assistive listening devices, and even cochlear implants are now viable options for people living with a unilateral hearing loss! Please note that not all situations can be treated and the decision should be made with the assistance of an experienced audiologist and/or ENT. However, it is very important that amplification be considered in order to assist the child with equal and fair access!

MYTH #5

UNILATERAL HEARING LOSS DOES NOT QUALIFY FOR AN IEP.

FACT

Given the updated research and understanding of how unilateral hearing loss affects a child, eligibility can now be determined given medical documentation of the hearing and an educational impact. If your child is being evaluated for an IEP, make sure that an educational audiologist is a member of the team to ensure all parties are educated on the impacts and needs of the student!

Understanding how the research has changed will assist you in advocating for your child's needs as they grow. "Just one ear" is no longer acceptable. Addressing these issues early will assist all children in changing the statistics and ensuring success in the future! •

Note: This article was originally published in the March 2023 issue of EP Magazine.

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ABOUT THE AUTHOR:

Robin Bliven is the Outreach Director at The Virginia School for the Deaf and the Blind. She attended the University of Tennessee for her bachelors and masters degrees in Education of the Deaf and hard of hearing. She has taught in Pre-K-12th grade across the country in both itinerant and site based settings. Robin moved to Virginia and into the role of Outreach Director in 2021. She lives in Chesapeake, Virginia with her 2 daughters and cats. Robin spends her free time watching a lot of youth softball, driving people places, and doing copious amounts of laundry.

DEVELOPMENTAL MILESTONES: WHEN TO BE CONCERNED

BY BONNIE IVERS, M.A., PSY.D.

New parents are confronted by so much new information and so many new situations, it can be challenging to know what might be normal variations in child development and what might indicate their child needs specialized help. Since so much development takes place in the first few years of life and developmental categories have influence on one another, most experts agree that when a parent isn't sure if their child is on track, it's almost never too early to seek a developmental screening.

WHAT TO WATCH FOR : KEY DEVELOPMENTAL MILESTONES

It can't be emphasized enough that every child is an individual. However, here are some general guides for parents about what to expect during the first few months and years of their child's development.

1-3 MONTHS

- Child follows moving objects and faces, smiles back, and watches faces with interest.
- Child raises head and chest while lying on stomach, opens and closes hands, and brings hands or objects to mouth.
- Child listens to sounds, orients towards voices and people, and begins to make sounds, engages in back and forth coos.

4-6 MONTHS

- Child enjoys social play and games (especially peek-a-boo), responds to others' emotions, and uses voice to express pleasure or displeasure.
- Child is interested in mirror images and reaches for toys and other objects.
- Child balances head well, sits with support, and rolls from front to back and back to front.
- Child vocalizes different sounds, smiles spontaneously, and starts to laugh.

1 YEAR

- Child pulls up to stand and walks holding furniture. Child can stop, squat and then stand again.
- Child tries to imitate during play like clapping when you clap.
- Child begins to use objects correctly such as drinking from a cup. Child mostly feeds self with fingers and begins using a spoon.
- Child uses simple gestures such as shaking head to say NO or waving bye-bye, and cries when parent leaves.
- Child imitates animal noises and may say several simple words such as: mama, dada, hi and bye.

2 YEARS

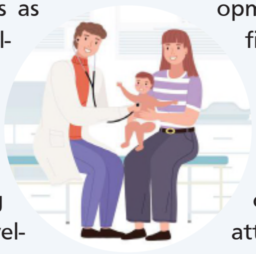
- Child uses simple two-word phrases.
- Child recognizes the names of familiar people and is excited about the company of other children.
- Child begins to sort by shapes and colors, starts simple make-believe play, and imitates the behavior of others.
- Child follows simple instructions, says 200-300 words, uses two to four-word sentences, and repeats words heard in conversations.
- Child walks and runs well, and may jump awkwardly. Child begins to throw, catch and kick balls, and turn doorknobs and lids.
- Child can drink through a straw and has good thumb and finger control.

3 YEARS

- Child shows affection for playmates and friends, and expresses a wide range of emotions.
- Child can stand on tiptoes, runs easily, and pedals a tricycle. Child walks upstairs unassisted, alternating feet.
- Child understands the concepts of "mine" and "his/hers" and uses simple phrases and 3-4 word sentences to communicate with others.
- Child matches objects to pictures, plays make-believe with dolls, animals and people, and can draw straight lines, and copy a circle.
- Child can wash and dry hands, dress and undress self except for buttons and laces, uses a spoon well and feeds self.

CHECKING 1-2-3: A well-structured developmental screening will involve expert professionals who assess the child's functioning in physical and cognitive abilities.

A CLOSER LOOK : WHAT HAPPENS AT A DEVELOPMENTAL SCREENING



If you suspect your child isn't reaching milestones as they should, see your pediatrician or seek out a developmental screening event in your community. A well-structured developmental screening will involve expert professionals who assess the child's functioning in key developmental areas mentioned above. This will include cognitive development, involving memory and imitative behavior, as well as physical development which refers to gross motor (such as walking) and fine motor (such as using a spoon) skills, along with vision and hearing. It will also cover communication, including both receptive language (understanding others) and expressive language (age-appropriate talking and other expression), social/emotional development which covers things like infant-caregiver attachment, and adaptive skills, such as feeding.

FURTHER INVESTIGATION : ADDITIONAL RESOURCES FOR PARENTS

In addition to your own pediatrician, there are numerous organizations that offer free educational materials to help parents understand and track their child's development. Here are a few that can be downloaded, many in multiple languages.

CDC

U.S. CENTERS FOR DISEASE CONTROL

Print and online materials as well as a mobile app for tracking developmental milestones.

www.cdc.gov/ncbddd/actearly/features/developmental-milestones-matter.html

Locate the early intervention contact in your state or territory:

www.cdc.gov/ncbddd/actearly/parents/states.html#textlinks

RCOC

REGIONAL CENTER OF ORANGE COUNTY

A comprehensive community resource providing links to hundreds of print and video materials on all aspects of child development, along with educational materials about specific conditions and a wide range of other topics of interest to parents of children with disabilities.

www.rcocdd.com/family-support/resources-and-support

Stanford MEDICINE

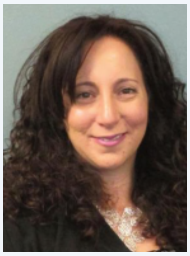
Children's Health

STANFORD MEDICINE

Offers excellent information about speech and language milestones from infancy to five years of age, and related topics.

www.stanfordchildrens.org/en/topic/default?id=age-appropriate-speech-and-language-milestones-90-P02170

ABOUT THE AUTHOR:



A clinical psychologist, Bonnie Ivers, M.A., Psy.D., is Clinical Director for Regional Center of Orange County, the private, nonprofit organization contracted by the State of California to coordinate lifelong services and supports for more than 27,000 Orange County residents with developmental disabilities and their families. The Regional Center is the first stop for those seeking to obtain local services and supports to help them live safely and with dignity in the community. Developmental disabilities include intellectual disabilities, autism, epilepsy and cerebral palsy. Learn more at **www.rcocdd.com**.

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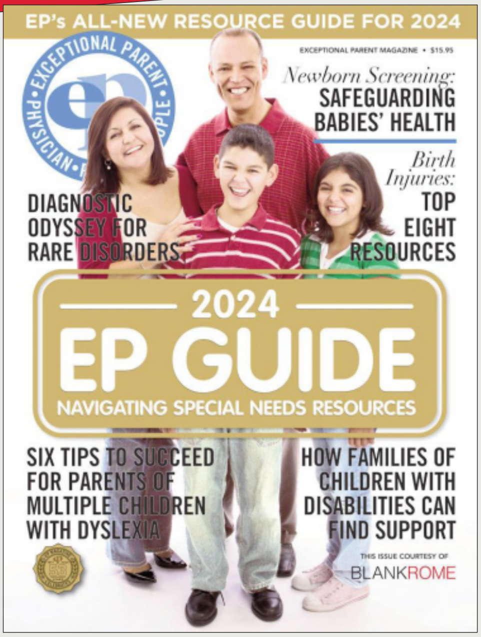

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EP MAGAZINE: THE JOURNAL FOR SPECIAL NEEDS FAMILIES AND PROFESSIONALS

ADVANCING HOME HEALTH CARE FOR CHILDREN WITH COMPLEX MEDICAL NEEDS

BY LAUREN AGORATUS, M.A.

Home health care is needed for many children with disabilities or children with complex medical needs.

WHAT WE KNOW

Home care can help children with special healthcare needs to better function at home, school, and in their communities. Current research and data on child-related home care is limited.

A recent literature review in *Pediatrics,* the publication of the national AAP (American Academy of Pediatrics) examined gaps and issued recommendations to improve this important service for children with complex medical needs and functional impairments.

CONCERNS WITH HOME HEALTH CARE FOR CHILDREN

Most services children with special healthcare needs receive, are in the home or community, not in the hospital or doctor's offices. Children with medical complexity, who are a subset of children with special healthcare needs, are most likely to require home health care. Research shows that 1 in 20 children are discharged from the hospital needing home care and/or DME (durable medical equipment).[1] Home care is covered by Medicaid under EPSDT (early and periodic screening, diagnostic, and treatment) and some private insurance. Care can be given by nurses (RN/LPN), CNAs (certified nursing assistants), or HHAs (home health aides), depending on which is medically necessary.

Access to Care: Some families are underinsured, have difficulty getting hours approved, or getting staffing due to the workforce shortage. One study showed that on average the child lost 40 hours per week of care, which fell on the family to provide.[2]

Child Health: Medicine errors occur frequently at home, often due to lack of sufficient supports or follow-up. Almost 50% of family caregivers and 80% of healthcare providers were unaware of these errors in a recent study.[3] In another study, 30% of hospitalizations were caused by difficulties/errors with home devices (feeding tubes, tracheostomies, ventilators).[4]

Family Caregiving: Family caregivers can be negatively affected by the physical demands (e.g. lifting), exhaustion from 24-hour caregiving, and forgoing their own health appointments. According to the Caregiver Community Action Network, respite is the #1 requested need, and more care receivers enter institutional care due to caregiver burnout than deterioration of the care receiver's condition.

Finances: Parents of children with medical needs may be greatly affected by the combination of medical bills and lost wages. Even with public and/or private insurance, families may still have extraordinary medical expenses. Parents may be unable to get additional education or be unable to work. Data showed that on average, families had $18,000 of additional yearly expenses for their children with complex medical needs.[5] About 14.5% of families with children who have special health care needs (CSHCN) reduce or stop working due to their child's health. This is known as "forgone family employment."[6]

NO PLACE LIKE IT : IMPROVING HOME HEALTH CARE

AMERICAN ACADEMY OF PEDIATRICS
Home Health Care Research for Children with Disability and Medical Complexity; *Note: Two of the authors are parents*
https://publications.aap.org/pediatrics/article-abstract/doi/10.1542/peds.2024-067966/200621/Home-Health-Care-Research-for-Children-With?redirectedFrom=fulltextARCH

ARCH NATIONAL RESPITE NETWORK
Respite Locator
https://archrespite.org/caregiver-resources/respitelocator

PARENT-TO-PARENT
www.p2pusa.org/parents

FAMILY VOICES
Family-to-Family Health Information Center/Family Voices
https://familyvoices.org

HOW CAN THIS BE IMPROVED?

The gaps mentioned above show the need for improvement in home health care for children. The article's recommendations include:

- *Partnerships with families, caregiver groups, and the youths themselves*
- *Creating a database to better track and monitor home healthcare outcomes*
- *Development of quality measures that matter to children and families*
- *More partnerships for patient and family-centered care*

Families of children with medical complexity can find relief through respite *(see Resources)*. Families can also get support from other trained volunteer families through Parent-to-Parent. If parents need help navigating the healthcare system, including insurance, they can contact the Family-to-Family Health Information Center in their state, territory, or tribal nation. Home health care can help support children with medical complexity and help their families thrive!

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ABOUT THE AUTHOR:

Lauren Agoratus, M.A. is the NJ Coordinator for Family Voices, NJ Regional Coordinator for the Family-to-Family Health Information Center, and Product Development Coordinator for RAISE (Resources for Advocacy, Independence, Self-Determination, and Employment). She also serves as NJ representative for the Caregiver Community Action Network as a volunteer. Nationally, Lauren has served on the Center for Dignity in Healthcare for People with Disabilities transplant committee (antidiscrimination), Center for Health Care Strategies Medicaid Workgroup on Family Engagement, Family Advisor for Children & Youth with Special Health Care Needs National Research Network, National Quality Forum-Pediatric Measures Steering Committee, and Population Health for Children with Medical Complexity Project-UCLA. She has written blogs and articles nationally, including publications in 2 academic journals (**https://pubmed.ncbi.nlm.nih.gov/?term=agoratus+l**). Lauren was named a Hero Advocate by Exceptional Parent Magazine (**www.epmagazine.com Archives June 2022**).

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ARE YOU HAPPY?

LESSONS FROM LIVING WITH AN EXCEPTIONAL PERSON

BY JORDAN JANKUS

I am writing this book to share my experiences of parenting an exceptional person, my daughter, Jessica. Her birth was difficult and she came into the world with multiple disabilities, but I am privileged to know her.

In her forties now, she lives her life as a person much younger, maybe four of five years old. Shadows in summer sunlight amaze her. She coos when holding her baby nephew. Assembling plastic blocks or TinkerToys entertains her for hours. She has faced many challenges but has learned a lot, thanks to all the people that have welcomed her into this world: her family, teachers, therapists, and caregivers. The fact that she has learned and we have learned, throughout this life experience, is the essence of this book. It's all about being committed to learning and growth, not accepting limits, and constantly adjusting to differences. Granted, her pace of learning has slowed over the years, but she still surprises us with some new act or expression. At the beginning of her life, we watched the seconds tick away on the clock, then the minutes. Now just the hour hands move, and more slowly than before. But I know there is a great soul inside with still more capacity for learning and living.

LIFE LESSONS: *(Above left)* Jessica has faced many challenges but has learned a lot, thanks to all the people that have welcomed her into this world: her family, teachers, therapists, and caregivers. *(Above right)* I hope that as I've aged I've become more attentive and aware as I've more fully embraced reality.

My hope for this book is that parents may come away from reading it with a sense that they aren't alone in their challenges of raising a child with developmental disabilities. I also want to encourage those who touch the lives of people with disabilities to understand the tremendous impact their work has on the people they serve.Your positive impact on their lives is never forgotten.

I also would love for people in the social support system: Special Education, Care Agencies, Medicare and Medicaid, to understand the importance of seeing each person as a unique, living, spectacular human being. People shouldn't get lost in the generalities of a diagnosis. Assumptions about a person shouldn't replace getting to know them as an individual.

I was away for a significant portion of Jessica's early years, working in corporate lending. This involved long hours and a considerable amount of travel. How much of this traveling was a relief from the challenge of caring for Jessica, I cannot say. But it definitely was an element, a pressure relief valve.

I didn't take her to her many evaluation appointments to try to figure out her needs. That was my wife's focus. She's the one that dealt more with professionals who sometimes didn't take the feelings of a young, worried mother into consideration. I was away on a business trip when Jessica had seizures and Cathy dealt with that. Not my finest moment. My ego was dependent on closing big deals and all of that was transitory. I came home to Cathy, Justin and Jessica, but I was mentally away for too much of our family life.

I hope that as I've aged I've become more attentive and aware as I've more fully embraced reality. But that's not for me to judge. I know that I've mentally sobered up and am completely present now. I regret that it took me so long to realize that reality is something to be embraced and not escaped.

This is a story of people that lived, and live, with challenges. I play a very imperfect role in all of it. Please look past my imperfections and instead see the things I've learned and the wonderful people that have made Jessica's life possible: her mother, her brother, Jessica's grandparents, aunts and uncles, teachers, direct-care workers, and all our close friends. Without their support and love, Jessica would not have thrived as she has.

I hope our story gives hope to many. Read next month as I continue sharing our journey.•

ABOUT THE AUTHOR:

Jordan Jankus is the proud father of Jessica, his adult daughter who was born with developmental delays. In addition to his role as a parent, Jordan worked in human support services for twenty-three years as a case manager, employment specialist, self-advocacy trainer, and assistive technology specialist. From his life experience, Jordan provides his thoughts on the critical subject of advocacy.

PHOTOS PROVIDED BY JORDAN JANKUS

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The goal is for the student fellows to add to the work of the senior scientists towards treatments and cures for Alzheimer's, Traumatic Brain Injury, autism, MS, brain cancer, PTSD, stroke, addiction, MS, depression, Parkinson's, ALS, pain, epilepsy and other brain diseases and conditions. The Summer Fellowship Program is funded strictly by events like the Endorphin Golf Outing & Dinner being held on June 3rd 2024, and donations often made in memory or in honor of loved ones.

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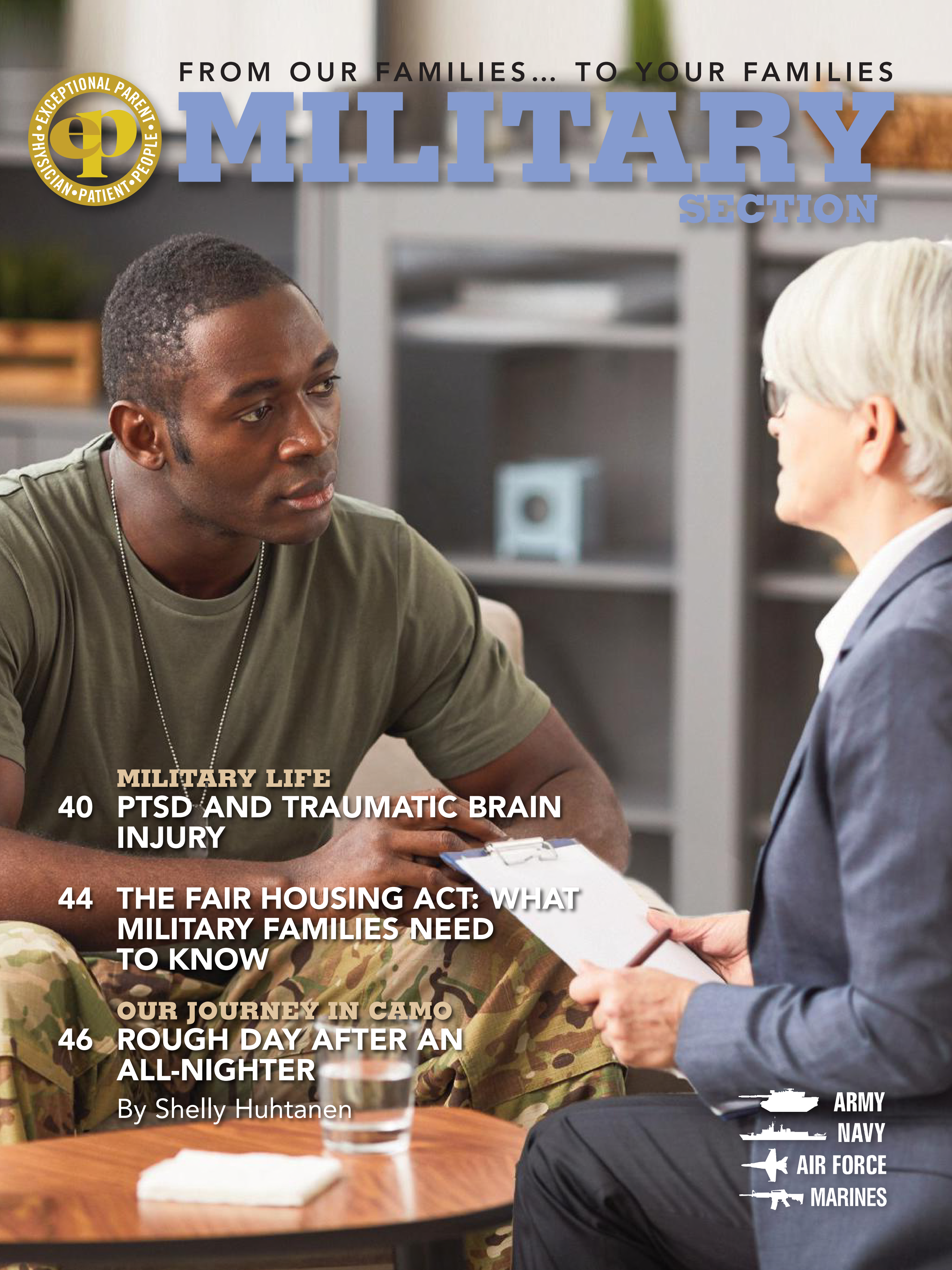

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COMBATTING TBI: Get professional help as soon as possible and learn everything you can about your spouse's injury so you can compare notes with doctors and the various medical care providers that you interact with.

PTSD AND TRAUMATIC BRAIN INJURY

Coping with the physical and emotional changes resulting from post-traumatic stress or a traumatic brain injury can be challenging, not only for the person with the diagnosis but also for family members and caregivers. While Military OneSource does not provide health care services, it can connect service members and their families with the appropriate resources for those diagnosed with PTSD or TBI.

RECOGNIZING COMBAT STRESS AND STRESS SYMPTOMS

Combat stress, also known as battle fatigue, is a common response to the mental and emotional strain that can result when service members are confronted with dangerous and traumatic situations. Symptoms include irritability, headaches, depression, loss of appetite, problems sleeping and changes in personality or behavior. A great resource for recognizing combat stress and stress symptoms is Understanding and Dealing With Combat Stress and PTSD (www.militaryonesource.mil/military-basics/wounded-ill-injured-and-caregivers/understanding-and-dealing-with-combat-stress-and-ptsd)

DEALING WITH COMBAT STRESS

Like an overused muscle, the brain of someone with combat stress needs to heal from too much exposure to trauma and stress. Recovery strategies include practicing relaxation techniques, getting adequate rest and working with a counselor to identify thoughts and behaviors that contribute to stress.

DISTINGUISHING COMBAT STRESS FROM POST-TRAUMATIC STRESS DISORDER

Combat stress is often confused with PTSD, which can occur after someone goes through a traumatic event such as war, assault or a disaster. While many of the symptoms are similar, combat stress and PTSD are different. Learn how to distinguish one from the other by visiting www.militaryonesource.mil/military-basics/wounded-ill-injured-and-caregivers/understanding-and-dealing-with-combat-stress-and-ptsd

National Center for
PTSD
POSTTRAUMATIC STRESS DISORDER

NATIONAL CENTER FOR PTSD

www.ptsd.va.gov

Explore the National Center for PTSD website and learn about PTSD, available treatments and where to get help. The National Center for PTSD advances the care and welfare of veterans and others who suffer from PTSD. This is accomplished through:

- *Research, education and training in the science*
- *Diagnosis*
- *Treatment of PTSD and stress-related disorders*

The National Center for PTSD website provides information, apps and videos. These resources address PTSD, PTSD treatment and where to get help. The site also includes information for families, friends and service providers.

RECOVERING FROM TRAUMATIC BRAIN INJURY

TBIs vary from patient to patient but can include dizziness, memory problems, difficulty focusing or seizures. The recovery process takes time. By educating yourself and your family members about the diagnosis and following the tips provided by Military OneSource, you may be able to aid your recovery. Discover a resource for recovering from traumatic brain injury by visiting Traumatic Brain Injury: A Guide for Caregivers of Service Members and Veterans at https://health.mil/News/Articles/2021/07/22/Caregiver-Guide-supports-service-members-and-veterans-with-TBI

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www.health.mil/Military-Health-Topics/Centers-of-Excellence/Traumatic-Brain-Injury-Center-of-Excellence/A-Head-for-the-Future

Visit the Defense Center of Excellence for Traumatic Brain Injury website to learn more about TBI and access resources specifically targeted to providers, patients and educators.

Military Health System Centers of Excellence provide diagnoses and treatment of diseases and conditions that impact military personnel and their families. Centers can speed the advancement of scientific knowledge and evidence-based practices with the help of a critical mass of experts.

The Traumatic Brain Injury Center of Excellence unifies a system of TBI health care. TBICoE reliably advances the science for the warfighter and stands ready to meet future brain health challenges.

The TBICoE supports, trains and monitors service members, veterans, family members and providers affected or caring for those affected by TBI. The TBICoE works at the macro level. Services include:

- *Screening and briefing service members heading into theater*
- *Performing predeployment provider training at military hospitals and clinics*
- *Gathering data mandated by Congress and the Defense Department*
- *Overseeing research programs*

TBICoE develops educational materials for military and civilian providers, and for service members, veterans and families.

WHEN YOUR SPOUSE HAS A TRAUMATIC BRAIN INJURY

As a spouse of a service member who has suffered a traumatic brain injury, you may be experiencing a range of emotions. It's important to allow yourself to feel every emotion that surfaces and attend to your own needs. Here are some strategies to consider as you prepare to take on your new role as a caregiver to your spouse.

After the injury, Your spouse may spend a few weeks and months in the hospital, which could be challenging for the two of you. In this phase of recovery, it may be helpful to:

- ***Gather information.*** *Learn everything you can about your spouse's injury so you can compare notes with doctors and other health professionals. Ask questions about your spouse's treatment program and take stock of the various medical care providers that you interact with during your hospital stay.*
- ***Pace yourself.*** *Don't spend all your emotional energy in one place because a brain injury requires long-term care. Save your strength for the long haul.*
- ***Understand your spouse's treatment program.*** *Your spouse's team of medical care providers will develop an individualized plan to treat the injury, which could require multiple hours of in-patient therapy per day.*

- ***Be understanding.*** *Don't take your spouse's hostile outbursts personally. Some TBI patients behave angrily toward their caretakers in the first few days and weeks of recovery. This behavior is a result of the injury and not a personal attack.*
- ***Get help.*** *Let your family and friends help you with the day-to-day stuff such as taking care of your children, preparing meals and other chores. Make sure you get plenty of rest and eat healthy meals. If you need assistance, contact a Military OneSource consultant, who will put you in touch with a trained counselor in your area.*

A HEAD FOR THE FUTURE

www.health.mil/Military-Health-Topics/Centers-of-Excellence/Traumatic-Brain-Injury-Center-of-Excellence/A-Head-for-the-Future

Visit A Head for the Future website to learn about TBI, and read stories of service members and veterans who recognized and got help for its symptoms. A Head for the Future is a Traumatic Brain Injury Center of Excellence initiative. It provides resources to help the military community prevent, recognize and recover from TBI.

The website includes TBI fact sheets, information on how to prevent, recognize and recover from TBI, and links to related publications.

Traumatic Brain Injury
Polytrauma System of Care
Department of Veterans Affairs

THE DEPARTMENT OF VETERANS AFFAIRS

www.polytrauma.va.gov/index.asp

The Department of Veterans Affairs website provides information on TBI and polytrauma.

The VA's Polytrauma System of Care is a network of specialized rehabilitation programs that helps veterans and service members with traumatic brain injuries and polytrauma. The network provides a number of services, including evaluation and treatment, a comprehensive plan of care, case management, patient and family education and training, and psychosocial support. Locate the nearest polytrauma system of care facility at www.polytrauma.va.gov/system-of-care/care-facilities/index.asp

GET SUPPORT FOR HEALTHY LIVING

If you or someone you know is suffering from combat stress, PTSD or a TBI, it is important to get professional help as soon as possible. The VA offers readjustment counseling for combat veterans and their families, including those still on active duty at community-based Vet Centers.

The Defense Centers of Excellence for Psychological Health and Traumatic Brain Injury is available 24/7 to provide information and local resources to service members. If you or someone you know is in crisis, contact the Military Crisis Line at 988, then press 1, or access online chat by texting 838255.•

– Military OneSource

PACT ACT FOR WOMEN VETERANS

YOU BELONG AT VA

The PACT Act is a new law that expands VA health care and benefits for Veterans exposed to burn pits and other toxic substances. Women Veterans, we know you were there too. VA is here for you.

The Act **(1)** expands and extends eligibility for VA health care for Veterans with toxic exposures and Veterans of the Vietnam era, Gulf War era, and Post-9/11 era, and **(2)** expands eligibility for benefits for Veterans exposed to toxic substances.

What new or expanded presumptions will the Act create and when will they be in effect?

VETERANS AND SURVIVORS CAN FILE CLAIMS FOR ALL CONDITIONS OUTLINED IN THE PACT ACT IMMEDIATELY.

For Gulf War and Post-9/11 Veterans, that includes:

Brain cancer, Glioblastoma, Respiratory *(breathing-related)* cancer of any type, Gastrointestinal cancer of any type, Head cancer of any type, Lymphoma of any type, Neck cancer of any type, Pancreatic cancer, and Reproductive cancer of any type, including cervical, ovarian, uterine and breast cancers. Vaginal and vulvar cancers are also on the presumptive list.

For Vietnam Veterans and other Veterans exposed to tactical herbicides, that includes two Agent Orange presumptive conditions:

High blood pressure (hypertension) and Monoclonal gammopathy of undetermined significance (MGUS).

How can Veterans apply for VA health care?

Apply **online** at VA.gov/health-care/apply/application/introduction.

Call our toll-free hotline at 877-222-8387,
M-F, 8:00 a.m. - 8:00 p.m. ET.

Mail a completed, signed Application for Health Benefits (VA Form 10-10EZ).

Bring a completed, signed VA Form 10-10EZ with you to your nearest medical center or clinic or get help through your state's Department of Veterans Affairs Service Officer.

Get help filing your claim by working with an accredited representative.

What are the PACT Act key components?

The Act **expands and extends eligibility for VA health care for Veterans with toxic-exposures** and Veterans of the Vietnam era, Gulf War era, and Post-9/11 era.

VA **will improve the decision-making process** for determining what medical conditions will be considered for presumptive status.

Every enrolled Veteran will **receive an initial toxic exposure screening** and a follow-up screening at least every five years. Veterans who are not enrolled, but who are eligible to enroll, will have an opportunity to enroll and receive the screening.

VA health care staff and claims processors will receive **toxic exposure-related education and training.**

The Act requires **research studies** on mortality of Veterans who served in Southwest Asia during the Gulf War, Post-9/11 Veteran health trends, and Veteran cancer rates.

The Act will help VA **build a stronger, more skilled workforce** to meet the growing demand for benefits and services.

The Act authorizes **31 new facilities** across the country, providing greater access to VA health care.

How can a Veteran file a claim?

Veterans who would like to file a claim must complete VA Form 21-526EZ to apply for benefits and submit any supportive evidence.

To learn about standard VA disability claims, supplemental claims, secondary claims, and more, visit: VA.gov/disability/how-to-file-claim/when-to-file.

If a Veteran was previously denied a claim, what can they do?

VA will contact Veterans when a presumption of service connection is established or changed. However, **Veterans previously denied a toxic-exposure related claim** are encouraged to file a supplemental claim. Once a supplemental claim is received, VA will review the claim under the new law.

VA

U.S. Department
of Veterans Affairs

Learn more and sign up at VA.gov/PACT
Download the VA Health and Benefits App
Call us at 1-800-MyVA411 (1-800-698-2411)
Find a VA at VA.gov/find-locations/

THE FAIR HOUSING ACT

WHAT MILITARY FAMILIES NEED TO KNOW

The Fair Housing Act protects people from discrimination when they are in the process of renting or buying a home. The law prohibits discrimination in housing because of race, color, national origin, religion, sex (including gender identity and sexual orientation), familial status and disability.

The Fair Housing Act applies to most housing options, including military installation housing. In fact, many states have fair housing laws that provide even greater protections.

HOW THIS RESOURCE HELPS

The Fair Housing Act (www.hud.gov/program_offices/fair_housing_equal_opp) requires housing providers to:

- *Make reasonable accommodations for people with disabilities. A property owner, however, is not required to make changes that would create an undue financial or administrative burden.*
- *Allow people with disabilities to make reasonable modifications. Property owners must allow residents to make reasonable changes to their units if those changes are neces*sary for the tenant to use the unit fully.

The Fair Housing Act also makes it illegal — based on your or a family member's disability — to:

- *Refuse to rent a dwelling or to accept a legitimate offer*
- *Evict someone*
- *Use different applications or criteria*
- *Segregate people into specific units or areas*
- *Ask if anyone has a disability*
- *Refuse to make or allow reasonable modifications or accommodations*

If you live in privatized housing on a military installation, your property managers are required — at no cost to you — to make reasonable accommodations that abide by the Americans with Disabilities Act (www.ada.gov/law-and-regs/ada).

HOW TO ACCESS THIS RESOURCE

For your specific state (www.hud.gov/states) Fair Housing laws, contact your public housing agency (www.hud.gov/program_offices/public_indian_housing/pha/contacts). If you believe your rights may have been violated, file a complaint (www.hud.gov/program_offices/fair_housing_equal_opp/online-complaint) with the U.S. Department of Housing and Urban Development's Office of Fair Housing and Equal Opportunity. You can also file a lawsuit in federal court within two years. However, deadlines for state court actions vary.

Service members and their families can also receive free legal assistance regarding reasonable housing accommodations at their local military legal assistance office (https://legalassistance.law.af.mil)

Visit the HUD Fair Housing website at www.hud.gov/fairhousing •

– Military OneSource

PROTECTING VETS: If you live in privatized housing on a military installation, your property managers are required to make reasonable accommodations that abide by the ADA.

OUR JOURNEY IN CAMO SHELLY HUHTANEN

Rough Day After an All-Nighter

I realize that I need to do things for myself as well. It’s a balancing act. Some days are tougher than others.

“Broden, go to sleep. You’ve got clinic tomorrow.” I stumbled back into my bedroom and glanced over at my clock on my bedside table. It was 11:30pm. I thought to myself, “Please don’t have it be one of those nights where he can’t go to sleep.” What seemed like 30 minutes later, I rolled over and heard a burst of laughter. I laid on my back hoping it was a dream. After a few minutes, I heard another giggle. Again, I rolled over to look at the clock. I saw the numbers 2:34am glaring back at me. I groaned and rolled on my side, off the bed and opened the door into Broden’s room, “Buddy, you gotta go to sleep. You have a full day today.” As I rubbed his back to sooth him, he rolled over and said, “You leave.” Rolling my eyes admitting defeat, I nodded my head in agreement and slowly walked out of the room. I knew it was going to be one of those days. It was going to be one of those days when I question why I’m teaching again and why I put so much on my plate. Before I knew it, my alarm was blaring by my head at 5am and I slowly rolled over to turn it off.

Marks’ CPAP machine had worked wonders that night and had maximized every moment of his sleep, “Did you sleep alright last night?” I opened one eye and mumbled to him that it was a rough night and he needed to start my coffee. After some caffeine in me, I thought to myself, “I’m back in business.” When it was time for Broden to shower, I slowly slid open the door. He was on his back with his arms stretched out, with blankets wrapped around his waist and one leg. I sat on one side of the bed and gently rubbed his tummy, “Sweetheart, it's time to get up. You have to take a shower and get to clinic.” For a few moments there was no movement at all. As I continued to talk with him and then rub his legs and feet, he slowly started to roll around and then opened his eyes, “Ah yes. I told you the morning would come quickly. You need to get up and get moving.”

He slid out of bed and got in the shower. After his breakfast, he put his coat on and got in the car. We were a few minutes late, but I knew I could easily get to work on time. When we pulled into the parking lot, his RBT came out to meet us, “Broden had a long night, but I think he’s ready to go. Hopefully he’ll sleep good tonight.” His RBT smiled, “Ok Broden, maybe we’ll take some walks today to keep things moving along.” Broden smiled and gave me a kiss before walking into the building.

With the steady fluctuation of coffee and water, I thought I was in the clear. I was semi coherent as I taught class, and

FINDING EQUILIBRIUM: “There are days when Broden needs a mom who needs to be completely focused on him.”

PHOTO PROVIDED BY SHELLY HUHTANEN

I hadn't received any phone calls from the clinic. I thought to myself, "Well, this wasn't too bad. I'll head to bed early tonight, and the week will be back on track." Late afternoon, I rolled into the parking lot to pick up Broden. His afternoon RBT came out with Broden to greet me, "Broden had a pretty good day, but he's been yawning. I hope he sleeps good tonight." After hugging Broden, I assured him that we would plan on an early night and try to set him up for a good night's sleep. As I closed out with his afternoon RBT, I could see Broden starting to visually get upset, and then he started to scream. Broden's RBT looked alarmed and said, "Do you need my help? I can stay out here and help you guys through this." I shook my head no, "Go back inside. I got this. We'll work through it."

> "It was one of those days when I question why I'm teaching again and why I put so much on my plate."

Once Broden's RBT walked away I opened his door, "Broden what's wrong?" He didn't stop screaming. I soon realized that a certain video wouldn't play on his phone and that is what was upsetting him, "I know you're tired and your video isn't playing, but there's nothing we can do about it. I'm sorry!" Realizing there was no way to console him there in the parking lot, I made sure his seatbelt was on, and I shut the door. I knew the only way we could work through this was to get him home. Home was a 25-minute drive through downtown Columbia.

Broden screamed the entire way through town. I almost got into an accident reaching back to tell Broden to get his seatbelt on, when I heard him taking it off while on Trenholm Road. Once we were at the side gate at Fort Jackson, I rolled down the window to show the gate guard my ID card. Broden's screams grew louder once the seal of the window was broken, "Sorry! My son is very upset. Here's my ID." The gate guard looked concerned, but still smiled and let me through. As I took deep breaths and got through the neighborhood, I pulled into the driveway and got Broden in the house, "Go upstairs, Broden!"

I threw my coat on the table, let the dogs outside to go to the bathroom, and then dropped my bookbag on the floor. I walked out onto the front porch and closed the door behind me. It was the quietest space I could find. I sat in the rocking chair and watched the trees blow in the wind. I watched cars drive over a small bridge that was in front of our house. After about 20 minutes of deep breathing and silence, I walked back in the house and went upstairs to check on Broden. He had finally calmed down. He was tired and started to feel the effects of staying up the night before. I went into my bathroom and started a bath. I sat in the bath until I could hear Mark home from work, walking in the door.

I looked over when I heard the bathroom door creak open. Mark didn't have to say too much, "Are you ok? Broden had a rough day?" I nodded as I slipped deeper into the water. Mark sat on the side of the tub, "I'm sorry you guys had a rough day. I'll get dinner going and check on Broden again." After the bath, I walked into Broden's room and sat in his chair, "We're going to go to bed early tonight, and tomorrow is going to be a better day, right?" Broden looked over exhausted and said, "Yea."

There are some days that are hard, and they challenge me. Lately, I have asked myself why I still teach and volunteer, because there are days when Broden needs a mom who needs to be completely focused on him. After I sleep on it, and a new day starts, I realize that I need to do things for myself as well. It's a balancing act. Some days are tougher than others. It's ok to do things for myself, even when some days require me to find a quiet place to find that balance and calm. Sometimes it's on my front porch or in my bathtub.•

OUR JOURNEY IN CAMO

Shelly Huhtanen is an Army wife stationed at Fort Jackson, SC. She enjoys sharing her experiences of her day-to-day life caring for her son with autism. Shelly authored ***Giving a Voice to the Silent Many*** that encompasses many stories of raising a child with autism in the military. She also teaches Public Communication at the University of South Carolina and has contributed to *EP Magazine* for over 10 years.

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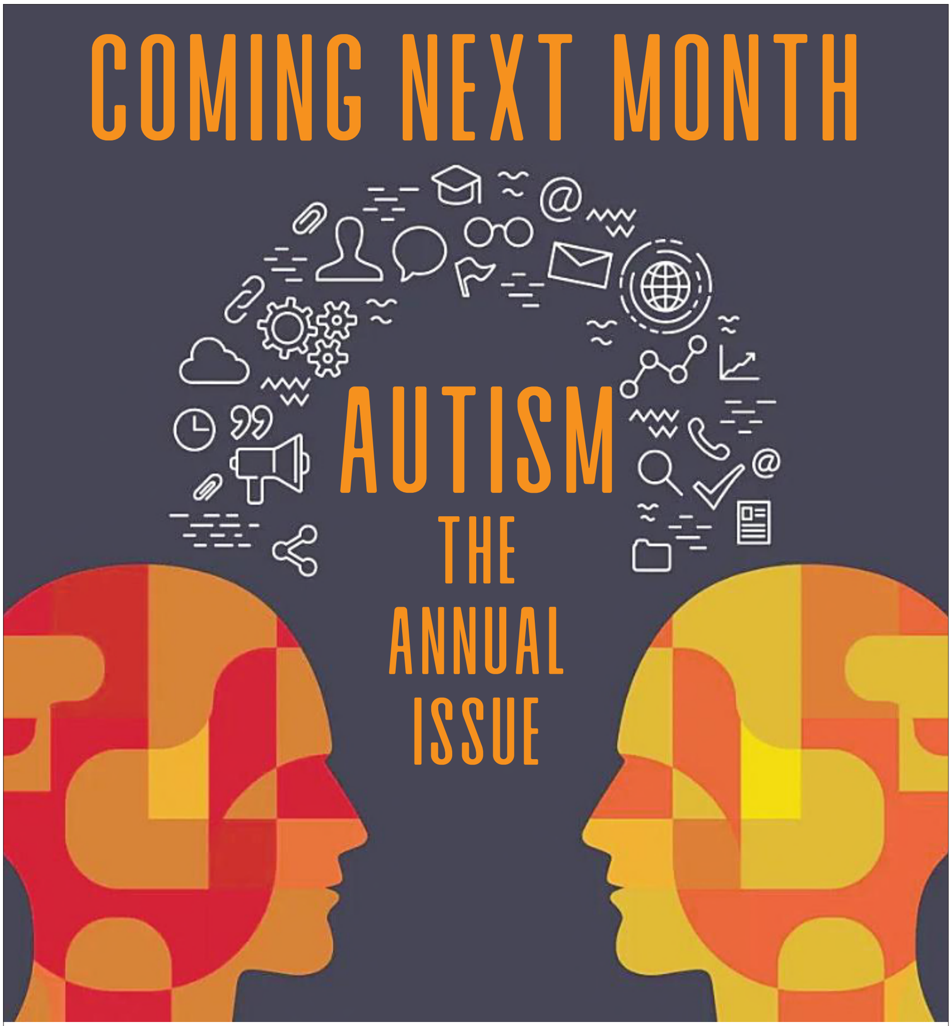

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