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MAGAZINE
JUNE 2024
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INSIDE • COOPER'S STORY:

THE VITAL ROLE *of* SUMMER CAMPS *for* CHILDREN WITH DISABILITIES

ANNUAL SUMMER FUN ISSUE:

SUMMER PLANNING FOR AUTISTIC CHILDREN

Charlie and Jude Lamb

PLUS • LIFE WITH USHER SYNDROME:

MAKING CONNECTIONS

ALSO:

COMMUNITY INCLUSION INCLUDES THE ARTS

EP MAGAZINE
1971 2024
53
YEARS
CELEBRATES

CONTENTS

JUNE 2024 VOLUME 54 ISSUE 6

ANNUAL SUMMER FUN ISSUE

AN EP FOCUS ON SUMMER ACTIVITIES

ON OUR COVER

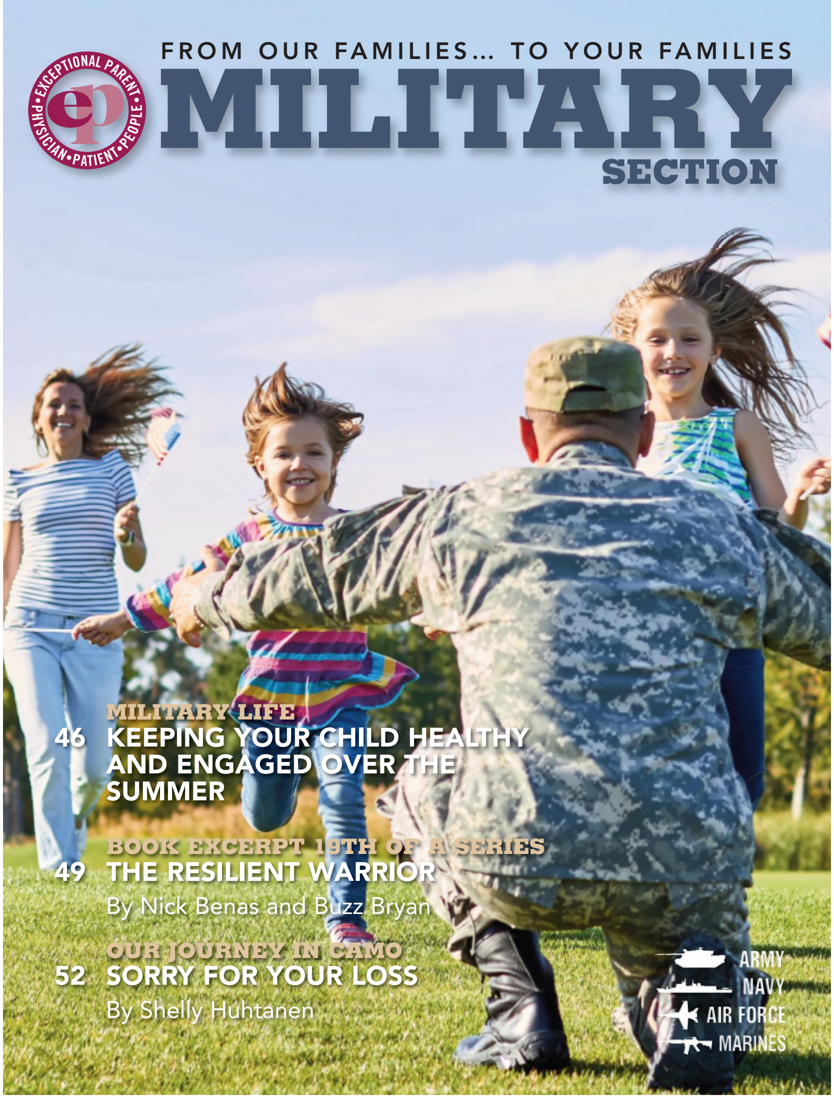
EP Magazine's Annual Summer Fun Issue is focused on helping reduce or avoid academic or behavioral regression over the summer. The disruption of familiar routines and environments, and limited access to school-based and other support services can be difficult for some children, especially those with special needs. Our contributors offer guidance and advice for creating an enriching summer experience. *Coverage begins on page 12.*

CONTENTS

JUNE 2024 VOLUME 54 ISSUE 6

DEPARTMENTS

MILITARY SECTION



MILITARY LIFE
46 KEEPING YOUR CHILD HEALTHY AND ENGAGED OVER THE SUMMER
BOOK EXCERPT 19TH OF A SERIES
49 THE RESILIENT WARRIOR
By Nick Benas and Buzz Bryan
OUR JOURNEY IN CAMO
52 SORRY FOR YOUR LOSS
By Shelly Huhtanen

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Summer Success

The arrival of summer and the disruption of familiar routines can present unique challenges and lead to regression of skills.

The end of the school year brings with it a certain sense of relief for families raising children with special needs. Gone are the early morning wake-up times, transportation duties and homework assignments. Also gone, however, is the familiar routine, as well as school or program support towards hard-won educational progress. As the weather gets hotter, some parents feel as if they're jumping out of the frying pan into the fire!

As Marta Chmielowicz writes in this month's cover story, "Summer Planning for Autistic Children" "For parents of autistic children of all ages, the arrival of summer can present unique challenges. The disruption of familiar routines and environments can be difficult for some autistic children, and limited access to school-based or other support services can lead to regression of skills."

> Our Annual Summer Fun Issue offers multiple resources and guidance on avoiding the summer slide.

Our Annual Summer Fun Issue offers multiple resources and guidance on avoiding the summer slide. In "Spectrum of Fun: Evidence-Based Strategies for Children with ASD on School Breaks," Mireille Ukeye, Ph.D. presents a list intended to create a supportive and enriching summer experience for children with special needs. In her article "Cooper's Story: The Vital Role of Summer Camps for Children with Disabilities," Melissa Smith focuses on the importance of specialized summer camps that offer children the opportunity for growth, while relieving caretakers who are often in a state of emotional, mental, and physical exhaustion.

Frequent *EP Magazine* contributor Pamela Aasen examines the effect isolation has on individuals with disabilities. She explains how her activism and that of others has led to the creation of several summer camps and conferences that cater to those living with Usher syndrome.

EP Magazine's articles are filled with helpful information and resources, as well as inspiring stories. Please share the magazine with friends, family and colleagues.

Remember, your comments, suggestions, and questions are welcome at **epmagazinevp@gmail.com** or **fsimon@epmagazine.com**. Your participation helps maintain the relevance of our magazine. We also urge you to share our posts and follow us on **facebook.com/exceptionalparentmag**, Instagram **@epmzine** and X (formerly Twitter) **twitter.com/epmzine**. It's easy to subscribe and get "EP for Free" – just visit **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. As EP's Editor In Chief, Faye sources and edits articles, creates partnerships with businesses and not-for-profit organizations, and develops relationships with EP's writers, corporate partners, readers and staff.

Information and Support for the Special Needs Community

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WHAT'S HAPPENING

NEW MOVIE EZRA DEPICTS THE STRUGGLES AND JOYS OF RAISING A CHILD ON THE AUTISM SPECTRUM

THE GOOD FIGHT: *(Left to right)* Robert De Niro, Bobby Cannavale and William A. Fitzgerald star in the new movie *Ezra,* which will be in theaters this month.

Bobby Cannavale, Robert De Niro and Rose Byrne lead a notable ensemble drama focused on caring for a neurodivergent child in the new movie *Ezra*.

Ezra follows Max Brandel (Cannavale), a once successful late-night comedy writer turned less-successful stand-up comedian, who struggles through the failure of his career and marriage. After moving in with his father, Stan (De Niro), Max and his ex-wife Jenna (Byrne) remain at odds on how to best raise their autistic son, Ezra (William Fitzgerald).

Director Tony Goldwyn's family-focused feature hit theaters May 31 from Bleecker Street after debuting at last year's Toronto International Film Festival. Vera Farmiga, Whoopi Goldberg, Rainn Wilson and Goldwyn round out the film's cast.

> *There was a concerted effort to include people in the cast and crew with close personal and family experience with neurodivergence.*

The movie follows Max, a stand-up comic who lives with his father who decides to take his autistic son, Ezra, on a road trip amid questions about the boy's future.

Ezra is played by first-time actor William A. Fitzgerald, now 15, who is on the spectrum. "We were only willing to cast an autistic actor to play the titular role because authentic casting is so important," said Alex Plank, an associate producer who has autism and worked to ensure authentic representation. "I encouraged him to bring his own twist to the character and for everyone to give him the space to experiment with things. That included him ad-libbing some lines that made the character his own."

Later in the preview's footage, Cannavale says, "A dad's job is to take his son down the field. If he gets tackled, all that dad wants is for that kid to pick up the ball and to take it the rest of the way."

Goldwyn (*Conviction, The Last Kiss*) directed the film from a script by Tony Spiridakis. Goldwyn, Spiridakis, William Horberg and Jon Kilik serve as producers.

Ezra premiered at TIFF in September. In his review for *The Hollywood Reporter,* critic Michael Rechtshaffen wrote, "It may possess all the telltale markings of standard-issue fall film fest audience awards fodder, but Ezra, about an 11-year-old who's unmistakably on the spectrum, earns its crowd-hugging stripes legitimately thanks to its superb ensemble and sensitive direction that never gets in the way of its knowing script."

The film's producers said there was a concerted effort to include people in the cast and crew with close personal and family experience with neurodivergence and they screened the film along the way with members of the autism community to get feedback. In addition, the movie's end credits were crafted at Exceptional Minds, a digital arts program for adults with autism.

"As parents of neurodivergent children, everyone's experience is so varied, so wildly different depending on the child," Spiridakis told *Written By*'s Even Henerson. "I hope *Ezra* helps families who are in some sort of turmoil and gives them the indication that this will be difficult, but it can also be the most wonderful experience if you get through it by using humor and just loving each other."

PHOTO COURTESY BLEECKER STREET

WHAT'S HAPPENING

ROLL MOBILITY IS MAPPING ACCESSIBILITY FOR MILLIONS OF PEOPLE WITH MOBILITY ISSUES

Denver, Colorado-based Roll Mobility Inc. introduces Roll Mobility, the innovative app paving the way for improved accessibility and mobility for those with mobility issues across the country.

ON A ROLL: The app is a free, community-driven accessibility tool designed to make life easier for people who use wheelchairs or have mobility issues.

Launched in 2023, Roll Mobility has quickly become the leading app for finding and reviewing accessible locations. With a community of over 1,000 monthly active users and growing, Roll Mobility allows people to search for nearby accessible places like restaurants, stores, hotels, parks and more.

Designed specifically for wheelchair users and individuals with accessibility issues, Roll Mobility takes the guesswork out of venturing into public spaces. Although all public places are supposed to be accessible under the Americans with Disabilities Act (ADA), many establishments are still exempt due to grandfathering clauses. This leaves individuals who utilize wheelchairs uncertain about whether or not they can participate in certain activities, making planning outings a daunting and frustrating task.

A key feature of Roll Mobility is the simple, guided rating scale that allows anyone to contribute reviews. Users just answer a few questions about the physical accessibility of a place, and the app automatically generates a rating - either green for fully accessible, yellow for mostly accessible, or red for not accessible. This crowdsourced accessibility information helps build confidence for the disabled community so they can live active, spontaneous lives.

Says Joe Foster, one of the founders and CEO of Roll Mobility: "The disabled community faces so much uncertainty due to the sheer lack of visibility around accessibility. Is that hot new bakery down the street really wheelchair friendly? Will my friend's apartment be accessible for game night? We created Roll Mobility to solve these daily questions that 12% of American adults with mobility disabilities face."

With new locations and reviews being added by the minute, Roll Mobility's database now includes over 3,000 registered accessible places nationwide and counting. The app also integrates innovative navigation features, including a parking finder for accessible lots and more.

Roll Mobility puts the power back in the hands of the users, providing them with essential information on accessibility features such as ramps, elevators, accessible restrooms, and parking spaces. By leveraging the collective knowledge of its user community, the app creates a reliable and comprehensive database of accessible establishments in the local area, ensuring that individuals can make informed decisions about where to go and what to expect.

As we move towards a more inclusive world, apps like Roll Mobility are crucial to increasing accessibility and giving the disabled community confidence, visibility, and freedom.

Download Roll Mobility for free on iOS and Android. For more info, visit **rollmobility.com**

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MEDICAID 'UNWINDING' DECRIED AS BIASED AGAINST DISABLED PEOPLE

BY DANIEL CHANG

Jacqueline Saa has a genetic condition that leaves her unable to stand and walk on her own or hold a job. Every weekday for four years, Saa, 43, has relied on a home health aide to help her cook, bathe and dress, go to the doctor, pick up medications, and accomplish other daily tasks.

She received coverage through Florida's Medicaid program until it abruptly stopped at the end of March, she said. "Every day the anxiety builds," said Saa, who lost her home health aide for 11 days, starting April 1, despite being eligible. The state has since restored Saa's home health aide service, but during the gap she leaned on her mother and her 23- and 15-year-old daughters, while struggling to regain her Medicaid benefits.

"It's just so much to worry about," she said. "This is a health care system that's supposed to help."

Medicaid's home and community-based services are designed to help people like Saa, who have disabilities and need help with everyday activities, stay out of a nursing facility. But people are losing benefits with little or no notice, getting bad advice when they call for information, and facing major disruptions in care while they wait for the issue to get sorted out, according to attorneys and advocates who are hearing from patients.

UNWOUND: Jacqueline Saa has a progressive genetic condition called Ehlers-Danlos syndrome that leaves her unable to stand and walk on her own. Florida's Medicaid program provides her with a home health aide to help her with various everyday tasks — but she said her coverage abruptly stopped at the end of March with little notice.

In Colorado, Texas, and Washington, D.C., the National Health Law Program, a nonprofit that advocates for low-income and underserved people, has filed civil rights complaints with two federal agencies alleging discrimination against people with disabilities. The group has not filed a lawsuit in Florida, though its attorneys say they've heard of many of the same problems there.

Attorneys nationwide say the special needs of disabled people were not prioritized as states began to review eligibility for Medicaid enrollees after a pandemic-era mandate for coverage expired in March 2023.

"Instead of monitoring and ensuring that people with disabilities could make their way through the process, they sort of treated them like everyone else with Medicaid," said Elizabeth Edwards, a senior attorney for the National Health Law Program. Federal law puts an "obligation on states to make sure people with disabilities don't get missed."

At least 21 million people nationwide have been disenrolled from Medicaid since states began eligibility redeterminations in spring 2023, according to a KFF analysis.

The unwinding, as it's known, is an immense undertaking, Edwards said, and some states did not take extra steps to set up a special telephone line for those with disabilities, for example, so people could renew their coverage or contact a case manager.

As states prepared for the unwinding, the Centers for Medicare & Medicaid Services, the federal agency that regulates Medicaid, advised states that they must give people with disabilities the help they need to benefit from the program, including specialized communications for people who are deaf or blind.

The Florida Department of Children and Families, which verifies eligibility for the state's Medicaid program, has a specialized team that processes applications for home health services, said Mallory McManus, the department's communications director.

People with disabilities disenrolled from Medicaid services were "properly noticed and either did not respond timely or no longer met financial eligibility requirements," McManus said, noting that people "would have been contacted by us up to 13 times via phone, mail, email, and text before processing their disenrollment."

Allison Pellegrin of Ormond Beach, Florida, who lives with her sister Rhea Whitaker, who is blind and cognitively disabled, said that never happened for her family.

"They just cut off the benefits without a call, without a letter or anything stating that the benefits would be terminating," Pellegrin said. Her sister's home health aide, whom she had used every day for nearly eight years, stopped service for 12 days. "If I'm getting everything else in the mail," she said, "it seems weird that after 13 times I wouldn't have received one of them."

Pellegrin, 58, a sales manager who gets health insurance through her employer, took time off from work to care for Whitaker, 56, who was disabled by a severe brain injury in 2006.

Medicaid reviews have been complicated, in part, by the fact that eligibility works differently for home health services than for general coverage, based on federal regulations that give states more

PHOTO BY JACQUELINE SAA

flexibility to determine financial eligibility. Income limits for home health services are higher, for instance, and assets are counted differently.

In Texas, a parent in a household of three would be limited to earning no more than $344 a month to qualify for Medicaid. And most adults with a disability can qualify without a dependent child and be eligible for Medicaid home health services with an income of up to $2,800 a month.

The state was not taking that into consideration, said Terry Anstee, a supervising attorney for community integration at Disability Rights Texas, a nonprofit advocacy group.

Even a brief lapse in Medicaid home health services can fracture relationships that took years to build.

"It may be very difficult for that person who lost that attendant to find another attendant," Anstee said, because of workforce shortages for attendants and nurses and high demand.

Nearly all states have a waiting list for home health services. About 700,000 people were on waiting lists in 2023, most of them with intellectual and developmental disabilities, according to KFF data. Daniel Tsai, a deputy administrator at CMS, said the agency is committed to ensuring that people with disabilities receiving home health services "can renew their Medicaid coverage with as little red tape as possible."

CMS finalized a rule this year for states to monitor Medicaid home health services. For example, CMS will now track how long it takes for people who need home health care to receive the services and will require states to track how long people are on waitlists.

Staff turnover and vacancies at local Medicaid agencies have contributed to backlogs, according to complaints filed with two federal agencies focused on civil rights.

The District of Columbia's Medicaid agency requires that case managers help people with disabilities complete renewals. However, a complaint says, case managers are the only ones who can help enrollees complete eligibility reviews and, sometimes, they don't do their jobs.

Advocates for Medicaid enrollees have also complained to the Federal Trade Commission about faulty eligibility systems developed by Deloitte, a global consulting firm that contracts with about two dozen states to design, implement, or operate automated benefits systems.

KFF Health News found that multiple audits of Colorado's eligibility system, managed by Deloitte, uncovered errors in notices sent to enrollees. A 2023 review by the Colorado Office of the State Auditor found that 90% of sampled notices contained problems, some of which violate the state's Medicaid rules. The audit blamed "flaws in system design" for populating notices with incorrect dates. Deloitte declined to comment on specific state issues.

In March, Colorado officials paused disenrollment for people on Medicaid who received home health services, which includes people with disabilities, after a "system update" led to wrongful terminations in February.

Another common problem is people being told to reapply, which immediately cuts off their benefits, instead of appealing the cancellation, which would ensure their coverage while the claim is investigated, said attorney Miriam Harmatz, founder of the Florida Health Justice Project.

"What they're being advised to do is not appropriate. The best way to protect their legal rights," Harmatz said, "is to file an appeal."

But some disabled people are worried about having to repay the cost of their care. Saa, who lives in Davie, Florida, received a letter shortly before her benefits were cut that said she "may be responsible to repay any benefits" if she lost her appeal.

The state should presume such people are still eligible and preserve their coverage, Harmatz said, because income and assets for most beneficiaries are not going to increase significantly and their conditions are not likely to improve.

The Florida Department of Children and Families would not say how many people with disabilities had lost Medicaid home health services.

But in Miami-Dade, Florida's most populous county, the Alliance for Aging, a nonprofit that helps older and disabled people apply for Medicaid, saw requests for help jump from 58 in March to 146 in April, said Lisa Mele, the organization's director of its Aging and Disability Resources Center. "So many people are calling us," she said.

> **"Saa received a letter shortly before her benefits were cut that said she 'may be responsible to repay any benefits' if she lost her appeal."**

States are not tracking the numbers, so "the impact is not clear," Edwards said. "It's a really complicated struggle."

Saa filed an appeal March 29 after learning from her social worker that her benefits would expire at the end of the month. She went to the agency but couldn't stand in a line that was 100 people deep. Calls to the state's Medicaid eligibility review agency were fruitless, she said.

"When they finally connected me to a customer service representative, she was literally just reading the same explanation letter that I've read," Saa said. "I did everything in my power." Saa canceled her home health aide. She lives on limited Social Security disability income and said she could not afford to pay for the care.

On April 10, she received a letter from the state saying her Medicaid had been reinstated, but she later learned that her plan did not cover home health care.

The following day, Saa said, advocates put her in touch with a point person at Florida's Medicaid agency who restored her benefits. A home health aide showed up April 12. Saa said she's thankful but feels anxious about the future.

"The toughest part of that period is knowing that that can happen at any time," she said, "and not because of anything I did wrong."

KFF Health News correspondents Samantha Liss and Rachana Pradhan contributed to this report.

ABOUT THE AUTHOR:

Daniel Chang, Florida correspondent, covers Florida and the South. He joined KFF Health News in 2022 after 22 years at the Miami Herald, where his health care reporting focused on access to care for low-income patients; accountability of physicians, hospitals, and state health agencies; and the covid-19 pandemic. He co-reported the series "Birth & Betrayal," about a Florida program that shields doctors from liability for catastrophic birth-related injuries, which received a George Polk Award for state reporting. He was part of the team awarded the Pulitzer Prize for breaking news for coverage of the Surfside, Florida, condominium collapse in 2021. A graduate of Florida International University, he is a native Floridian and fluent in Spanish.

WHAT'S NEW

MORE SUN MORE FUN

HANGING CHAIR POD

This rugged hanging chair pod provides children with a quiet and warm place to play while bringing them a sense of security and providing a soothing feeling. Hung indoors or out, it can help them regulate their senses in order to relax their body and mind. Made from 100% cotton canvas material with double seamed, reinforced nylon edges and featuring a soft PVC air cushion, the hanging chair pod can hold up to 200 pounds and is easy to disassemble and store at any time. This unique swing chair has a built-in side pocket design for children to stow books, tablets, toys or other objects to keep them close by. Includes hanging tent, inflatable cushion, air pump, rope, hook, wall fixture, bolts, and detailed instructions for safe installation and use. The hanging chair pod will not let you down!

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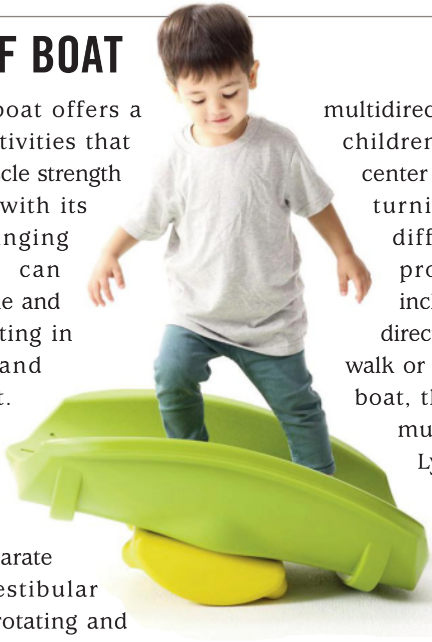

This rocking leaf boat offers a variety of sensory activities that improve children's muscle strength and balance control with its rotating and swinging platforms. Children can swing and turn the table and imagine they are floating in the water, turning and landing on the raft. Toddlers can sit safely in the rocking leaf boat, or they can stand, sit or lie on it and have fun. Two separate bases provide vestibular stimulations such as rotating and multidirectional wobbling so that children learn to change their center of gravity by rocking or turning the boat. The two different base structures provide stimulation, including rotation and multi-directional swing. As children walk or crawl across the rocking boat, their concentration and muscle strength improves. Lying in the rocking boat improves children's core strength and upper muscle fitness.

WEPLAY
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FUN SUN PLUSH TOY

This fun sun plush toy is here to brighten up the room, but there's no need for shades or sunblock – this chubby, cuddly bundle of rays is content to glow softly and warm your child's heart. He's an all-weather friend in buttery gold, sporting cheery corduroy chocolate feet. Kids of any age will love this cute character, perfect for hugging, playing and relaxing.

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SUCTION CUP ROBOTS

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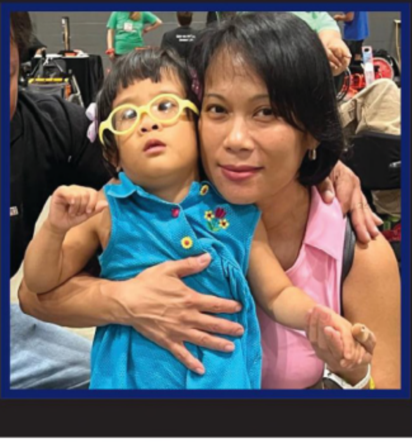

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COMMUNITY INCLUSION INCLUDES THE ARTS

ART IS ESSENTIAL: An artist discusses her work at an VSA Access Special Arts exhibition at the Kennedy Center in New York City.

BY LAUREN AGORATUS, M.A.

Inclusion of people with disabilities must include all facets of community life, including the arts.

ART AND COMMUNITY INCLUSION

Individuals with disabilities have the right to be included fully in their communities. The arts are a key component of community life, and so they must be fully accessible to people with disabilities. In *Why Is Art Essential for the Human Experience,* Ethan Garcia writes, "Art can inspire us to think and feel deeply, and to engage with the world around us in new and meaningful ways. It can also have a significant impact on our mental health and well-being, by providing us with a sense of purpose and meaning, and by helping us cope with difficult emotions and experiences." Inclusion of people with disabilities in the arts improves their overall wellbeing and quality of life.

HOW PEOPLE WITH DISABILITIES CAN BE INCLUDED

There have been organizations for people with disabilities such as VSA Access Special Arts *(see Resources)* for many years. VSA is just one example and offers workshops and special education training. Some of their categories are:

- *Young musicians*
- *Playwright discovery*
- *Emerging artists*

The movement has changed from focusing on events specific to those with disabilities, to making events and participation in the arts accessible to all.

NEW INCLUSIVE INITIATIVES IN ART

Technology has played a key role in disability accessibility, including the arts. There are adaptive art tools and other assistive technology. Tools could include accommodations for both physical and intellectual/developmental disabilities (I/DD). For example, people with visual impairments can use color identifying apps. Individuals with intellectual/developmental disabilities can have the art process broken down into a series of steps or tasks. Eye

PHOTO COURTESY ACCESS VSA

tracking software can help people with paralysis to draw digital art. Voice activated software can help create projects.

FINDING THE RIGHT TECHNOLOGY

According to AbilityX *(see Resources),* helpful apps include:

- ✓ *Adobe Creative Suite - voice activated and also software for visual impairment*
- ✓ *Procreate – digital drawing or painting*
- ✓ *Doodle Buddy – drawing with stamps or stencils*
- ✓ *ArtRage – imitates mediums such as oil painting, watercolor, charcoal drawings*

AbilityX also notes some speech and language apps to help with the creative process.

A new venue, called Access Gallery in Denver, CO, provides a way for artists with disabilities to have a career in art. The gallery "combats ableism through art." They use artwork to breakthrough stereotypes of people with disabilities. Access Gallery is free and open to the public. This is an inclusive non-profit organization where people with disabilities can sell their artwork. As the AbilityX article states, art without limits can empower artists with disabilities.

CENTERS FOR INDEPENDENT LIVING

There are Centers for Independent Living in each state which help people with disabilities with independent living skills. Visit **www.ilru.org/projects/cil-net/cil-center-and-association-directory**

The Progressive Center for Independent Living in NJ shared with us some of the artwork created during their recreation sessions:

Sunny days are light
Sunlight brings smiles to our faces
Dark thoughts disappear
Fluffy dogs are cute
Goofy ones bring joy to all
Love goofy fluff balls

— by Sammie Saat *(with permission)* •

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**).

EXPRESS YOURSELF : INCLUSION FOR PEOPLE WITH DISABILITIES IN THE ARTS

AbilityX

ART WITHOUT LIMITS:
Empowering Artists with Disability Through New Technologies on Creativity
https://abilityx.io/news/art-without-limits-empowering-disabled-artists-with-new-technologies-on-creativity

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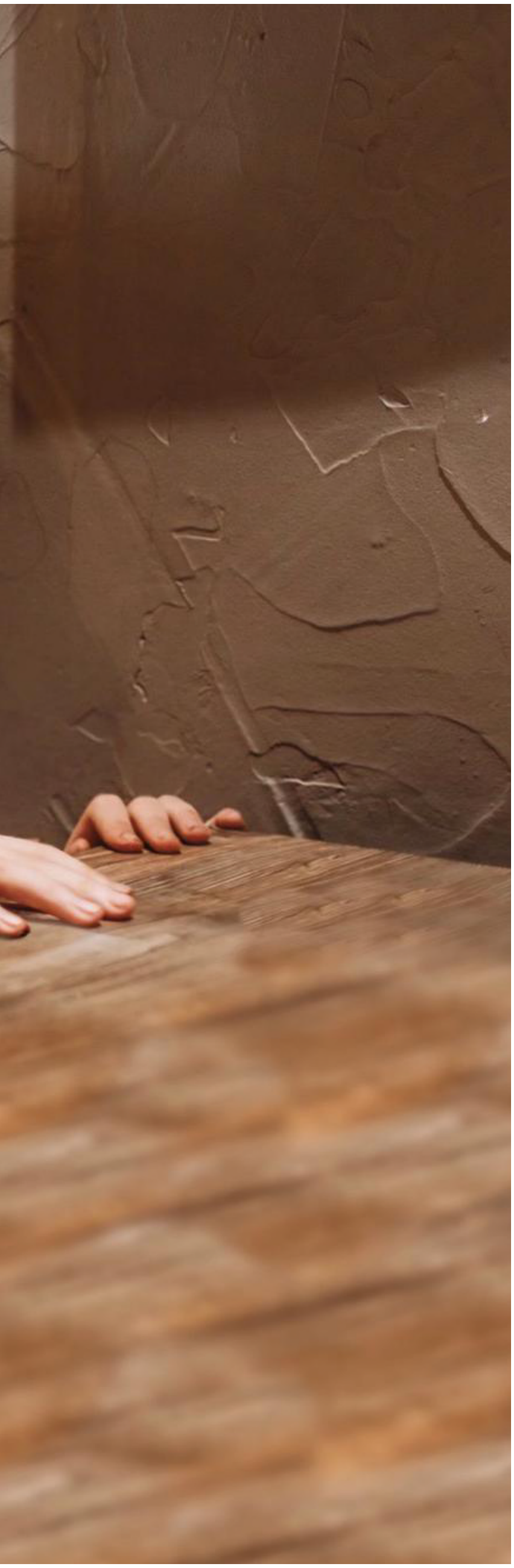
“These tips for summer planning can help ensure that your child has a safe, enjoyable and enriching summer experience.”

SUMMER PLANNING FOR AUTISTIC CHILDREN

BY MARTA CHMIELOWICZ

Summer is here, bringing with it beach trips, bike rides, family vacations, and carefree days. While the break from the school year gives families opportunities to make new memories, for parents of autistic children of all ages, the arrival of summer can also present unique challenges. The disruption of familiar routines and environments can be difficult for some autistic children, and limited access to school-based or other support services can lead to regression of skills.

PHOTO PROVIDED BY EILEEN LAMB



SLICE OF LIFE: Charlie *(left)* and his younger brother Jude anticipating their pizza; "Encouraging opportunities to pursue the autistic child's interests and incorporating them into learning and social activities can help encourage autistic children to engage and participate in summer activities."

However, with thoughtful planning, families can create inclusive summer experiences that meet their child's needs, ensuring that all family members can enjoy everything summertime has to offer.

Here are some tips for planning summer activities for your autistic child:

1. SUMMER DAY CAMPS

These camps can offer opportunities for growth and socialization in a structured and supportive environment – but finding a good fit is essential.

One key aspect of successful summer planning is communication. Before enrolling your child in camps and activities, speak with the organizers to discuss your child's needs and any necessary accommodations. This will help you decide whether the activity is a good fit and help you identify any potential challenges. The more specific you are about your child's needs, the better they can be accommodated.

Eileen Lamb, autistic advocate, mother of three, founder of @theautismcafe, and social media director at Autism Speaks, says that safety is her top priority when choosing a summer program for her son Charlie, who has level 3 autism. Charlie experiences severe challenging behaviors, like elopement, pica (the compulsive eating of non-food items) and aggression, that require constant monitoring and support. Before enrolling Charlie in a summer program, Eileen meets with the camp organizers to discuss his behaviors and makes sure that they have the needed experience.

> "Speaking to the organizers will help you decide whether the activity is a good fit and help you identify any potential challenges."

"Charlie is nonverbal and communicates basic needs with his iPad, so camp employees need to have a basic understanding of how to navigate an augmentative and alternative communication (AAC) device. I also need them to be able to keep track of his behaviors, because that's one of the ways we understand how he's feeling. I also like when they have experience with applied behavior analysis (ABA) and know strategies to redirect him and keep him safe."

Because Charlie is nonverbal, Eileen says that it can be difficult to find programs where he is understood. He often can't communicate why he is in distress, so it's important for organizers to have good instincts and lots of experience working with autistic children with high support needs.

"Another good tip I have, is writing things down for people he's going to be with, like you do with a babysitter," Eileen adds. "I give them little tips and tricks about Charlie: like things he likes and things he doesn't like. I also give them a copy of our behavioral intervention plan, so they have an idea of how to deal with the behaviors, if they emerge."

2. SPECIAL INTERESTS

Keep in mind your child's special interests when choosing summer activities.

A great way for autistic children to form connections and build relationships with others is through shared interests. Many children with autism have special interests, or intense areas of focus, and enthusiasm around certain topics, TV shows or activities. Special interests can vary widely among autistic people, ranging from trains and dinosaurs to music and technology.

Understanding and respecting an autistic child's special interests is important for supporting their well-being and fostering their strengths. Encouraging opportunities to pursue their interests and incorporating them into learning and social activities can help encourage autistic children to engage and participate in summer activities.

Summer camps and clubs often offer a variety of activities spanning different interests, such as: sports, arts and crafts, nature and more. For example, this year, Eileen's younger son Jude, who has level 1 autism, will be attending soccer camp. In previous years, he attended space camp and chess camp.

"I have two very different approaches when choosing activities for Charlie and Jude because of their very different needs," says Eileen. "For Charlie, my main concern

VARIATIONS ON A THEME: *(Above left)* Charlie cools off by the pool; *(Above right)* Jude enjoying a summer snack; “I have two very different approaches when choosing activities for Charlie and Jude because of their very different needs. For Charlie, my main concern is safety. For Jude, my main concern is that he has fun and enjoys his interests, because his needs are different from Charlie’s.”

is safety. For Jude, my main concern is that he has fun and enjoys his interests, because his needs are different from Charlie’s. He can keep himself safe. With Charlie, at any second he can bolt and elope.”

3. SUPPORT

Think about the support your child needs to prepare them for the new activity.

Many autistic children thrive on routine and predictability. The shift from the structured school day to the less predictable summer schedule can be upsetting to some, leading to increased anxiety and difficulty coping with change. In these cases, it may be helpful to use visual schedules and social stories before the activity, to show your child what they can expect. Autism Speaks offers resources on how to use visual supports and social stories to prepare children for new events and activities.

If your child is nervous about participating in a summer camp or activity, providing emotional support and reassurance is key. “Jude has anxiety, and sometimes he doesn’t want to go to camp in the morning because he’s afraid he’s not going to have fun,” says Eileen. “We always try to remind him that he’ll have fun, that he’s never regretted participating before, and that if anything happens and he wants to go home, we’re just a phone call away. It’s really just giving him reassurance that, worst-case scenario, we’re 10 minutes away, we’ll pick him up, and he’s safe. At the end of the camp, he’s usually sad it’s over and wants to go again.”

After the activity, your child may need quiet time to recover from a sensory-intensive activity, or an opportunity to move after a sit-down activity.

4. FURTHER OPTIONS

If summer camps are not an option, consider extended school year programs or therapies to prevent summer regression.

Many autistic children experience summer regression, or a decline or loss of skills and progress over the summer break from school. Whether it's continuing therapy sessions, participating in extended school year programs, or incorporating skill-building activities into daily routines, maintaining consistency and structure can help reduce regression.

This year, Eileen says that Charlie qualified for an extended school year, meaning that he will be attending school for the full month of June. “To get an extended school year, you need to prove that if the child doesn’t attend over the summer, they will regress,” explains Eileen. “It’s not necessarily easy to prove, but since we track Charlie’s behaviors, we could show that the challenging behaviors increased over last summer and that he did regress without extended school .” Once the extended school year ends, Charlie will attend full-time ABA sessions to build his communication skills.

By following these tips for summer planning and recognizing the unique needs of autistic children during the summer months, you can help ensure that your child has a safe, enjoyable and enriching summer experience. •

ABOUT THE AUTHOR:

Marta Chmielowicz is the Content Manager of Mission Delivery at Autism Speaks, where she leads science communications to advance the mission of Autism Speaks to create an inclusive world for all individuals with autism throughout their lifespan.

SUMMER fun

MAKING CONNECTIONS

BY PAMELA AASEN

For individuals with disabilities and their families, the world can feel isolating. But as I've seen throughout my journey with my sons, finding a supportive community can be transformative. Camps like USHthis demonstrate the power of connection.

DIRECT CONNECTION: *(From left)* Ethan, Ava, and Gavin at USHthis UK summer camp 2022; The camp provides an opportunity for youth with Usher syndrome to engage with peers and mentors with Usher syndrome, learn about available resources, acquire strategies to resolve challenges, and foster connections that will last a lifetime.

PHOTOS PROVIDED BY PAMELA AASEN

Providing a safe space where individuals with disabilities can connect with peers who understand their unique challenges can foster a supportive community that empowers them to build confidence and thrive.

These experiences lead to lasting friendships, foster a sense of belonging, and reduce feelings of isolation. In my January 2021 article for this magazine, I wrote about the importance of mentors, role models, and peers as necessary supports to help a child with a disability be successful. They need mentors to help guide them, role models who can inspire them, and peers who can understand them. These connections can be forged in diverse settings such as: specialized summer camps, school vacation programs, online communities, local support groups, and conferences offered by different disability organizations.

I was first exposed to the importance of having a place to make these connections 40 years ago. My first summer job and an experience that solidified my career choice as a Special Education teacher was in 1984 when I worked as a counsellor at a summer camp in New Brunswick, Canada for children and adults with various disabilities. For over seven decades, Camp Rotary has hosted hundreds of campers across the province, offering a supportive and judgement-free environment where the campers can explore their potential, and create lasting memories.

It was a profound experience and the first time I became aware that, when children are surrounded by others who face similar challenges, they feel more comfortable trying new things and pushing their boundaries. The surge in confidence and self-esteem can be transformative and empowering, and demonstrated the importance of being involved in a community that shares the same lived experience. Bringing this experience and understanding to the classroom helped me as a teacher, but it became deeply personal when my own children were diagnosed with Usher syndrome. I had to think about finding opportunities where they could make these connections.

My sons, Ethan and Gavin, were born deaf, are progressively losing their vision, and have severe balance issues due to vestibular dysfunction. Early on, before we learned of the Usher Syndrome diagnosis, we sought out events to connect with others going through the anxiety and intenseness of auditory verbal therapy to teach our children to listen and speak. We only knew about their hearing loss at that time, and had chosen cochlear implants.

Since Usher syndrome is a rare genetic disorder affecting multiple senses, it creates a unique set of needs for children. Finding opportunities that catered to these specific needs was a challenge.

Attending family education and recreational events hosted by the Cochlear Implant Program at the Hospital for Sick Children in Toronto became our first bridge to making connections. Here, surrounded by other families who also have children with hearing loss, we began building a network of support. These special events that happened three or four times a year were milestone moments, as we saw the excitement Ethan and Gavin felt seeing other children with cochlear implants. One of the family day

SEEN AND HEARD: *(Left)* Ethan, Ava, and Gavin at USH Connections Conference 2022; *(Right)* Ethan and Gavin introduce a speaker at the conference.

BROTHERS IN ARMS: The Morrobel brothers at USHthis Camp in 2019; "Held for the first time in the United States in 2019 and again in 2023, USHthis provided a space for connection and shared experiences, specifically designed for young people with Usher syndrome. At USHthis, campers forge lasting bonds with mentors, role models, and peers who truly understand their challenges."

events took place at a summer camp, and it was a joy watching the children surrounded by nature, enjoying a variety of activities where the children could participate while connecting to peers in a supportive environment.

We wanted to further these opportunities, so we looked for organizations in our area that provided events for learning and building a supportive community. We participated in conferences organized by VOICE, an organization dedicated to families with children who are deaf or hard of hearing. Through their programs and services, we gained valuable information and support that enriched our knowledge and connected us with experts in the field of hearing loss. Their annual VOICE Family Camp is a weekend retreat that provides a space for families to connect on a deeper level, share experiences, and build lasting friendships. The camp offers a variety of activities including educational workshops, outdoor adventures and social events, all designed to foster communication and create a strong sense of community.

> **"Deafness is an integral part of Ehtan and Gavin's identity. As hearing parents, we simply wanted to offer them the opportunity to connect with the hearing world."**

During this time, I also became a Volunteer Advocate for Cochlear Canada and eventually ended up working part-time as the Volunteer Advocate Coordinator. It was a great opportunity to make personal and professional connections. I even got to attend Cochlear University at the North American headquarters in Denver, Colorado. In the process of trying to help others, I gained valuable knowledge about hearing loss, for my family. Collaborating with other advocates, professionals, and families created an amazing support system that helped me feel connected. As much as I was trying to build connections for my children, my husband and I needed it as well.

While choosing cochlear implants and listening and spoken language for Ethan and Gavin, we also wanted them to explore the Deaf Community. It wasn't about "fixing" them. Deafness is an integral part of their identity. As hearing parents, we simply wanted to offer them the opportunity to connect with the hearing world. Recognizing the rich diversity within the Deaf Community, we sought experiences that went beyond cochlear implants. Silent Voice Canada offered an ASL summer camp for deaf and hard of hearing children that, alongside their Family Communication Program, provided an introduction to the Deaf community. It was an amazing experience that I brought with me years later, when I had the opportunity to start New Jersey's first Deaf Mentor Program in 2018 through the SPAN Parent Advocacy Network.

In 2009, when the boys were 5 and 7 years old, we were faced

USH Partners support the community building efforts of the Usher Syndrome Coalition, ensuring our collective ability to find and support everyone living with Usher syndrome.

Brothers Ethan and Gavin Morrobel were diagnosed with Usher syndrome type 1B when they were 5 and 7 years old...just as they were becoming proficient users of listening and spoken language. This began a litany of appointments with new specialists and more meetings with their school. They met their new challenges head-on, advocating for themselves, spreading awareness, raising money and eventually becoming Student Ambassadors for Ava's Voice. Ethan and Gavin live by their motto, 'If it doesn't challenge you, it doesn't change you.'

Ethan and Gavin Morrobel
Ages 17 and 14
Both have USH 1B
New Jersey USA

FULLY ENGAGED: *(Above left)* Pam and her husband Carlito at the USH Connections Conference 2019; *(Above right)* the brother's portrait for the Usher Syndrome Society's Shine a Light on Usher Syndrome display at the USH Connections Conference 2022; "Sharing experiences with mentors, role models, and peers who understand, fosters confidence, reduces isolation, and empowers individuals to thrive."

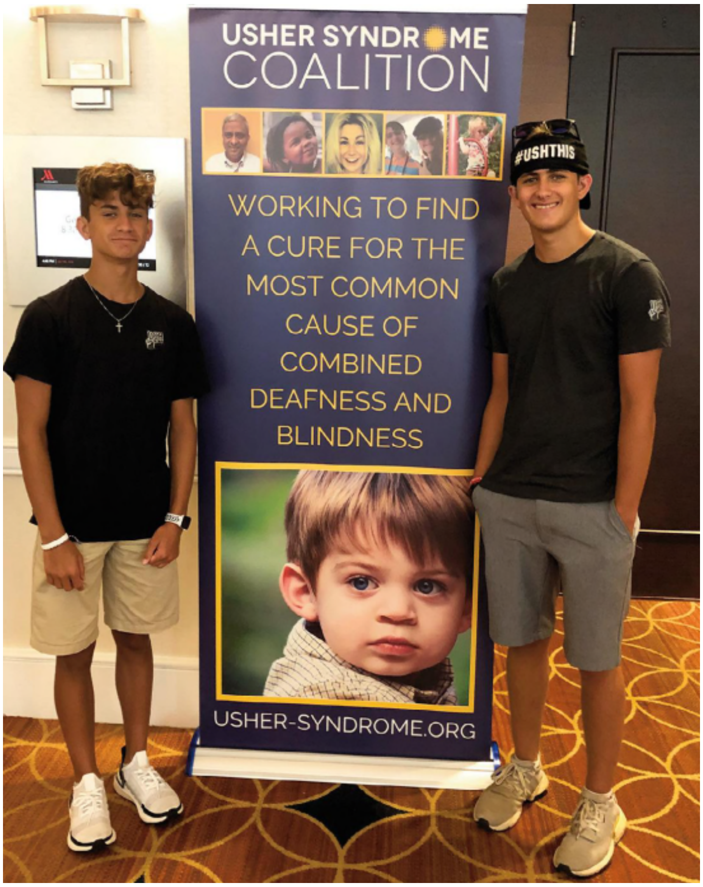
with a new reality that would challenge us and redefine our future. With the diagnosis of Usher syndrome, our previously supportive community dynamic seemed to alter. We found ourselves feeling isolated again, facing a new reality that felt outside the scope of our established connections. The grief we had tucked away after the initial hearing loss diagnosis resurfaced, this time deeper and more profound. It was as if the rug had been pulled out from under us. We were back to square one, lacking the knowledge and experience to navigate this new situation. In some ways we were starting over and had to find a new community of support that understood the challenges of Usher syndrome.

> **"Ethan and Gavin's presentations became a powerful tool, not just to educate, but also to demonstrate the strength found in shared experiences."**

The first organization we connected with was the Fighting Blindness Canada (FBC). We actively participated in the annual learning series and conferences they offered, that brought families living with vision loss together with researchers. Raising awareness for this rare condition and supporting research were initial priorities. We started an annual golf tournament called Twilight for Sight and Sound that raised money for Fighting Blindness Canada and the Hospital for Sick Children Cochlear Implant Program. Finding treatments or a cure remains a constant aspiration, but we also felt that we were missing a supportive community specifically for families like ours. We pictured a network of mentors, peers, and role models who could share their experiences with our children, and provide invaluable guidance and inspiration, equipping them with the tools to navigate their own paths with strength and resilience.

During this time, Ethan and Gavin were building upon the unique connection they shared as brothers, both having Usher syndrome. Speaking and presenting together at schools, university classes, and teacher training workshops wasn't just about advocacy. Their presentations became a powerful tool, not just to educate, but also to demonstrate the strength found in shared experiences. My husband and I also felt that talking to others would help them understand their differences, while at the same time highlighting for themselves and others, what made them special. Since it was what we were given in life, we were grateful they had each other, but still felt they needed others who understood the challenges of living with Usher syndrome.

Then, my husband discovered the Usher Syndrome Coalition, which was founded by the Dunning family in Boston in 2008 to build a network of support. He joined the monthly calls that began in 2010, giving us a connection to the community we



POSTER BOYS: Ethan and Gavin at USH Connections Conference 2019; "Organizations like Ava's Voice and the Usher Syndrome Society are lifelines, offering not only support but also inspiration and hope for a brighter future."

were searching for. However, we still lacked the support of having other families around us. That changed in 2014 when an opportunity presented itself for my husband in his company. But it meant moving our family to New Jersey. Finding connections with other families facing Usher syndrome was a top priority. Before we made the decision to move, the Usher Syndrome Coalition connected us to the Center on Deafblindness in New Jersey, and initial conversations gave us the assurance we needed to make this change for our family. The Usher Syndrome Coalition is now a global resource for families and researchers. The monthly support calls eventually became the USH Connections conference.

> **"Having a peer like Ava provides a unique sense of freedom and acceptance. Sharing similar challenges allows them to embrace life with a shared outlook."**

Through the Center on Deafblindness, I connected with Carly Fredericks, a passionate advocate for her daughter Ava, who also has Usher syndrome. This connection sparked a friendship between our families, and together, we embarked on a mission to provide the support network we craved for so many others. Carly had founded Ava's Voice, an organization with the mission of empowering youth with Usher syndrome, and to educate families and school communities. Ethan, Gavin, and Ava fulfill that mission through speaking and presenting about Usher syndrome at workshops, schools/universities, teacher trainings, parent to parent meetings, fundraisers, retreats, conferences, and family activities. My sons certainly understand each other deeply, but their connection with Ava added another dimension. Having a peer provided a unique sense of freedom and acceptance. Sharing similar challenges fosters a bond that is without judgment, and allows the three of them to embrace life with confidence and a shared outlook.

Through attending the USH Connections Conference, I was introduced to the Usher Syndrome Society. It was founded by Nancy Corderman, the mother of two children diagnosed with Usher syndrome, which aims to raise awareness and accelerate research. Through initiatives like photo exhibits, video journalism, live discussions, and experiential fundraising events, the Society educates the public about the realities of living with Usher syndrome, fosters a supportive community, and raises funds for research towards effective treatments. My sons have been featured in their Sense Stories, and their portraits are proudly displayed in the Society's Shine a Light on Usher Syndrome exhibits. The Society also creates docuseries and films to further raise awareness and inspire hope. Our family enthusiastically supports their efforts any way we can.

The connections we've forged with other families affected by Usher syndrome has been a lifeline. Sharing this journey with those who understand the unique challenges we face has been invaluable. Over the past two decades, we've navigated uncharted territory, learning countless lessons along the way. Writing these articles allows me to share our story, hoping to make the path a little easier for other families who are, like we once were, faced with the devastation of the diagnosis, and wondering what the future will look like.

We have actively sought opportunities for Ethan and Gavin to connect with their peers. While programs like the Rochester Institute of Technology's "Explore Your Future" for deaf and hard-of-hearing students provided valuable experiences, a critical gap remained: the lack of experiences specifically tailored for young people with Usher syndrome. This is where the connection with Carly and Ava's Voice came in. Working together over the last several years to empower youth with Usher syndrome, we recognized the distinct need to create opportunities for those connections. Witnessing the positive impact of the connection between Ethan, Gavin, and Ava fueled the desire to create similar opportunities for others.

This shared vision materialized in the form of the USHthis Summer Youth Camp. Held for the first time in the United States in 2019 and again in 2023, USHthis provided a space for connection and shared experiences, specifically designed for young people with Usher syndrome. At USHthis, campers forge lasting bonds with mentors, role models, and peers who truly understand their challenges. Since its inception, the camp has expanded beyond its US roots. Thanks to the incredible connections made with Chloe Joyner from Usher Kids UK, USHthis hosted successful camps in

MAKING CONNECTIONS : USHER SYNDROME INFORMATION AND RESOURCES

CAMP ROTARY
New Brunswick, Canada
www.camprotary.ca

AVA'S VOICE
https://avasvoice.org

USHERKIDS UK
www.usherkidsuk.com

USHERKIDS AUSTRALIA
www.usherkidsaustralia.com

ROCHESTER INSTITUTE OF TECHNOLOGY
National Technical Institute for the Deaf
www.rit.edu/ntid

COCHLEAR AMERICAS
www.cochlear.com/us/en/home

VOICE
For Children who are Deaf or Hard of Hearing
www.voicefordeafkids.com

SILENT VOICE CANADA
https://silentvoice.ca

FIGHTING BLINDNESS CANADA
www.fightingblindness.ca

SPAN PARENT ADVOCACY NETWORK
https://spanadvocacy.org

the UK in 2022 and 2023. The future is bright, with camps planned in both the US and the UK for 2024. Further connections with Emily Shepard and Holly Feller, the founders of Usher Kids Australia, promise exciting possibilities for bringing USHthis Down Under in 2025.

The Usher Syndrome Coalition is a central hub for the global Usher syndrome community. Their mission is to connect individuals living with Usher syndrome to essential resources, ongoing research efforts, and most importantly, each other. The Coalition achieves this by working alongside a network of dedicated organizations called USH Partners. This collaboration allows the Coalition to continuously grow connections and support within the Usher community. USH partner Ava's Voice provides an opportunity to make those connections at the USH Connections Conference for youth with Usher syndrome from birth to 17 years old. USHangouts provides a space for them to build friendships, share experiences, and gain strength from their shared journey. USH partner the Usher Syndrome Society offers conference participants with Usher syndrome the opportunity to have their portraits taken and share their personal stories for the "Shine a Light on Usher Syndrome" exhibit to give a face and voice to this rare disease.

For individuals with disabilities and their families, the world can feel isolating. But as I've seen throughout my journey with my sons, Ethan and Gavin, finding a supportive community can be transformative. Camps like USHthis, conferences like USH Connections hosted by the Usher Syndrome Coalition, and organizations like Ava's Voice and the Usher Syndrome Society demonstrate the power of connection. The Usher Syndrome Society further amplifies the power of connection by sharing stories through their photo exhibits, films, and documentaries. These narratives not only educate the public, but also foster empathy and inspire hope. Sharing experiences with mentors, role models, and peers who understand, fosters confidence, reduces isolation, and empowers individuals to thrive. These connections are lifelines, offering not only support but also inspiration and hope for a brighter future. By fostering connections, we can empower individuals, regardless of ability, to feel included and reach their full potential. •

ABOUT THE AUTHOR:

Pamela Aasen is a graduate of UNB in Canada with Undergraduate degrees in Early Childhood and Special Education and a Master's degree in Special Education. Pam has 25 years of teaching experience working with diverse communities in the U.S., Canada and the Dominican Republic. She is the mom of two sons with Usher syndrome. For the last 10 years she has worked in a professional capacity in the Deaf, Hard of Hearing, and Deafblind community. In 2020 Pamela received the Early Hearing Detection and Intervention (EHDI) National Family Leadership Award.

Traveling with your service dog will provide you with the continued help and comfort you have at home.

They love to assist you and want to be with you, to be sure you are well taken care of.

Travel and Summer Fun with a Service Dog

BY ELLEN LENOX SMITH

It is amazing how traveling with a service dog can provide so much assistance for you. Before the passing of my service dog, Maggie, I learned she was able to relieve me of the burdens that traveling adds to a medically compromised person. So, let me share what I mean by this!

Useful Vest

A service dog usually wears a vest with zippered pockets on both sides. I liked using this, not only to identify that she was a working, skilled girl, but also for my convenience, with limited ability to hold any weight with my arms. I was able to put my medications, earplugs for flying, credentials needed to identify me, money, and even my tickets in those pockets, to have easy access to them. For fear of possibly losing access to her food if put into a carry-on or checked-in suitcase, I filled her measured food meals into those pockets, too. I was also able to include a traveling bowl that folds up, into the pockets, so that I could always, easily take a moment to give her a drink.

WOMAN'S BEST FRIEND: Maggie was alway's by the author's side. "Since Maggie passed, I can't tell you how many people still continue to ask where she is, for she made an impression on others in such a positive way."

Using Her Mouth

I had times of having to travel in a wheelchair, which can truly limit flexibility and movement. So, my service dog was able to carry my tickets in her mouth and even hand them to the correct person, all on command. She was able to carry a plastic bottle of water, also. In hotels (like at home), she was able to assist in opening the refrigerator or cupboard that had a rope on them. She was commanded to tug the rope to open the door, and able to then close it with her paws, or by nudging her nose against the door. While in a refrigerator, my service dog was trained to find my medicine bag or container of water, and then hand it to me. After, she was commanded to close the door.

Using Paws and Nose

A service dog has the capacity, upon command, to provide assistance by using their nose or paw to open a door by pushing the handicap button. I even was able to have her trained to nudge the nightly air mattress that I used, which had to be inflated each evening. In the AM, she was able to turn it back off, preventing me from having to bend or get out of bed, especially since my leg braces were off, as I take them off when I sleep.

Comfort and Calming

Living life as a handicapped person certainly creates stress, and at times while traveling. An example is, when you are expected to climb up the stairs to get into a plane when you aren't able to. So, the whole group of passengers has to wait while they bring the portable ramp to the airplane, so you can be pushed up. This feels embarrassing to me, so having had her to reach out to comfort me, was magical. I always found that just rubbing my fingers between the tip of her ears calmed me down. And then, having her at my feet on a plane or train continues to provide a calming effect. Service dogs are allowed with you which is a true gift of comfort, whether on a train, plane, boat, or in a car, etc.

Peace Of Mind

A caregiver will also report, as my husband constantly expressed, that a service dog allows some peace of mind for them. Leaving a medically needy person you care for with the service dog, gives an opportunity for a caregiver to step away. The dogs can be trained to even search for the phone, when needed. They provide company and the much-needed help they are trained for.


AT YOUR SIDE: Maggie monitors the author at the pool *(left),* and on on a plane *(right).* “In her backpack, Maggie was able to carry my pool cards, earplugs, goggles, and phone, for possible emergencies. On top of that, a well-trained service dog is able to stay on command at the side of the pool, as another lifeguard for you”

Her Presence

When people observe a truly well-behaved service dog, I have found that they tend to have a heart and show more compassion. Also, I experienced with people drawn to her, that my husband and I were connected to more social contacts. In fact, since she passed, I can’t tell you how many people still continue to ask where she is, for she made an impression on others in such a positive way. She also symbolized that I had medical challenges.

Examples of Summer Activities

The Beach: A service dog is allowed on the beach to assist you. I always included her, but made sure we had an umbrella to keep her cool, along with water and her bowl. She was able to help me off the chair or get up from the sand, by being my stability. I was able to put my hands on the center of her back to safely transition.

The Pool: Service dogs can provide tremendous assistance to allow you to visit and enjoy a pool. In her backpack, Maggie was able to carry my pool cards, earplugs, goggles, and phone, for possible emergencies. On top of that, a well-trained service dog is able to stay on command at the side of the pool, as another lifeguard for you. Maggie got to know me so well, that she could sense when I needed to get out of the pool due to overextending myself. She would be in a commanded down sleeping position, but when she sensed my oxygen levels were going down, she first would stare at me. When that didn't work, she sat up and almost jumped into the water. I learned quickly that when she looked at me, it was time to get out - and she was right. I was pushing myself. This was done by her, as she was never trained to do that! I learned to watch her and pay attention to her, for she knew I pushed myself, but she protected me.

Outside Walks: Whether you must use a wheelchair, walker, or crutches, a service dog helps to make the adventure safer for you. For starters, you are not alone and have a guide that will pay attention to your safety and health. They are able to carry items to ease the walk and assist you in situations that require more stabilization. They are able to help you, by you placing your hands

HITTING THE ROAD : TIPS FOR TRAVELING WITH YOUR SERVICE DOG

Pack your dog’s food and include extra, just in case the trip has unexpected delays. I like to pack them into the side vest pockets

Remember as you travel to provide the dog with timely opportunities to relieve him/herself. There are relief locations provided now at airports.

Remember to include the poop bags, since we are responsible to clean up after our dogs

Pack a drinking bowl – and remember you can get ones that fold up and are light to travel with.

You need to protect your dog from heat, so if on the beach, be sure to bring an umbrella

Service dogs are rewarded for their efforts with small pieces of their food, so be sure to pack enough extra for the length of the trip.

Think about what you do to exercise your dog at home, and bring anything that would be part of that process - ball, frisbee, etc

Animals may have a need for medication. Be sure to pack whatever is needed for your dog.

I would encourage you to include their identification in their vest

TICKET TO RIDE: Maggie holds Ellen's tickets with her mouth; "Traveling in a wheelchair can truly limit flexibility and movement. So, Maggie was able to carry my tickets in her mouth and even hand them to the correct person, all on command."

on the center of their back to get up and down, along with carrying your phone or other medical or safety needs.

Travel Excursions: Planning a trip to a cottage or cabin, hotel, or even to another state can certainly create anxiety, as to how you will be able to manage with your disability. Understand that your service dog is legally allowed to be by your side, to assist and comfort you no matter what you choose. I prefer including her ID card and working vest as we travel, to make sure others realize that she is truly a trained and approved dog. There are unfortunately many out there buying fake jackets to pass their pets as service animals. Maggie barked on command for alerting my husband that I needed help, which is important. But, a service dog barking in a store, unless helping her owner, should not be expected behavior. Fortunately, her credentials and behavior quickly provided proof of her true skills.

They are allowed at your feet with you on a plane, train, or bus. They are allowed to stay with you in your hotel room. They are allowed to lie under the table while you eat. But, I always call in advance when making plans, to make sure everyone is notified that I will be arriving with a service animal. Entering a store, I shared her presence and if they question allowing her to enter, I asked to speak to the manager. I make it clear, politely, that they would be breaking the law if they did not allow my entrance with her.

Traveling with your service dog will provide you with the continued help and comfort you have at home. They love to assist you and want to be with you, to be sure you are well taken care of. Have fun and see what adventures you can enjoy together, and enjoy your summer •

ABOUT THE AUTHOR:

Ellen Lenox Smith has emerged as a leading voice for patients living with pain in Rhode Island and the country. She suffers from two rare conditions, Ehlers-Danlos Syndrome and sarcoidosis. She enjoyed a career, predominantly in the field of education, before having to resign due to health. She devotes much of her time to advocacy. Presently, she is a co-director for Cannabis Advocacy for the US Pain Foundation, along with being on their board, runs Rhode Island Patient Advocacy Coalition, and was appointed by the governor to both the Adaptive Telephone Equipment Loan Program and the RI Medical Cannabis Oversight Committee representing patients, and helps run the RI EDS Support group. A proud mother of four sons and five grandchildren, Ellen is also an organic gardener, and prior to her disability, was a master swimmer and high school swim coach. She has spoken to: the FDA, Brown Medical students, Blue Cross nurses, and physical therapy students in RI and CT, along with speaking at the EDS national conferences. She is also the author of two books: *It Hurts Like Hell!: I Live With Pain – And Have A Good Life Anyway* and *My Life as a Service Dog!*

– Note: This article was republished from EP Magazine June 2023

SUMMER *fun*

TIPS FOR LOWER-STRESS SUMMER FUN AND VACATIONS

BY BONNIE IVERS

If you're planning a family vacation or get-together this summer, or are considering a day or overnight camp for your child with special needs, advance planning is key to ensuring the time is enjoyable and fulfilling for everyone. Here are some helpful tips to dial down the stress and dial up the fun for the whole family this summer.

STRESS BREAKER: When you exercise, your body's stress hormones like adrenaline and cortisol go down and your brain produces more of the natural "feel good" substances like endorphins. That's why many people find that exercise improves their moods.

GET EVERYONE INVOLVED

Planning summer activities together can be useful and a fun family activity. Brainstorming together about what each family member might enjoy doing, including people and places they'd like to visit can help everyone feel a sense of ownership in the final plans. This process can also flush out possible areas of conflict and discomfort that can be avoided with advance planning.

PREPARING FOR SUMMER CAMP

Both day camps and overnight camps can be wonderful opportunities for children to practice social and other skills, discover new interests, become more independent, and make new friends. However, many children with developmental disabilities are challenged by the changes in routine, environment and people the camp environment may bring.

To help ease the transition and make a great experience for your child, it's a good idea to visit the facility in advance. Connect with the camp administrator to see if you can set up a time to tour the camp, so your child can become familiar and comfortable with the sights, sounds and smells they'll encounter. Taking a few photos of your visit can help remind your child about that camp environment and build on their preparation.

It's also a good idea to create a one-page descriptive profile that captures key information about your child and how they need to be supported, to give to the camp staff. Visit **www.php.com/elearning/introduction-to-one-page-profiles** to access free information about creating a person-centered profile.

RESOURCES TO SIMPLIFY AIR TRAVEL

Going through airport security can be especially challenging for those traveling with family members who have special needs. To help make the process easier, the U.S. Transportation Security Administration (TSA) can provide a Passenger Support Specialist. Families concerned about the checkpoint process or who needs special accommodations, can ask a TSA officer or supervisor for help from a Passenger Support Specialist.

Parents may also call the TSA Cares hotline at 1-855-787-2227 ahead of time to ensure a Passenger Support Specialist can be onsite when needed. You may also request assistance through the TSA screening checkpoint by completing the form at this link **www.tsa.gov/contact-center/form/cares**.

The agency's website (**www.tsa.gov/travel/passenger-support**) also features short videos on screening procedures for travelers with Autism or Intellectual Disabilities, and those who use mobility devices such as wheelchairs. Families can also download and complete TSA's Disability Notification Card which includes contact information for TSA Cares.

In addition, Regional Center of Orange County's website features links to numerous helpful articles and resources for air travel. For more information, visit: **www.rcocdd.com/family-support/resources-and-support/travel**.

FUN FAMILY REUNIONS

Whether you'll be visiting relatives or friends or inviting them into your home, these new situations can be particularly challenging for those with developmental disabilities.

Before welcoming guests or visiting another's home, be sure to walk your child through what to expect. For example, share photos of unfamiliar guests. Remind the child about behaviors that might be okay at home, but not acceptable elsewhere. Also, prep those you'll be visiting to avoid hurt feelings or awkwardness if your child refuses a hug or otherwise behaves differently.

Often, family reunions include some special meals or traditional family recipes. Since some of these may be unfamiliar, it's a good idea to try to minimize disruptions by bringing some favorite foods, as well as toys or other items that will help calm your child. Many individuals with sensory issues will also benefit from having a "safe zone" where they can retreat to be alone or simply away from the strong smells, bright lights and loud noises of big gatherings.

DON'T SKIMP ON SELF-CARE

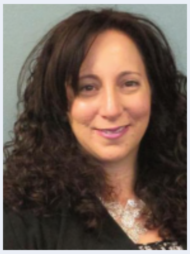
When we take care of ourselves physically, mentally, emotionally and spiritually, we are better able to cope with stressful situations in our daily lives, as well as the different circumstances we encounter while away from home.

One important de-stressor that often gets ignored on family vacations is daily exercise. When you exercise, your body's stress hormones like adrenaline and cortisol go down and your brain produces more of the natural "feel good" substances like endorphins. That's why many people find that exercise improves their moods.

It's also smart to stay hydrated by drinking enough plain water, and to seek out healthy foods whenever possible. Unhealthy foods, like soda, alcohol, and sugary snacks actually cause your body stress, while many healthy foods reduce stress hormones in your body. Some good stress-fighting choices include: herbal teas, nuts like almonds and walnuts, fatty fish such as salmon, fruits like avocados and blueberries, and vegetables like asparagus and broccoli.

Finally, take a moment or two each day to practice breathing deeply. It can immediately calm your body and your mind. Simply inhale deeply through your nose, feeling your stomach relaxing and pushing outward as you inhale. Hold your breath for a few seconds, then slowly exhale through your mouth for five to 10 seconds.

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 26,000 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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IES Brain Research Foundation thanks everyone who attended, sponsored, donated, helped spread the word, and volunteered! More information and photos will be posted soon at www.iesbrainresearch.org

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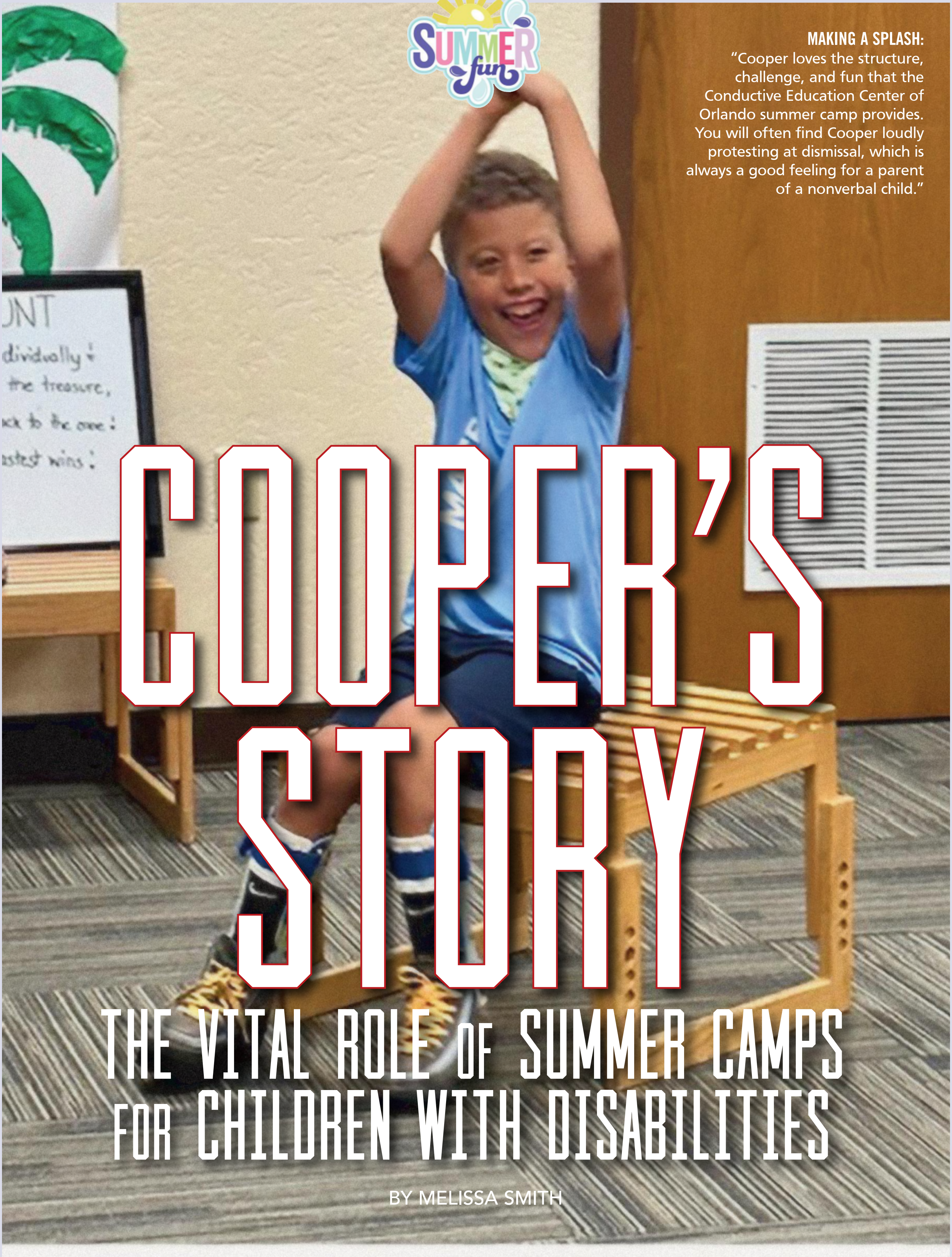

MAKING A SPLASH: "Cooper loves the structure, challenge, and fun that the Conductive Education Center of Orlando summer camp provides. You will often find Cooper loudly protesting at dismissal, which is always a good feeling for a parent of a nonverbal child."

COOPER'S STORY

THE VITAL ROLE OF SUMMER CAMPS FOR CHILDREN WITH DISABILITIES

BY MELISSA SMITH

PHOTOS PROVIDED BY MELISSA SMITH

With summer quickly approaching, many parents find themselves in a panic, as they search for summer camps to keep their kids engaged during the long break from school.

As a mom of three, it can be quite challenging to find the right camps to fit each child's specific needs and desires. It is even more challenging when you have a child with a disability. The options are extremely limited for children with disabilities and their unique needs. It has been a journey for me to find the right fit for our family.

OUR STORY: THE IMPORTANCE OF INCLUSIVE SUMMER CAMPS

Our oldest son, Cooper is 12 years old and has a rare chromosome abnormality and Cerebral Palsy. He has global delays, is nonverbal, and uses a walker to walk. He is smart, stubborn, full of joy, and almost never turns down an opportunity for a hug. After he was born, we were told that they couldn't find anyone in the world with the same chromosome abnormality, and therefore, doctors couldn't really tell us what to expect other than developmental delays. We were not at all prepared for all the obstacles that we would face. The first few years were a blur of medical appointments, therapy, and surgeries. Despite the many challenges along the way, my husband and I have always been committed to helping Cooper thrive in a world that isn't exactly made for him.

Cooper loves to be around other kids, learn new things, and engage in fun activities. Like many kids with disabilities, he relies on routine and structure to get through his days. This is how he knows what to expect, which makes him feel safe in the world. Every morning, he looks at my feet while he eats breakfast. If I am wearing shoes, he knows he is going to school. If my feet are bare, he knows it's a weekend. If it's a weekend, he points to my shoes and hopes I'll go put them on, because he wants to go to school. In the past we have done summers without summer camp, and we noticed how much he missed the routine and watched him regress. His skills and behavior quickly declined and, honestly, it was hard for me to keep him engaged and entertained for an entire summer. Cooper requires constant supervision, which is challenging with his two younger siblings running around. It quickly became apparent that a whole summer was too long for him to go without the structure and stimulation that his school provides.

OUR SOLUTION TO THE SUMMER CAMP DILEMMA

Many parents work, or like me, have several children to care for during the summer. A child with a disability usually needs more supervision and medical care than typical kids, and all kids need a lot of attention. We can find ourselves exhausted and on the

HAPPY CAMPER: Cooper interacts with his CECO camp counselors; The summer camp is open to all kids with motor disabilities, not just kids who attend during the school year.

TO EACH HIS OWN: Cooper with his parents and siblings; Cooper needs summer camp for the whole summer, while his siblings like to do a few weeklong camps with time to relax in between.

verge of burnout if we don't have support during the summer. Truthfully, most of us are already there, even with support. Caretakers are often in a state of emotional, mental, and physical exhaustion.

When we were on a search for the right summer camp for Cooper, we were looking for some core factors.

1. *Ensuring they operate throughout the whole summer, so I don't have to search for several camps to keep him busy.*
2. *Making sure they were well-staffed with a 1:1 student-to-staff ratio. This ensures he stays focused, able to participate in all activities and, most importantly, safe.*
3. *We wanted them to work on goals specific to each child, while keeping things fun and entertaining for the kids.*

We are lucky to have found that at the Conductive Education Center of Orlando (CECO; **www.ceco.org**). It happens to be where he attends school during the year. They open summer camp up to all kids with motor disabilities, not just kids who attend during the school year. People travel from all over the country and even other countries to attend. We are grateful to live close. He loves the structure, challenge, and fun that this summer camp provides. You will often find Cooper loudly protesting at dismissal, which is always a good feeling for a parent of a nonverbal child.

THE CALL FOR MORE: ADVOCATING FOR INCREASED ACCESS AND SUPPORTIVE CAMP OPTIONS

Over the years, we have figured out the summer routine that works best for us. Cooper needs summer camp for the whole summer, while his siblings like to do a few weeklong camps with time to relax in between. My hope is to see more options for kids with disabilities in the future. We need more camps that can provide enough staff to responsibly care for the kids. I would also love to see more summer camp scholarships for those in need. Every child with disabilities should have the opportunity to go to summer camp. Every caretaker, already on the brink of burnout, should have the opportunity to send their child to summer camp. I am hopeful that we will see these options grow in the future, as I already see so many new and exciting opportunities for people with disabilities and their families on the horizon. •

ABOUT THE AUTHOR:

Melissa Smith lives in Orlando, Florida with her husband and three kids. She is a stay-at-home parent and caretaker of a child with a disability. She is passionate about balancing family life and personal growth. She loves to write, paint, read, and listen to podcasts in her free time.

WHY INCLUSIVE SWIMMING MATTERS

BY JOEY ENOS

> *“INCLUSIVE SWIMMING ALLOWS A SPACE FOR A KID WHOSE ROUTINE IS ALREADY PACKED WITH PHYSICAL THERAPY AND OCCUPATIONAL THERAPY TO GO AND BE ACTIVE, MOVE WITH JOY AND FREEDOM, INTERACT WITH OTHERS, AND HAVE FUN.”*

MAKING A SPLASH: The author and his son Sammy take part in their inclusive swim program; “Swimming is the great equalizer and an inclusive swimming program can provide space to accommodate all abilities of children to participate.”

PHOTOS PROVIDED BY JOEY ENOS

WHAT NORMALIZES DISABILITY

My child Sammy is such an amazing teacher on so many different levels. He provides these incredible opportunities to reflect on yourself and the world around you.

But, at every level in our society, having a disability is perceived as "not normal." There's a standard of where your kid should be… and then there's a clearly defined line between what's considered normal and not normal. For any kid who is different or disabled, there's a fixation on "How do we fix this?" in order to achieve this sense of "normalcy." It's exhausting. I'd love for people who don't have any connection with people with disabilities to normalize it.

One of the many things inclusive swim programming for kids with disabilities does is provide this sense of normalcy that a lot of our families don't get to experience… and this starts with the locker room. Before class, all of the families who have kids with disabilities are in the locker room together, getting ready for class. tantrums, vocalizations, drooling, or even the presence of a wheelchair differentiates our families in shared spaces. It might even look alarming to some, but for our families, it's a normal part of the process of getting ready for the pool. Because we're in a group together, it's a supportive environment. It also creates opportunities for others in the locker room to see what our lives are like in this shared space, even when others may find it challenging.

Very rarely do families with kids who are disabled ever get the chance to get together or have the opportunity to hang out and talk. Having a shared experience with other families of children with disabilities makes it a safe place. Having interactions with similar kiddos and seeing caring volunteers work with our kids in this amazing, warm structured environment, it is a godsend.

CREATING OPPORTUNITY

What I like about the program we attend (SNAPkids) is that the approach to inclusive swimming is that it's not about meeting a certain goal or someone else's criteria. There's no finish line so to speak; it's about how our kids can progress based on their abilities and have fun while they do it. Swimming in an inclusive program creates an opportunity for kids to work on developing swim skills without the heavy burden of having to achieve specific, structured goals. When Sammy was smaller, it felt like this structure and goal-oriented focus was every second of every day. In the water it's "just" swimming. It allows a space for a kid whose routine is already packed with physical therapy and occupational therapy to go and be active, move with joy and freedom, interact with others, and have fun. A while ago, we had a routine where I'd take Sammy swimming and my partner would take the day off. There's a normalcy to being able to drop your kid off to do an activity, and then getting to sit back, watch, and enjoy.


WATER WORLD: *(Above left)* Sammy is all smiles after his swim; *(Above right)* Enjoying a day at the beach.

It's important that Sammy gets to develop his own relationships with the volunteers and other kids in the water. His weekly swim is one of the few moments outside of school where he spends time with other people and is wholly independent from his parents doing his own activity and enjoying his own autonomy separate from us. Swimming has also given Sammy a newfound body awareness and it's just been an incredible experience. And to be able to find a space and have that all navigable for people in wheelchairs and for kids of all abilities is amazing.

The reality is that it's difficult to find activities that Sammy can participate in. One of the singular biggest losses for us during COVID was losing our in-person inclusive swim program. It was heartbreaking. It meant he lost out on the socializing that comes with his time interacting and befriending volunteers who work for the program, as well as precious time in the pool being able to move his body freely.

WHY SHOULDN'T KIDS WITH DISABILITIES SWIM?

When your child is given certain diagnoses, it feels like you're being dictated to what your child is capable of. You hear doctors say, "Your child is not going to be able to do this,or your child is not going to be able to do that." But how do they know? We don't know. Why shouldn't kids with disabilities swim? Why shouldn't they be able to move their body in whatever ways they can?

Swimming is the great equalizer and an inclusive swimming program can provide space to accommodate all abilities of children to participate. Mobility is not a limitation. I want to acknowledge that it's a lot of hard work on the part of the parents to do these activities for their kids because it involves planning and coordination and having the right equipment, like a wheelchair accessible van, but it's so worth it.

Another unique aspect of the inclusive swim program we participate in is that there are volunteers in the pool, many of whom are students pursuing degrees in the medical field, where this kind of one-to-one experience with kids like Sammy is really formative. Some volunteers look like they've been working with kids with disabilities forever. And when you see what volunteers who receive training to work with kids in the water can do, it's inspiring because it widens the possibilities of what other activities could be made available for kids with disabilities. The experiences the volunteers have in working with kids like Sammy also helps to normalize disability. You realize this could be replicated elsewhere or with other activities with someone like Dori Maxon, who has the knowledge to make these things accessible. Though in reality, there are very few activities available for kids like Sammy. The Bay Area needs more programming available for children with disabilities.

> **"THE EXPERIENCES THE VOLUNTEERS HAVE IN WORKING WITH KIDS LIKE SAMMY ALSO HELPS TO NORMALIZE DISABILITY."**

There's no cookie cutter way to navigate the path ahead as the parent of a child with disabilities. You learn to be adaptable and adjust expectations. Inclusive swimming is a great option to help your child's light shine brightly. •

Sammy swims with SNAPkids, founded by Dori Maxon PT, in the San Francisco Bay Area. SNAPkids' mission is to enrich the lives of children and young adults with disabilities by providing community-based accessible swimming programs. These programs enable children to swim, exercise, make friends, and just be kids having fun in the water. Learn more at: **snapkids.org**

ABOUT THE AUTHOR:

Joey Enos lives with his partner Anna MacNeil. They have recently moved to San Mateo to raise their 9-year-old son, Sammy. Raised in Alameda California, Joey Enos has been an artist his whole life and has had a professional career in museum collections and art services throughout the Bay Area. Joey received a Master of Fine Arts from UC Berkeley Art Practice in 2014. Joey published his first book in 2022, *Radical As Folk*, a historical document of the history of the Emeryville Mudflat Sculptures. After living in Emeryville for many years, Joey and Anna moved the family to the San Francisco Penisula for Sammy's schooling. Sammy has been diagnosed with Cerebral Palsy, Epilepsy, and Cortical Visual Impairment. With the security of being close to a supportive network of schools and services, the family enjoys exploring new and exciting experiences for Sammy and the family, including adaptive surfing and sports.

– Note: This article was republished from EP Magazine June 2023

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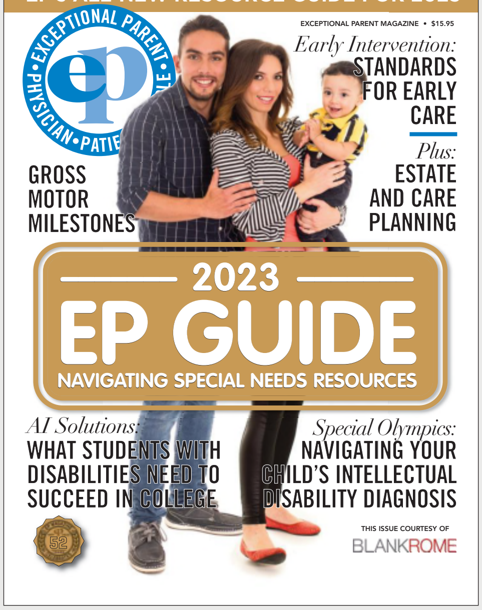

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Summer Fun!

AN EP FOCUS ON SUMMER ACTIVITIES

BY RENEE WILLIAMS

Creative Ways to Have Fun While Teaching Children All Summer Long

PHOTO COURTESY RENEE WILLIAMS

BEACH BOY: The author's son enjoys the sun and sand at the shore. "We select activities that he might engage in and that will strengthen his intellectual functioning and address his weaker areas."

Summer brings back such fond memories for me. Growing up, summer meant quality time with family and friends, enjoying backyard barbecues, going to zoos and parks, making new friends at summer camps, road trips, travel abroad, and much more.

Most of my time was spent outdoors, learning and engaging in activities that weren't often possible during the school year.

This nostalgic sense of summer fun is what my husband and I aim to create yearly for our boys.

The Importance of Play

Play, or engaging in activity for enjoyment and recreation, is essential for children's development. For children with autism spectrum disorder (ASD), engaging in play can be very challenging due to deficits in social skills, communication, and imitation. These deficits impact their ability to engage in meaningful play with peers or adults. Often, children with ASD learn static skills more easily, such as: numbers, letters, colors, and shapes, because of their predictability. This need for sameness and rigidity can limit their interest in toys and objects, reducing their desire to explore and play.

Our Approach to Summer Activities

During the summer, we focus on providing our sons with many play-based activities. I have two children, one who is 8 years old and one who is almost 12 years old. I research meaningful ways to engage them in fun, educational activities. To do this effectively, we try to understand their unique profiles, including sensory motor experiences and needs (smell, vision, hearing, taste, tactile, motor, balance), developmental age, and their current preferred leisure activities. (Solomon, R. (2021). The Play Project: Parent Guide, 29-30)

Understanding their strengths and weaknesses also helps in planning activities that are meaningful and help prevent the summer slide.

Understanding Our Younger Son's Needs

Our younger son has a diagnosis of autism and severe communication deficits, which impact his interpersonal relationships, play, leisure, and self-regulatory skills. He often appears internally preoccupied, making it challenging to engage him in play activities with peers. He doesn't show much interest in pretend play, and doesn't use toys to represent other things. Our goal is to learn his current interests and abilities, so that we can select activities that he might engage in and that will strengthen his intellectual functioning and address his weaker areas.

Activities to Foster Development

Because play is a major vehicle for developing cognitive and problem-solving skills, it's important to strengthen these skills in our children. Here are some activities we engage in during the summer to improve our sons' pretend play, problem-solving, cognitive, and social skills:

- *Going to the beach, playing in sand, building sandcastles, learning water safety*
- *Races and games with simple rules (stop, go) like potato sack races and red light, green light*
- *Road trips to new places*
- *Throwing and catching, rolling back and forth a ball*
- *Playing basketball and learning to dribble.*
- *Bowling*
- *Gardening as a family and discussing how plants grow*
- *Encouraging structured and unstructured play times with siblings and peers*
- *Playing hot potato, tag, hide-and-seek and musical chairs*
- *Going on treasure/scavenger hunts*
- *Doing obstacle courses in the backyard (short or long, depending on ability)*

- *Bean bag toss*
- *Kicking a soccer ball and playing soccer*
- *Having and going on playdates*
- *Packing picnic items together and going on a picnic*
- *Visiting free museums and parks*
- *Having barbecues*
- *Going to a carnival or county fair*
- *Playing sidewalk chalk games*
- *Watching indoor and outdoor movies*

Encouragement and Support

Provide opportunities for play for your children throughout the summer. Remember that play is work for children with autism, and reinforcers may be needed to increase this behavior. Be aware of what your child finds motivating and use these items as reinforcers to engage them in new activities. Observing what they do during play or free time can help identify these motivators. Offering a child a choice between several toys and observing which one they select and engage with the most, can also be useful.

Integrating children with disabilities into mainstream activities promotes a more inclusive and accepting community and fosters understanding, empathy, and friendships.

Visual Aids

Visual aids can be extremely helpful, especially if your child is non-verbal or has a speech deficit, like my son currently does. These visual aids can serve as prompts, helping your child express what they want to do during the day. My son also uses an AAC (Augmentative and Alternative Communication) device to communicate. We create a "summer fun" category. This serves as a choice board and a mode of communication for him, making it easier for him to advocate for his preferences and participate actively in planning activities.

Promoting Inclusion

Another very important aspect of summer fun is creating more opportunities for inclusion for our children. Children with disabilities are often segregated from their typically developing peers because of their "special needs" (Feinberg et al., 2014). Participating in community activities that allow them to interact with diverse populations is a key focus for us during the summer. Keeping children with disabilities apart from their typically developing peers can lead to larger problems later in life, and keeps them from having the opportunity to experience young children's natural openness to new experiences and inclusive attitudes toward differences.

Inclusion and opportunities for typical social experiences during childhood play-based learning activities are critical to the healthy development of all children and society. Integrating children with disabilities into mainstream activities helps foster understanding, empathy, and friendships among all children, promoting a more inclusive and accepting community. •

ACTION PACKED: *(Clockwise from top)* The author and her family take a stroll on the beach; The author's younger son stays active with a soccer ball and gardening tasks; Visual aids help her son express what he wants to do during the day.

ABOUT THE AUTHOR:

Renee C. Williams, M.S. Ed. is a member of Christ Church and active participant in many of its ministries. She is also a NJ based Sales and Marketing Manager at a Chemical Process Parts Manufacturer. She recently graduated in 2023 from Monmouth University with a Master of Science in Education with a concentration in Autism and Applied Behavioral Analysis. She serves as a Community Autism Research Ambassador for Family Voices. She is also the inventor of a patented shoe accessory. Renee recently started a business called Naissance US, making dresses, belts and bags. Her primary interests are: spending time with her family and friends, being the best educational advocate possible for her boys and for all children, reading, and making dresses, belts and bags.

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SUMMER fun

SPECTRUM OF FUN

EVIDENCE-BASED STRATEGIES FOR CHILDREN WITH ASD ON SCHOOL BREAKS

BY MIREILLE UKEYE, PH.D.

The school break offers children of all ages a well-deserved rest from the routine of school life, filled with opportunities for relaxation and exploration. However, for children with Autism Spectrum Disorder (ASD), this period can be fraught with challenges that can disrupt their sense of normalcy and comfort. Understanding and planning for the unique needs of children with ASD is crucial to transforming these breaks into enjoyable and developmental periods.

AN EP FOCUS ON SUMMER ACTIVITIES

AN ENRICHING SUMMER ENVIRONMENT : PLANNING SCHOOL BREAK ACTIVITIES

To effectively plan school break activities, it is crucial to gain a deep understanding of your child's needs and preferences. This can be achieved through observation, communication with your child, and consultation with professionals who work with your child.

SENSORY NEEDS

Pay close attention to your child's reactions to different sensory stimuli. Some children with ASD may have sensory reactions to loud noises, bright lights, or certain textures, while others may seek out intense sensory experiences. Make note of these needs and plan activities accordingly. For example, if your child is sensitive to loud noises, opt for quieter outdoor activities, like nature walks or visits to sensory-friendly playgrounds.

COMMUNICATION PATTERNS

Observe your child's communication style and preferred modes of expression. Some children with ASD may struggle with verbal communication and prefer alternative methods, such as: sign language, picture exchange systems, or augmentative and alternative communication (AAC) devices. By understanding and respecting your child's communication preferences, you can facilitate more meaningful interactions and ensure your child feels understood and valued.

INTERESTS AND PREFERENCES

Identify your child's special interests and preferred activities. If your child has a strong fascination with a particular topic or activity, incorporate related experiences into your school break plans. This will not only keep them engaged and motivated, but also provide opportunities for learning and skill development. For example, If a child shows profound interest in specific subjects, such as dinosaurs or trains, integrating these into the school break plans can maintain their engagement and provide educational opportunities (Koegel et. al., 2001).

CREATING STRUCTURED ROUTINES

Despite the break from school, maintaining a structured routine can help mitigate the anxiety that may come with the unstructured nature of school breaks. A predictable schedule that outlines times for meals, activities, and relaxation can provide a framework that reduces stress. Visual schedules are especially effective, utilizing symbols or pictures to represent different parts of the day's activities (Hodgdon, 2015). These can empower children with ASD by visually communicating the day's expectations in a clear, comprehensible format. Involving children in the creation of these schedules can also foster a sense of involvement and control, enhancing their engagement with the planned activities. (Mesibov et al., 2005)

ADAPTING ACTIVITIES FOR SENSORY SUPPORT

Many school break activities can be overwhelming for children with ASD, due to sensory sensitivities. When planning activities, consider ways to adapt them to create a more sensory-friendly experience. For activities involving loud noises or bright lights, provide your child with noise-canceling headphones or sunglasses to help manage sensory input (Myles, 2000). If your child is sensitive to certain textures or fabrics, dress them in comfortable, sensory-friendly clothing and bring along alternative options or fidget toys for added comfort.

For water-based activities like swimming or water play, provide your child with sensory-friendly swimwear and/or flotation devices to enhance their comfort and safety. Additionally, consider sensory-friendly adaptations like entering the water gradually or using a sprinkler or water table for a more controlled experience. When visiting new places or participating in unfamiliar activities, prepare your child by providing social stories or visual supports that outline what to expect and how to navigate the sensory aspects of the experience. This can help reduce anxiety and increase your child's understanding and participation.

USING REINFORCEMENT AND REWARDS

Positive reinforcement remains a highly effective strategy for encouraging desirable behaviors in children with ASD. This might include praise, small rewards, or earning privileges for engaging in challenging activities (Cooper et al., 2007). Be specific with your praise, highlighting the specific behavior or effort you want to reinforce. For example, "Great job sitting and listening during story time!" or "I am so proud of how you tried the new activity today." In addition to tangible rewards, consider incorporating natural reinforcement into activities. For example, if your child loves spending time outdoors, use outdoor activities like nature walks, gardening, or exploring local parks as opportunities for reinforcement. By aligning reinforcement with your child's interests and preferences, you can increase their motivation and engagement in activities, while also fostering a positive and supportive environment.

BUILDING FRIENDSHIPS AND FACILITATING COMMUNICATION

Breaks provide ample opportunities for children with ASD to develop social skills and build friendships. Arrange playdates with peers who share similar interests, and

AN ENRICHING SUMMER ENVIRONMENT : PLANNING SCHOOL BREAK ACTIVITIES cont.

encourage your child to participate in group activities, or camps tailored to their needs. When facilitating social interactions, provide guidance and support as needed, helping your child navigate social cues and develop communication skills. Teach specific social skills, such as taking turns, and sharing, through modeling, role-playing, and positive reinforcement (Williams White et al., 2007).

Incorporate social stories or visual supports to help your child understand social situations and appropriate behaviors (Reichow & Volkmar, 2010). For example, create a social story about making friends at camp, or a visual schedule outlining the steps for joining a group activity. In addition to in-person interactions, technology can also be a valuable tool for facilitating communication and maintaining social connections. Encourage your child to use social media, video calls, or online forums to connect with peers, friends, and family members, particularly if they struggle with face-to-face communication. Provide guidance and supervision, as needed, to ensure safe and appropriate online interactions.

SEEKING PROFESSIONAL GUIDANCE

Navigating the complexities of school break activities for children with ASD may require additional support and guidance from professionals. Therapists, teachers, counselors, and behavior specialists can offer personalized strategies and interventions to address specific challenges, and promote positive outcomes for your child. Consider seeking support from professionals who specialize in areas such as sensory integration, social skills development, behavior management, or communication interventions. They can provide tailored strategies and techniques to help your child thrive during school breaks. Consider reaching out to your child's school or local autism support organizations for recommendations and resources. Many offer summer programs, social groups, or parent education opportunities that can be invaluable for families navigating school holidays.

STAYING AFLOAT: Understanding and planning for the unique needs of children with ASD is crucial to transforming summer breaks into enjoyable and developmental periods.

Navigating school breaks with a child with ASD involves thoughtful planning and adaptation of activities to meet their unique needs. By understanding the individual's sensory needs and interests, maintaining structured routines, adapting environments, employing consistent reinforcement, facilitating social opportunities, and seeking professional advice, families can create a supportive and enriching summer environment for their children. •

ABOUT THE AUTHOR:

Mireille Ukeye, Ph.D. is a school psychologist and an assistant professor of school psychology in northern California. Her research uses multiple modes of investigation to better understand autism spectrum disorders (ASD) and other behavioral disorders to determine the most effective approaches to treating and supporting students with ASD and other behavioral needs in schools. Additionally, her research investigates the different ways that mental health providers can support families with children with disabilities.

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JUNE IS ALZHEIMER'S AND BRAIN AWARENESS MONTH

10 WAYS TO **LOVE YOUR BRAIN**

START NOW. It's never too late or too early to incorporate healthy habits.

HIT THE BOOKS

Formal education will help reduce risk of cognitive decline and dementia. Take a class at a local college, community center or online.

BUTT OUT

Smoking increases risk of cognitive decline. Quitting smoking can reduce risk to levels comparable to those who have not smoked.

BREAK A SWEAT

Engage in regular cardiovascular exercise that elevates heart rate and increases blood flow. Studies have found that physical activity reduces risk of cognitive decline.

FOLLOW YOUR HEART

Risk factors for cardiovascular disease and stroke – obesity, high blood pressure and diabetes – negatively impact your cognitive health.

Growing evidence indicates that people can reduce their risk of cognitive decline by adopting key lifestyle habits. When possible, combine these habits to achieve maximum benefit for the brain and body.

STUMP YOURSELF

Challenge your mind. Build a piece of furniture. Play games of strategy, like bridge.

HEADS UP!

Brain injury can raise risk of cognitive decline and dementia. Wear a seat belt and use a helmet when playing contact sports or riding a bike.

BUDDY UP

Staying socially engaged may support brain health. Find ways to be part of your local community or share activities with friends and family.

FUEL UP RIGHT

Eat a balanced diet that is higher in vegetables and fruit to help reduce the risk of cognitive decline.

TAKE CARE OF YOUR MENTAL HEALTH

Some studies link depression with cognitive decline, so seek treatment if you have depression, anxiety or stress.

CATCH SOME ZZZ'S

Not getting enough sleep may result in problems with memory and thinking.

Visit alz.org/10ways to learn more.

alzheimer's association®

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FROM OUR FAMILIES... TO YOUR FAMILIES

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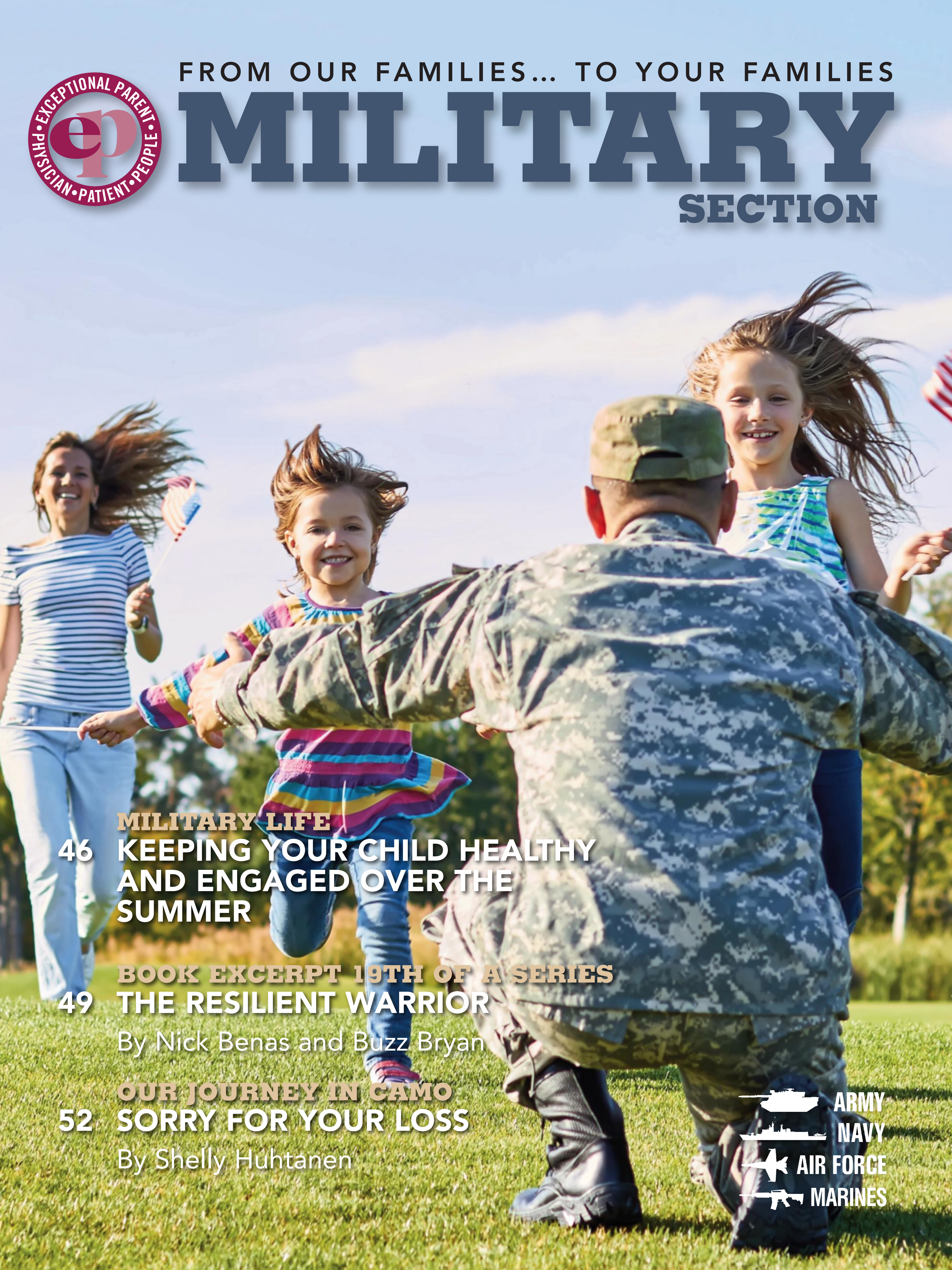
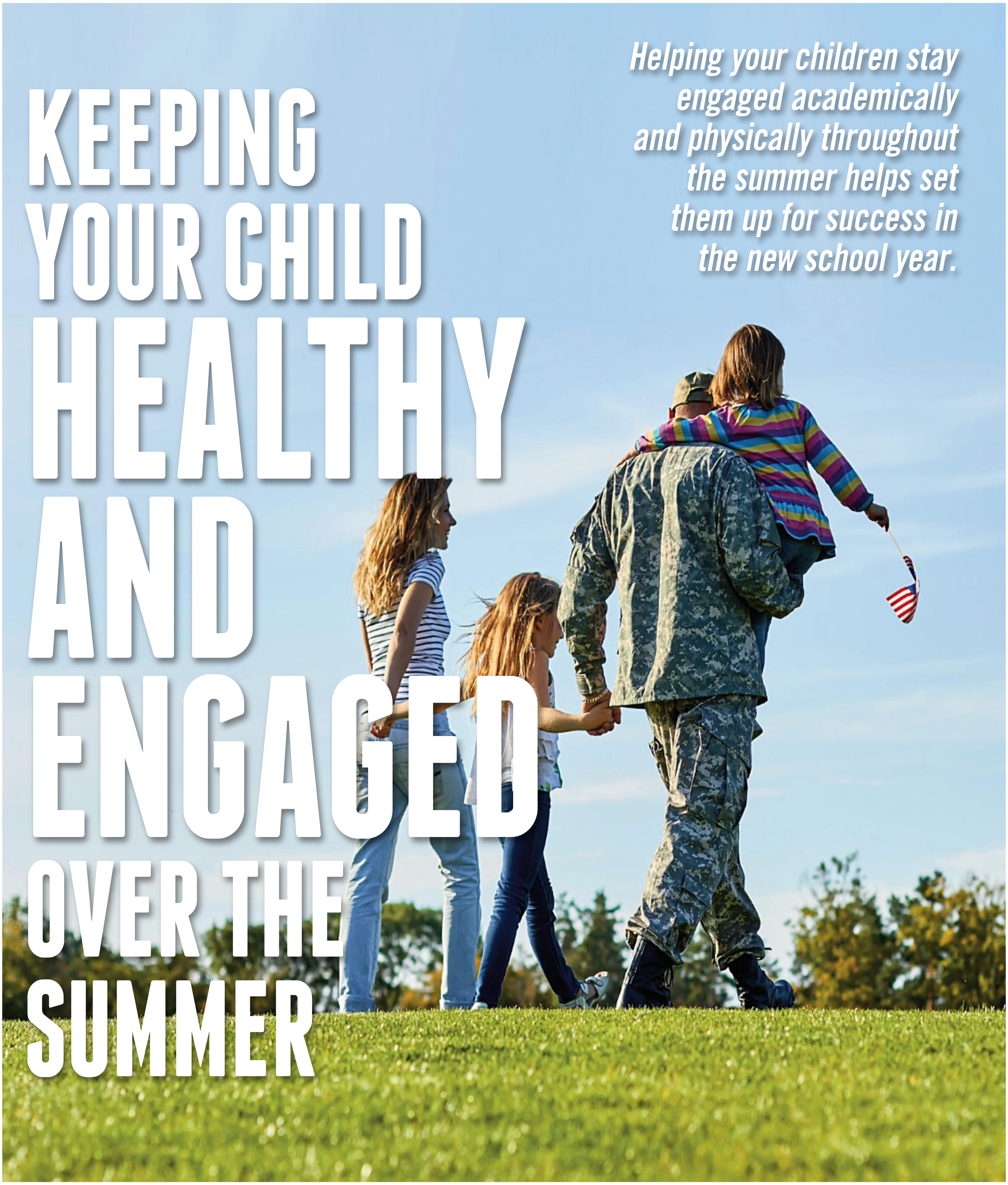


KEEPING YOUR CHILD HEALTHY AND ENGAGED OVER THE SUMMER

Helping your children stay engaged academically and physically throughout the summer helps set them up for success in the new school year.



A little leisure is much needed when school lets out; however, children with special needs thrive with a little structure. It's beneficial to maintain a routine during the summer as a way to keep your child learning and developing healthy habits.

HEALTHY AND ENGAGED : SETTING YOUR CHILD UP FOR SUCCESS

Here are a few ideas to help your child with special needs have a healthy and happy summer:

SEEK OUT A SUMMER PROGRAM

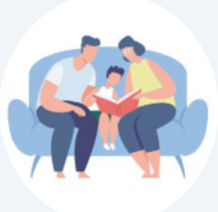
Check your installation, local schools, recreation centers and other community-based organizations for programs on topics that might interest your child. **www.militaryonesource.mil/benefits/defense-department-summer-camps**

CONSIDER CHILD CARE SERVICES

Plan activities or outings for your child when you are tied up with work or other activities. The Department of Defense offers military parents the option to find expanded hourly child care services through free access to a national database of caregivers. **www.militaryonesource.mil/parenting/child-care/military-child-care-services**

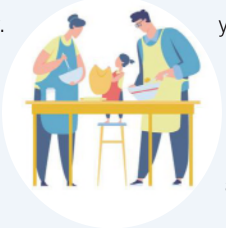
CRACK OPEN A BOOK

Whether reading with your younger children or encouraging your older children to read on their own, summer reading can help keep brains engaged and study habits fresh. **www.militaryonesource.mil/recreation-travel-shopping/mwr**



TAKE A FIELD TRIP

Visit parks, museums, zoos or nature centers for low-cost educational opportunities for your entire family. **www.militaryonesource.mil/recreation-travel-shopping/recreation/hobbies/blue-star-museums**



COUNT, TRACK AND MEASURE

Find fun ways to incorporate numbers into everyday tasks. Measure items around the house or track daily temperatures. Go to the grocery store and practice adding, subtracting or multiplying the prices of items.

THINK AHEAD

Check with your child's school to see if there are summer packets of math and reading skills activities to help prepare for the next school year.

GET MOVING

Don't forget to schedule time for your child to play and burn off energy with some sunshine and exercise.

SNACK HEALTHY

A healthy diet is just as important in the summer as it is during the school year. Keep plenty of fruits and vegetables on hand to encourage good snack habits. **www.militaryonesource.mil/health-wellness/prevention-care/giving-your-child-a-happy-healthy-start**

RECHARGE

Keep a regular summer bedtime to make sure your child is getting enough sleep.

Helping your children stay engaged academically and physically throughout the summer helps set them up for success in the new school year. Contact your local Exceptional Family Member Program Family Support provider and look for a Parent Training and Information Center near you to see what types of summer programs are available to your family. •

LOOKING FOR FAMILY ACTIVITIES THIS SUMMER?

Free Admission

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BOOK EXCERPT 19TH OF A SERIES ★ U.S. MILITARY

THE RESILIENT WARRIOR

THE OUTDOORS

Book Editor's Note: Featuring self-help, mental health, and mind and body tactics from a variety of sources – veterans, former and active U.S. Marines, Navy, Army Rangers, Green Berets, family members and caretakers – ***The Resilient Warrior*** *is collaborative collection providing needed wisdom for complete well-being for all of us. The first step to thriving is surviving, and the first step to surviving is knowing how to get what you need, when you need it. The following excerpt of this essential self-help guide to living a healthy, resilient, fulfilled and better life is the nineteenth in a series that EP Magazine has featured over the last several months.*

Experience the outdoors and use it as a source for enhanced well-being.

Dr. Byron Davis is a Marine Corps veteran (2008–2013). As a Marine, Dr. Davis witnessed the struggles of fellow unitary Marines because of their overseas service in campaigns, such as Operation Enduring Freedom and Operation Iraqi Freedom. It was during this time that he realized the significance of posttraumatic stress disorder and just how misunderstood the disorder was among his fellow warriors. As a result, he began his journey toward obtaining his doctoral degree with his focus in the field of psychology, with the hopes of developing unique approaches to alleviating PTSD symptoms. While working in Afghanistan as a security contractor, Dr. Davis reflected on his own past and how he utilized Mother Nature to combat stress, prior to joining the Marine Corps. It was during this period of reminiscence that the idea of Dogs of War Outdoors was created. Dr. Davis followed through with the idea. In 2018, after gaining traction among fellow warriors across all branches of service, he created the Dogs of War Foundation. Since then, the organization has taken many warriors on outdoor adventures such as: hunting, fishing, hiking, and camping trips to help combat PTSD. Mother Nature provides both serenity and calmness with no side effects. In an age where medical providers attempt to suppress our struggles with narcotics, it is essential that we explore other avenues available to help us cope. Over the course of many years, Dr. Davis developed a theory relevant to suicide among our nation's warriors. There are three things that we need to push forward with our lives:

Camaraderie - When we enter the military, we create indestructible bonds. We maintain a willingness to sacrifice our own lives for our fellow warrior, and they will do the same for us. That isn't something that is common in society. When we exit the military, we lose that camaraderie and therefore lose a piece of our soul.

Comfort - While surrounded by fellow warriors, we know they have our back. We do not need to consistently search for threats and struggle with the thought of falling prey to a hunter. We can relax, because we know we're safe.

Adrenaline - We are trained to kill while in the military, and there is no other adrenaline that parallels a hunt for human beings. But it isn't necessarily the hunt for human beings that provides the adrenaline. It's just the hunt. It's that familiar feeling of being a predator once again. We do not need ample amounts of adrenaline. We need just enough to satisfy our

HUNTING FOR SOLACE: Being in the outdoors and knowing that we're safe and secure presents a level of tranquility that cannot be matched elsewhere.

desire to do exactly what we're trained to do. Regardless of the activity, being surrounded by nature helps us relax. When we're on a hunting, fishing, camping, or hiking trip, we allow ourselves to observe other living creatures carrying out their lives, surrounded by only the sounds of nature. Being in the outdoors and knowing that we're safe and secure presents a level of tranquility that cannot be matched elsewhere. Undesirable noise pollution isn't present; only the desirable and calming sounds of the wilderness, such as the wind blowing through the canopy. The air is fresh, and the water is pure. We aren't consistently looking over our shoulder in search of threats. Our attention is focused on the living creatures around us, which have very few responsibilities outside of just survival, and we can relate. We share commonalities. For many of us, our only goal at that point in our lives is just survival. For a moment, we don't feel as though we are a burden on others, and we have a desire to live. Mother Nature does not offer criticism, and as a result, we can think through our struggles without fear of judgement or repercussion. We aren't broken or abnormal. Rather, we are just a different type of normal. We are the result of an evolutionary mindset, and have been molded into a warrior. From a biological perspective, we look no different than others. However, our minds operate differently. We are both prepared for and maintain an expectation of violence each day, which most wouldn't understand. It is the belief of Dr. Davis, that our traditional means of psychological treatment is less effective on our veteran population. Yet, mainstream psychological agendas consistently utilize these approaches and often fail. An exploration of alternative treatment options is crucial, especially considering that veteran suicide remains a significant issue. Currently, there are many organizations in America that dedicate their time and service to the protection of our nation's veterans. •

MORE ABOUT DR. BYRON DAVIS:

After serving in the Marines from 2008 – 2013, Dr. Byron Davis worked at Spring Hill Police Dept. from 2015 -2021 where he was a narcotics K-9 officer and then a task force agent working with Tennessee Bureau of Investigations Human Trafficking Task Force. Then Byron went to the Rutherford County Sheriff's Office and retired from law enforcement in 2023.

ABOUT THE AUTHORS:

Nick Benas grew up in Guilford, Connecticut. The author of *Mental Health Emergencies, Warrior Wisdom, Tactical Mobility,* and co-author of *The Warrior's Book of Virtues,* Benas is a former United States Marine Sergeant and Iraqi Combat Veteran with a background in Martial Arts (2nd Dan Black Belt in Tae Kwon-Do and Green Belt Instructor in Marine Corps Martial Arts Program). Nick attended Southern Connecticut State University for his undergraduate degree in Sociology and his M.S. in Public Policy. He has been featured for his business success and entrepreneurship by more than 50 major media outlets, including *Entrepreneur Magazine, Men's Health,* ABC, FOX, ESPN, and CNBC.

Richard "Buzz" Bryan is currently the Outreach Coordinator for the West Palm Beach VA medical center. The co-author of *The Warrior's Book of Virtues,* Buzz previously served as the OEF/OIF Transition Patient Advocate (TPA) for the Veterans Integrated Service Network (VISN4) based in Pittsburgh, PA for ten years, working specifically with Iraq and Afghanistan veterans. Buzz was a member of the Navy/Marine Corps team and retired from the United States Navy in July 2011 after 22 years of honorable service as a Fleet Marine Force Senior Chief Hospital Corpsman.

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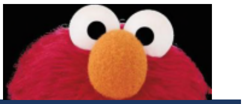

WE OFFER

Sesame Street's *Talk, Listen, Connect* resources help military families and their young children cope with deployments, changes and grief. Visit Military OneSource to learn more.

Sesame Workshop
http://www.sesameworkshop.org

Sesame Street for Military Families
http://www.sesamestreetformilitaryfamilies.org

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Learn all of the ways Military OneSource can support you. Call **800-342-9647** or visit us at **www.MilitaryOneSource.mil** to find OCONUS calling options or to connect online.
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DOG DAYS: The author shares the couch with Bo; "I have always understood and accepted Broden's uneasiness for affection, but I think the dogs that I have had in my life tend to fill that void."

Sorry for Your Loss

I came home to Mark on the couch, crying while holding our other dog, Scout. The pain was excruciating, but we knew it was necessary.

"Just do it now. It's too painful. If I take him home, I won't be able to bring him back to do it." As I laid on the floor with my 12½-year-old dog, Bocephus, I knew it was time to say goodbye. He was my dog. Bo was the one who came to lick my face every morning at 5 am. He was the one who would jump on the bed and nestle in the corner of my legs when I went to bed. I kept telling myself he was going to beat the odds, but after not responding to the blood transfusion or the long list of medications we gave him, there was nothing else to be done. I kept asking the internal medicine doctor, "Are you sure there isn't anything else we can do?" I kept crying and running my hands down Bo's aged boney body, "I'm so sorry. I wish you could stay with me."

I called Mark at work, "Bo has to leave us. I should be the one to do it. You pick up Broden from clinic and I'll meet you at home." Mark said softly, "I understand. I'll see you at home." Hayden was in the middle of college final exams in Alabama. I knew that if I didn't let him say goodbye to Bo, he'd never forgive me. As a mom, it was devastating watching my son, away from home, crying through the phone, telling Bo how much he meant to him, and then begging me to keep him alive so he could hug him one more time. I had to convince Hayden that Bo was in too much pain. It was the most loving act we could do for him. It was his time.

The internal medicine doctor came back in the room, "Do you want to be present when it happens?" I answered, "Absolutely. I want to be the last person he sees." They came in and laid a blanket on the floor in the room. Bo was in too much pain to lay on the blanket and chose the hard cold floor instead. "I'm going to sit here on one side of him and will tell you when I adminis-

PHOTOS PROVIDED BY SHELLY HUHTANEN

SWEET SORROW: I knew it was time to say goodbye. He was my dog. Bo was the one who came to lick my face every morning at 5 am. kept telling myself he was going to beat the odds, but there was nothing else to be done.

ter the medication. I nodded and laid down next to him. As he sprawled out with his chest and belly on the floor, I laid my head on the floor so I could look directly in his eyes. He shifted his head and looked directly at me,. “Sweetheart, we’re going to take a nap together. I’m right here.” Bo looked exhausted as he slowly lifted his head, licked my nose and laid his head back down.

“First, I’m going to give him medicine that will make him go to sleep. Are you ready?” I nodded my head as I laid there with my arm around him. As she injected the medicine, Bo nuzzled his head into my neck, “I love you so much. You are the best dog I ever had. I will miss you so much.” She then said, “Now I’m going to stop his heart.” I held on to him tight, “It’s ok. I’m right here.” The internal medicine doctor slowly grasped her stethoscope and laid it to his chest, “He’s gone.” As I sobbed, I replied, “That’s it? Already?” With tears in her eyes, she nodded to confirm.

We wrapped him up in the blanket that was on the floor, and she walked me out of the building to my car. I came home to Mark on the couch, crying while holding our other dog, Scout. The pain was excruciating, but we knew it was necessary. A wise woman said, “With everything in life there is always a beginning, a middle, and an end. For Bo, his life with you had to end.”

> “As he sprawled out on the floor, Bo shifted his head and looked directly at me.‘Sweetheart, we’re going to take a nap together. I’m right here.’”

Mark and I have always had dogs in our home. The king-size bed in our bedroom is not just for us to have plenty of room, it’s also for our dogs. Our dogs give us the cuddles and affection we yearn for every day. In a way, our dogs give us the affection and cuddles our son Broden is not able to give. Broden enjoys his independent quiet time in his room and if I’m in his room for too long, he’ll tell me to leave. I look forward to that one kiss in the morning before ABA clinic, and if I’m lucky, I might get a kiss when I pick him up. On a good day, I’ll ask for a hug and might get a few seconds of cuddle time with him. Those moments are fleeting, but never taken for granted. I’ve always understood and accepted this about Broden, but I think the dogs that I have had in my life tend to fill that void.

As I was crying in my coffee the other day and looking at the box of Bo’s ashes by my side of the couch, I noticed a post-

MOM”S BEST FRIEND: “The king-size bed in our bedroom is not just for us to have plenty of room, it’s also for our dogs. In a way, our dogs give us the affection and cuddles our son Broden is not able to give.”

ing for a dog, “I found this dog that seems to have been dumped in a nearby neighborhood. A friend is feeding him, and the dog just sleeps on the front porch. No one will claim him. I don’t have the heart to take him to a shelter. Is there anyone who will give him a loving home?” I didn’t think. I just typed, “I just lost my Bocephus. I’ll take him.” After deciding to meet at a local dog park, I met a beautiful black lab. I squatted down in the grass and put my face close to his and looked into his eyes, “Do you want to come home with me? I’ll love you forever.” He looked into my eyes and licked my nose. That’s all I needed. I looked at the gentleman who brought the lab and said, “Thanks, I’ll take him.” Before I knew it, I was driving down the road back to my house with a black lab’s head nestled in my neck.

With our current dog, Scout, slowly acclimating to the black lab, I went online to see what name would best suit this sweet boy. After one or two minutes of searching, I decided to name him Cooper. I texted my husband at work, “We got a dog. His name is Cooper.” Mark knows me too well and didn’t fight the decision. His only response was, “Oh ok. So, his name is Cooper?”

Broden came home from clinic and walked through the door. He could tell there was some extra commotion with another active dog in the house. When Cooper nudged Broden’s leg for acknowledgement, Broden became annoyed and ran upstairs to his room. When Broden was in his room, I went upstairs, “Cooper is going to be with us. I’ll do my best so you can still have your quiet time and routine.” Broden responded, “You can leave.” I cracked the door and shuffled back downstairs to help Cooper and Scout get more acquainted.

> “There will never be another dog like Bocephus. I will love him forever. My hope is that Broden will soon realize that Cooper is here to stay.”

Broden should be allowed to be who he is, have his space, and give affection when he sees fit. I adore him and will take whatever I can get, whenever I can get it. For some reason, my dogs help fill that void for me, and the more I watch my husband, I think it helps fill that void for him, as well. There will never be another dog like Bocephus. I will love him forever, but I’m hopeful that Cooper will realize that the love we have to give is endless, and my hope is that Broden will soon realize that Cooper is here to stay. •

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.

REMEMBER ★ HONOR ★ TEACH

Help Wreaths Across America Remember, Honor, and Teach on December 14, 2024 at 12:00 pm *(Wreath Placement Beginning at 8:00 am)* by sponsoring a wreath, volunteering, or inviting friends to help.

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The Irene & Eric Simon (IES) Brain Research Foundation is a volunteer-run nonprofit whose mission is to help advance research toward treatments and cures for brain diseases and conditions. The Irene & Eric Simon (IES) Brain Research Foundation Summer Fellowship Program in Neuroscience attracts bright, motivated students to neuroscience. These remarkable students are mentored for the summer by brilliant neuroscientists heading top-notch labs. The Foundation will have given 116 summer fellowships as of Summer 2024.

Many fellows have gone on for PhDs or MD/PhDs in neuroscience, have published papers and even won awards. 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.

REMEMBER THE FALLEN HONOR THOSE WHO SERVE TEACH OUR CHILDREN THE VALUE OF FREEDOM

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2. Select "Location to Support." There is a drop-down menu on the right of "Arlington National Cemetery."
3. Scroll through the list to select your location of choice.
4. If a participating cemetery you would like to support is not listed, scroll to the bottom of the list and select "choose another cemetery to support." You will enter that cemetery name, and your donation will count towards our goal.

TO VOLUNTEER:

1. Select "Volunteer."
2. Select a location to volunteer. If the cemetery is not listed, select "Lookup by Cemetery Name" OR " Lookup by City or Postal Code."
3. Complete Registration.

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