PLUS: UNITED STATES MILITARY SECTION

EXCEPTIONAL PARENT
MAGAZINE
JUNE 2023
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SUMMER FUN & TRAVEL ISSUE:

INTERNATIONAL TRAVEL: GREAT OPPORTUNITIES *for* YOUTH WITH DISABILITIES

INSIDE:

FUN WAYS TO PREVENT SUMMER READING SLIDE *in* DYSLEXIA

Travel With A Service Dog

Ellen Lenox Smith and Maggie

AND:

TO TRAVEL *or* NOT TO TRAVEL

PLUS:

HELPING PEOPLE WITH DISABILITIES LIVE IN THEIR COMMUNITIES – RATHER THAN INSTITUTIONS

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JUNE 2023 VOLUME 53 ISSUE 6

SUMMER FUN AND TRAVEL

FEATURES

ON OUR COVER

EP Magazine's Annual Summer Fun and Travel Issue offers excellent advice, helpful tips and sound resources for families aiming to replace the routines of the school year with beneficial activities and recreation. Ellen Lenox Smith recalls all of the benefits that her service dog Maggie provided during the summer months of outdoor activities and travel. *Coverage begins on page 12.*

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Summer Plans

For families raising children with disabilities, the break in routines during the summer can pose certain challenges.

Here we are on the doorstep of summer. We turn our attention away from school and homework to warm weather activities and vacation plans. As our readers well know, for families raising children with special needs, the break in routines during the summer months can pose certain challenges.

EP's Annual Summer Fun and Travel Issue presents a wide variety of resources and articles to help address these families' concerns. For parent's who are seeking a recreation program with the proper fit for their child's individual needs, Bonnie Ivers, M.A., Psy.D. offers a solid set of tips to help them find it in her article "How to Evaluate Recreation Programs for a Child with Special Needs." For parents or caretakers staying close to home, Elizabeth Boyajian has contributed a selection of ideas for keeping children engaged and active in her piece titled "Summer Fun Across the Spectrum." One of the most quintessential summer activities – swimming – is the focus of Joey Enos' piece, "Why Inclusive Swimming Matters," in which he conveys how significant his son Sammy's inclusive swimming program has been to his development.

> "EP's Annual Summer Fun and Travel Issue presents a wide variety of resources and articles to help address families' concerns."

For those who plan to travel to vacation destinations or to visit distant family, our June issue is a great resource. In "To Travel or Not to Travel," Pamela Aasen submits a thoughtful personal story containing a myriad of tips to make summer travel easier. Ellen Lenox Smith recounts all of the ways that her service dog Maggie made travel a smoother and less stressful experience in her article "Travel and Summer Fun with a Service Dog."

Summer also presents a unique set of problems for parents of neurodivergent children who are prone to the summer slide. In her article "Fun Ways to Prevent the Summer Reading Slide in Dyslexia," Georgie Normand recommends a course of action informed by her many years of teaching, as well as research and writing on the subject.

We encourage you to share these helpful articles with colleagues family, and friends. We also invite you to check out our revamped social media outlets. Like us on Facebook and share our posts at **facebook.com/exceptionalparentmag**, share from our Instagram feed at **instagram.com/epmzine** , and follow us on Twitter at **twitter.com/epmzine** . Plus, it's easy to subscribe and receive "EP for Free" – just visit **www.epmagazine.com** and click EP for Free Sign Up. Have a terrific summer!

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

AUTISM IN THE FAMILY TREE: RESEARCHERS HAVE FLIPPED THE SCRIPT ON ASD GENETICS

Scientists long thought that siblings born with ASD share more of their mother's genome than their father's. But Cold Spring Harbor Laboratory Associate Professor Ivan Iossifov and Professor Michael Wigler have now shown that, in many cases, it's dad who might be playing a bigger genetic role.

For decades, Cold Spring Harbor Laboratory scientists and collaborators have invested sizable resources into deciphering the genetic causes of autism spectrum disorder (ASD). Their efforts have produced useful insights for diagnosticians, therapists, and educators, helping to change the way people think about this common neurodevelopmental disorder. Now, they've taken their work another step further, overturning popular assumptions about autism and its genetic origins.

Autism spectrum disorders cover a range of neurological and developmental conditions. They can affect how a person communicates, socializes, learns, and behaves. ASD may also manifest as repetitive behaviors or restricted interests. In the United States, it affects around one in 36 children.

"There are children diagnosed with autism who are high functioning," Iossifov says. "They have a completely productive life, although they have some minor troubles in social interactions, as most of us do. But also, there are children diagnosed with autism who never learn to speak, and they have definitely a difficult life."

Over the last two decades, CSHL scientists have led a multimillion-dollar effort to uncover the genetic origins of autism. They discovered thousands of genes that, when damaged, may cause a child to be born with ASD. But their work was not able to account for all cases of ASD. So Iossifov and Wigler set out to find the missing sources.

The duo analyzed the genomes of over 6,000 volunteer families. They found that in families that have two or more children with ASD, the siblings shared more of their father's genome. Meanwhile, in families where only one sibling had ASD, the children shared less of their father's genome. While the discovery reveals a new potential source of ASD, it also poses a provocative question. Could other disorders play by the same genetic rules?

No one is sure how the father's genome makes its mark on children with ASD. But Iossifov has a couple interesting ideas. He thinks some fathers may carry protective mutations that fail to get passed on. Or fathers may pass down mutations that trigger the mother's immune system to attack the developing embryo. Both theories offer hope for parents of children with ASD and other neurological disorders like schizophrenia.

"Our future research is exciting," Iossifov says. "If one of those theories or two of them prove to be true, then it opens different treatment strategies, which can, in the future, affect quite a lot of families."

In addition, this research offers helpful tools for educators and therapists. It may allow for earlier diagnoses and a better overall understanding of autism.

ABOUT COLD SPRING HARBOR LABORATORY

CSH Cold Spring Harbor Laboratory

Founded in 1890, Cold Spring Harbor Laboratory has shaped contemporary biomedical research and education with programs in cancer, neuroscience, plant biology and quantitative biology. Home to eight Nobel Prize winners, the private, not-for-profit Laboratory employs 1,000 people including 600 sci-

WHAT'S HAPPENING

DEPARTMENT OF LABOR: CAREGIVING COSTS WOMEN NEARLY $300,000 IN LOST PAY OVER THEIR LIFETIMES

CARE DEFICIT: A first-of-its-kind report from the Department of Labor studying women in their early 40s calculated how much they lose as a result of their caregiving responsibilities for children and parents. The impact is especially high for Latinas.

BY CHABELI CARRAZANA FOR THE 19TH

The cost of caregiving on women's lifetime earnings now has a number: $295,000. A new report released Thursday by the Department of Labor projects how caregiving for children and parents affects women over the course of their careers, eating into their retirement savings and costing them wages and promotions.

The research projected the lifetime employment costs brought on by unpaid family care for women born between 1981 and 1985, now entering their early 40s, who have already taken on care for their children and will likely care for their parents, parents-in-law and spouses. The estimate is adjusted for inflation and is in 2021 dollars.

These figures, which appear in a report commissioned by the department's Women's Bureau, have not been estimated before.

"At some point in our lives we all need care, and women often provide this care in our families. And while family care may be priceless, that does not mean that there's no cost to those providing it," said Wendy Chun-Hoon, the director of the Women's Bureau, during a call with reporters.

The report focused on women because they are the most likely to provide unpaid caregiving: In 2021, 66 percent of women with children younger than age 6 participated in the labor force, compared with 94 percent of men with children younger than 6, according to the Bureau of Labor Statistics. The bureau does not collect any data on nonbinary people.

The numbers are still very likely an undercount, the Women's Bureau said. Because of limitations in the data, the research excludes care for adults with disabilities and caregiving costs unrelated to employment, such as the cost of day care and the emotional impact of caregiving.

Of the $295,000 figure, 80 percent is attributed to lost earnings due to caregiving and 20 percent is lost retirement income as a result of lower wages. The majority of the loss in wages comes from caring for children. Care for other adults totals only 15 percent of the costs, researchers found, because women are less likely to reduce their employment to provide it.

> *"6 percent of women with children younger than age 6 participated in the labor force, compared with 94 percent of men with children younger than 6."*

The impact of caregiving on women's earnings also varies widely across race, educational background and the number of children a woman has.

The loss in lifetime earnings is higher for mothers who are college-educated, averaging $420,000 in lost wages and retirement savings over their lifetimes. Mothers who completed high school lost $202,000 on average due to caregiving, and mothers who did not complete high school lost $122,000.

More children compounds the issue: On average, employment-related costs amount to $151,000 for mothers with one child, $343,000 for mothers with three children and $464,000 for mothers with five or more children.

The impacts are particularly outsized for Latinas, who are more likely to have more children and work in low-paying jobs with very limited flexibility, the report found. Less pay also means there are few child care options – the average annual cost of child care in the United States is nearly $11,000, which is out of reach for many Latinas. Without access to care, Latinas see their lifetime earnings slashed by 19 percent, the most of any racial group. That figure is 8 percent for Black mothers, 15 percent for White mothers and 14 percent for other groups, which includes Asian American, Pacific Islander and Native Hawaiian (AAPI) mothers. Small sample sizes make it difficult to separate out data for certain groups, including AAPI women.

DEGREES OF LOSS: The loss in lifetime earnings is higher for mothers who are college-educated, averaging $420,000 in lost wages and retirement savings over their lifetimes.

Black women, who are historically the group of women with the highest labor force participation rate, are the least likely to scale back their employment for caregiving. And so while that amounts to less lifetime lost earnings – $149,000 on average, the lowest of any group – that signals a scarcity of choice rather than economic prosperity.

"It's more of a story about how Black mothers can't afford to work less due to things like the wage gap, lower levels of household wealth, all kinds of other systemic inequalities that lead to worse economic outcomes for Black women and for Black families," said SJ Glynn, senior adviser for the Women's Bureau. "Even these small reductions can have a really problematic impact when it comes to immediate economic security, and then longer term retirement security."

> *"Since the pandemic, renewed focus has been put on reducing child care costs for families and recognizing the caregiving roles that women play."*

It's likely that care-related employment losses contribute to high poverty rates for elderly Black and Latinx adults, the report found.

Since the pandemic, renewed focus has been put on reducing child care costs for families and recognizing the caregiving roles that women play. The first women's recession occurred during the pandemic specifically because, due to the closure of child care centers, women left their jobs to care for children full-time.

Since then, the country has tried to pass a comprehensive child care plan that would overhaul the industry, and though that plan failed, other long-stalled legislation has passed. A one-time expansion of the child tax credit passed in 2021 after decades of inactivity. The Pregnant Workers Fairness Act and the PUMP Act, two pieces of legislation designed to protect mothers at work, also passed years after they were first introduced. And earlier this year, President Joe Biden built in a first-of-its-kind child care requirement for businesses seeking large federal subsidies and signed a slate of executive orders aimed at lowering the cost of child care and elder care.

And yet, quality child care remains inaccessible for most parents. Women still see a wage gap, earning 77 cents compared to every $1 earned by White men, and women of color are still consistently the furthest behind. All of those are historic problems that, without targeted legislation, will continue to hurt the economy, Chun-Hoon said.

"Gender and racial inequality combined with our nation's lack of care infrastructure and work/family policies… harms women, not just in the short term, but in the medium- and in the long-term," she said.•

ABOUT THE AUTHOR:

Chabeli Carrazana the economy reporter for The 19th. She was previously a business reporter in Florida covering the tourism industry for the Miami Herald and the space industry for the Orlando Sentinel, as well as labor issues and workers rights. In 2021, she was a national Livingston Award finalist for her coverage of the women's recession. Chabeli was born in Cuba and speaks fluent Spanish. Visit **https://19thnews.org** to read more.

WHAT'S HAPPENING

AUTISM SPEAKS LAUNCHES AUTISM BY THE NUMBERS TO INCREASE ACCESSIBILITY OF AUTISM INFORMATION

A BETTER VIEW: Autism by the Numbers encourages better understanding of select autism services, outcomes and policies across the U.S., including early diagnosis and intervention, healthcare costs and transition to adulthood.

Autism Speaks is bringing together data sources to address gaps in nationwide autism data with the launch of Autism by the Numbers, created in collaboration with the National Autism Data Center at Drexel University.

For the first time, the Autism by the Numbers Dashboard and Annual Report centralize autism data across the United States to foster insights into the systems that serve autistic individuals , spotlight accessibility of supports and services, and enable advocacy in key areas for the autistic community.

Autism by the Numbers encourages autistic individuals, families, advocates and researchers to better understand the utilization of select autism services, outcomes and policies across the U.S., including early diagnosis and intervention, healthcare costs and transition to adulthood.

"We're proud to introduce Autism by the Numbers as a first-of-its-kind dashboard that uniquely delivers autism information from across the nation in an accessible, authoritative hub," said Andy Shih, Chief Science Officer, Autism Speaks. "In mobilizing reliable and actionable data and offering guidance for future planning, Autism by the Numbers has the potential to transform the way we understand and meet the needs of the autistic community, making a positive impact in the lives of people with autism and their families."

In this collaboration, Autism Speaks and the National Autism Data Center at Drexel University conceptualized the project, identified data sources and engaged in the data analysis, as well as the visualization, of Autism by the Numbers.

"People and communities need data that can be accessed and used to navigate systems, from getting an autism diagnosis and linking to needed services, to understanding policies where they live," said Jessica Rast, Research Scientist at the National Autism Data Center at Drexel University. "Together, we are exploring additional data sources and identifying solutions across communities through Autism by the Numbers."

In delivering visibility into the landscape of autism services and supports, Autism by the Numbers offers a tool to facilitate planning and advocacy, and reinforces Autism Speaks' commitment to better support the diverse needs of all people with autism.

ABOUT AUTISM SPEAKS

Autism Speaks is dedicated to creating an inclusive world for all individuals with autism throughout their lifespan. We do this through advocacy, services, supports, research and innovation, and advances in care for autistic individuals and their families. To find resources, join an event or make a donation, go to **www.AutismSpeaks.org**. Learn more by following @AutismSpeaks on Facebook, Twitter, Instagram and LinkedIn.

ABOUT NATIONAL AUTISM DATA CENTER AT DREXEL UNIVERSITY

The National Autism Data Center is a project of the A.J. Drexel Autism Institute Policy and Analytic Center. The mission of the National Autism Data Center is to house and utilize data to create meaningful information for autistic individuals, their caregivers, policymakers, service providers, and stakeholders seeking to improve systems of care. We promote secondary analysis of national-level data that fuels population-level information about the care people report they need and the services they use.

WHAT'S HAPPENING

LAWMAKERS SEEK TO ADDRESS CONCERNS FACED BY AIRLINE PASSENGERS WITH DISABILITIES

With disability-related complaints regarding air travel up 50 percent in the last year, Representatives Steve Cohen (D-TN-9) and Pete Stauber (R-MN-8) and Senators Tammy Duckworth (D-IL) and John Thune (R-SD) introduced bipartisan, bicameral legislation to improve air travel for passengers with disabilities, notably passengers who use wheelchairs and other mobility aids.

The bipartisan Mobility Aids on Board Improve Lives and Empower All (MOBILE) Act would help ensure the U.S. Department of Transportation (DOT) takes additional actions to empower passengers who use mobility aids, such as manual and powered wheelchairs, to better prevent more disability-related incidents.

"Passengers requiring mobility aids such as powered wheelchairs to travel by air must be given reasonable accommodations and need to know that the FAA is carefully monitoring, and protecting, their rights to fly comfortably and without unnecessary inconvenience," said Congressman Cohen, Ranking Member of the Aviation Subcommittee. "I am proud to introduce the MOBILE Act to achieve these goals and am hopeful that significant progress for these passengers will be made."

"Many people with disabilities use personalized, custom wheelchairs in their daily lives, and damage to them can cost a fortune to fix," said Congressman Stauber. "This legislation will bring more transparency to the experience of wheelchair users during air travel and further study accessibility challenges. This is yet another step towards making air travel as safe and comfortable as possible for all passengers, and I look forward to working with Senator Duckworth, Senator Thune, and Rep. Cohen to get this across the finish line."

"As a frequent flyer whose wheelchair is regularly broken or damaged, I understand firsthand how deeply frustrating it is that our aviation system still fails to make sure every passenger with a disability is treated with dignity and respect," said Senator Duckworth, Chair of the Subcommittee on Aviation Safety, Operations and Innovation. "No air traveler should be left in the lurch or immobile on a plane, which is why I'm proud that after successfully writing the first law to require airlines to disclose the number of lost or broken wheelchairs, today I'm building on this progress by introducing this new bipartisan bill. It's long past time we make flying easier and more accessible for the millions of Americans with disabilities who travel by air each year."

"For passengers who use wheelchairs, traveling can oftentimes be difficult and frustrating," said Senator Thune. "I'm proud to join Senator Duckworth in introducing this common-sense legislation that would improve safety and accessibility for individuals who use mobility aids to help ensure their travel experience is as smooth and hassle-free as possible."

According to the DOT, more than 25 million Americans – more than 14 percent of whom use wheelchairs – report they have disabilities that limit their travel. Yet, thousands of wheelchairs and other mobility aids continue to be mishandled, damaged or lost each year.

The MOBILE Act would require the Secretary of Transportation to:

- *Issue a notice of proposed rule making requiring air carriers and foreign air carriers to publish dimensions of cargo holds;*
- *Evaluate the frequency and types of damage to wheelchairs and scooters;*
- *Develop and submit to Congress a strategic roadmap on researching the technical feasibility of accommodating passengers in wheelchairs in the main cabin; and*
- *If in-flight, in-wheelchair seating is determined to be technically feasible, assess the economic and financial feasibility of accommodating passengers with their wheelchairs in the main cabin during flight.*

In addition to Paralyzed Veterans of America, the legislation has been endorsed by Access Ready, All Wheels Up, The Arc of the United States, Association of People Supporting Employment First, Autistic People of Color Fund, Autistic Women and Nonbinary Network, Blinded Veterans of America, Caring Across Generations, Cure SMA, Disability Rights Education and Defense Fund, Family Voices, Muscular Dystrophy Association, National Association of Councils on Developmental Disabilities, National Disability Rights Network, National Multiple Sclerosis Society, Partnership for Inclusive Disaster Strategies, Amputee Coalition and United Spinal Association.


GOING MOBILE: 25 million Americans report that they have disabilities that limit their travel, and thousands of wheelchairs continue to be mishandled, damaged or lost each year.

PHOTO COURTESY USDA/TANYA E. FLORES

WHAT'S NEW IN TUNE WITH JUNE

BLIPBLOX SYNTHESIZER

The Blipblox is more than a toy, it is a completely new way for kids (and adults) to explore electronic music. It is a fully functional musical instrument designed to be safe and fun for everyone, even kids as young as 3 years old. The Blipblox's colorful buttons and knobs and a synchronized light show encourage kids to create crazy new sounds by adjusting real synthesis parameters like oscillators and filters, just like a real music producer. No need to connect a phone and no software to download. Just turn on the Blipblox Toy Synthesizer and start having fun. With the push of a button the Blipblox starts playing one of its hundreds of built-in melodies. Twist and turn the colorful controls to create fresh music from an unlimited palette of synthesized sounds. See the sound as the LED light show dances in beat with the music.This engaging and multi-sensory learning tool is terrific for students who benefit from music therapy!

THE SENSORY SITE
www.sensorysite.com

BUOY BALL SWING

The Buoy Ball Swing challenges balance reactions, builds core strength and provides vestibular input. With this sensory room staple, kids spin around, bounce gently or swing from side to side. It provides an upper body workout as they hold on to the rope and keep themselves upright while swinging. The Buoy Ball Swing supports kids with low muscle tone, motor planning difficulties or sensory processing disorder.Use during therapy sessions or add to a sensory space at home or in school. Wipes clean for easy maintenance.

FUN AND FUNCTION
www.funandfunction.com

RAINDROP FALLS SPLASH POOL

Kids and toddlers love this cascading, flowing waterfall outdoor playset with splish splash tipping water buckets and kids pool. This multi-level outdoor sensory table has plenty of room for friends to join in the fun, and enough water toys to keep toddlers and kids engaged for hours. Encourage STEM play by attaching a garden hose for rushing, flowing, sensory water table play. Pour water and watch the rain showers fall, fill the splash buckets to tip and create a waterfall wave that propels the boats into the pool. Stands up to tough play to last for years.

SIMPLAY3
www.simplay3.com

GREEN BUG SQUEEZE TOY

The Green Bug Squeeze Toy is perfect for use as an office desk toy or fidget toy, providing a satisfying and calming experience whenever you need it. An effective and fun way to relieve anxiety and stress. Squeeze the toy to pop the eyeballs out and watch them bounce back in. Made with high-quality materials, this toy is built to last and withstand even the most vigorous squeezing.

KIDENO
www.kideno.com

SUMMER FUN ACROSS THE SPECTRUM

BY ELIZABETH BOYAJIAN

Summer is the time for rest and relaxation. Schedules lessen, and free time is in abundance. However, before we can kick our feet up, it is our job as parents, caregivers, and service providers to seek out activities to keep our children (of all ages) and clients both physically and mentally engaged.

If you are in the unique position to be planning your summer for a child, adult or client with special needs, keeping their wants, needs, and necessary modifications in mind will set you up for success. We as parents and caregivers need to continuously consider the types of disabilities our children (of all ages) and clients have, and how they may affect a summer outing. For instance, those sensitive to sun and heat, may not fare well outdoors for long periods of time. Or those who are wheelchair bound may have trouble visiting a beach that does not have the correct terrain for their wheels. However, instead of focusing on what our family members and clients cannot do – below is a list of activities that can be done from the comfort of your own neighborhood, home – or even backyard!

FUN IN THE SUN : ENSURING A WELL-PLANNED SUMMER OF ACTIVITIES

1. PLAN A PICNIC

Pack up some of their favorite snacks, games, a portable music player, and a fun blanket, and head off to a nearby park for a picnic and people-watching! If the park is overly stimulated or too crowded – host a picnic in your backyard.

2. TIE DYE T-SHIRTS

Take their old white shirts that lost their luster and transform them into groovy tie-dye pieces. Watch as your family members and clients experiment with color and see their eyes light up when they receive their finished product.

3. WATER PLAY ALL DAY

Turn on your sprinklers, blow up a small pool, or fill up some water balloons! Challenge them to hit a certain target with their water balloons, and watch as they develop their gross motor skills from the various physical activities and exercises in spatial awareness.

4. GROW IN THE GARDEN

Plant some seeds in your community garden – or at home. It will be an exercise in sensory development as they work with their hands testing soil, pruning unwanted growth, and managing the produce grown.

5. POP OPEN THE PAINT

Set up some water color or acrylic paint and offer your family member or clients coloring sheets to paint. If they are not afraid to get messy, finger painting is a wonderful exercise (especially for those with cerebral palsy), as they can practice using muscles in their hands, fingers and arms!

6. MASTER A NEW RECIPE

Prepare your favorite meal together while teaching the basics of meal preparation. They will experience hands-on, how to properly wash, cut, portion, and prepare their food – unleashing a new found appreciation for meal time!

7. CHECK OUT YOUR LOCAL LIBRARY

Head over to the library to see what's new on the shelves. Be sure to check online to see if they scheduled any special performers or classes your family member or clients may enjoy!

8. HEAD TO THE BOWLING ALLEY

On a blazing hot day, seek the AC at your local bowling alley. Depending on their response, the bowling alley has a variety of stimulants to keep everyone engaged. Plus, many bowling alleys offer lifted gutters and adaptable equipment to ensure everyone leaves with the satisfaction that they knocked down a few pins!

9. VISIT YOUR COUNTY ZOO

Discover a new species and make some animal friends at your local zoo, while exercising sensory development. When you arrive make sure to visit with guest services and discuss your family member or client's needs, and explore what options they have for wheelchair users and assistive technology, like headsets or apps.

10. SEEK OUT A SOCIAL GROUP

Many inclusive states offer classes, social skills groups, and enrichment programs. These groups provide structure, support, and judgment-free environments where children and adults with a range of abilities can grow and learn, while having fun together with likeminded peers.

Every family member and client with special needs has their own individual likes, dislikes, and fears. Activities that include tactile and sensory exercises can help with cognitive development and fine motor skills. Making accommodations to the opportunities listed above will ensure a well-planned summer of fun for all involved. •

ABOUT THE AUTHOR:

Elizabeth Boyajian is a thought leader whose work intersects between human services, community impact, and social welfare. A graduate of Rutgers University, with a Master's Degree in Public Administration focused in Non-Profit Performance Management, Elizabeth is passionate about defining public problems and developing creative solutions. As the Director of Development at Spectrum for Living, a nonprofit organization providing comprehensive care to adults with developmental disabilities across Northern and Central New Jersey, Elizabeth oversees all fundraising and marketing initiatives. In her spare time she volunteers at the Bergen County Animal Shelter and serves on the Bergen County Human Services Advisory Committee.

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.

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.

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."

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 was a staff writer for National Pain Report and *1000 WATTS Magazine* before they shut down, was a former staff writer for Pain News Network, and with her husband speaks out to educate others about her condition and pain management. 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!*

Summer fun&travel

INTERNATIONAL TRAVEL OFFERS GREAT OPPORTUNITIES FOR YOUTH WITH DISABILITIES TO DEVELOP PERSONALLY AND PROFESSIONALLY

BY JUSTIN HARFORD

In this increasingly globalized world, greater cultural awareness is valuable for anyone, with or without a disability. Parents can support their child's development of global competence through purposeful travel and international tourism.

I caught the travel bug young when I was in high school. My parents took my brother and me on a business trip with them to Santiago, Chile. We spent about 10 days there, and the experience for me was fascinating. Everyone around us spoke a different language. We visited farms, went to restaurants, and even traveled to Easter Island, while my mom negotiated our way with her limited Spanish. Later, I took advantage of other opportunities for international travel, which included a choir trip to China with my sister, and a tour of Spain with my Spanish class.

Intrigued by these early international experiences, I was eager to explore the world more, but how was that going to work for me as someone who had been blind since I was very young? I was not going to be able to point and gesture the way my relatives could. That galvanized me to study Spanish which led to the discovery of my aptitude for languages.

I studied abroad, without my parents, for a year in Santiago Chile. I backpacked solo around the Southern Cone, noting phone numbers and addresses in a braille notebook bought from an arts and crafts store. I recruited sighted people to read class and archival materials to me, promising English lessons to the Chileans, and Spanish support to the Americans, in return for their help. I wrote my history thesis on a topic that had never been explored before, and I made friends that I continue to speak with today.

All of this happened because of my early childhood experiences traveling internationally with my parents or with the support of my parents.

SEEK OUT PURPOSEFUL INTERNATIONAL TRAVEL WITH YOUR KIDS

There are many programs that offer youth the opportunity to study or volunteer abroad. Websites like **www.gooverseas.com** or **www.goabroad.com** highlight a variety of options across the globe.

Some young people with disabilities are ready and eager to join a program on their own. Sara Giraldo, a visually impaired woman from Colombia, traveled to the United States as a volunteer with the Youth Ambassadors Program, at the age of 18. She had been enamored with American culture, ever since she was a 14 year-old, studying English at a local community center. She learned about the Youth Ambassadors Program, submitted her application, and was accepted, with her parents only finding out after. Her mother, Isabel, mostly worried about whether her daughter was adequately prepared at such a young age, to go abroad on her own, but after participating in program orientations for parents and learning about the emergency response plans in place, she felt better about it.

Others may benefit from being accompanied by a friend or a family member, especially if they are minors who have had limited experience living on their own. Sara Hamilton went with her 14-year-old daughter Jane, to Poland, to teach English to children with a program called Global Volunteers.

One aspect that influenced their decision to go with Global Volunteers had to do with Jane's sensitivity to sensory input, like certain noises and foods, and the occasional need to decompress, resulting from her neurological challenges due to Tourette, Generalized Anxiety Disorder and Autism Spectrum Disorder. The Global Volunteers staff was very professional and gracious, allowing them flexibility when Jane needed to step out. The program staff made sure plain, familiar food such as, bread and butter were available in addition to many unfamiliar foods.

In addition to being a meaningful bonding experience for mother and daughter, and an excellent opportunity to build teaching skills, while working with enthusiastic communities of children, they were able to prepare Jane to leave her parents behind, to study abroad with Youth for Understanding, in Japan the following summer.

As Sara explained, "it was extremely rewarding to be able to create authentic human connections with all of the children, the staff, and the other volunteers, and feel like we were spending time doing something that would make a difference in so many people's lives."

SUPPORT YOUR CHILDREN TO STUDY ABROAD

The US State Department recognizes the value of international exchange for youth, and offers a variety of opportunities, many of which come with funding. High School students can study a critical language with the National Security Language Initiative for Youth (NSLI-Y). Others can go to high school in another country. The Future Leaders Exchange (FLEX) Program offers funded opportunities to go to high school in Eastern Europe, for a year, while the Youth Exchange and Study Abroad (YES) Program offers similar opportunities in Africa and the Middle East. For a Western/European experience, the Congress Bundestag Youth Exchange (CBYX) offers the chance to spend a year at a high school in Germany. All of these programs include generous funding, and the only language prerequisite is a desire to learn the language.

PHOTOS PROVIDED BY JUSTIN HARFORD

Colton Treadwell, an individual with physical disabilities, had a strong interest in learning Russian. He was accepted to participate in a Russian immersion program through the Critical Language Scholarship (CLS) in Tbilisi, Georgia.

Because his father was in the service, Colton had grown up traveling and moving around all of his life. He was a fulltime power chair user, who, while growing up, had required a lot of support from his father with activities of daily living. Now, he aspired to study abroad in a country with minimal wheelchair access, and took the lead in setting up a support plan during his program. Colton's experience in Georgia forced him to be more resourceful and gain useful skills, particularly around traveling to locations that required multiple connecting flights. As Colton's father, James Treadwell, noted, "It doesn't feel as though I get as many off-schedule requests to come see him, as I did before he went abroad. So, I would see that as a gain." Through international travel, Colton found opportunities to feel like he was contributing to society and being more independent.

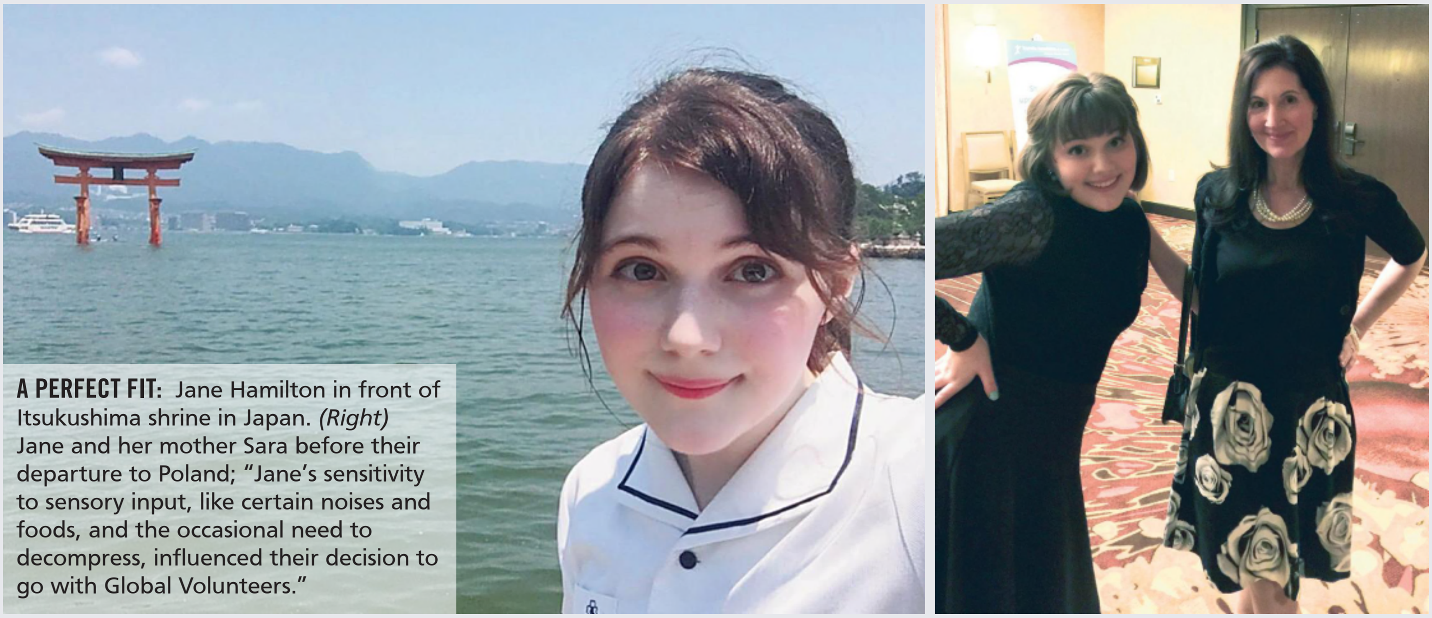
LANGUAGE LAB: The author reading a Braille sign at Iguazu Falls; "I recruited sighted people to read class and archival materials to me, promising English lessons to the Chileans, and Spanish support to the Americans, in return for their help."

ASK THE RIGHT QUESTIONS

Many programs are capable of supporting student participants with all sorts of disabilities. At the same time, adolescents may not always ask the right questions to determine whether a program can provide the support they need. That's where parents can be especially helpful. "At orientations, kids are mostly thinking about what they are going to eat, and where they are going to visit", reflects Sara. "Parents are concerned about where their children are going to get their medications."

During the planning for his experience in Georgia, Colton asked his father to share his concerns, which then helped guide his preparation for his exchange program. He invited his father to meetings with program staff and with an access advisor with the National Clearinghouse on Disability and Exchange, where they discussed the details of how his power wheelchair would get transported to the host country, and what it would look like for him getting from one place to another, once on the ground. James recalled that when he realized Colton's trip to Georgia might actually happen, he began to pay closer attention and really think about what he would absolutely have to have in place, in order to survive on his own, without James two hours away.

Parents can also support their children in more basic ways. Although Isabel was not able to directly support in the planning calls for Sara's program, due to limited English, she and her husband were available to support their daughter with putting together application materials.



A PERFECT FIT: Jane Hamilton in front of Itsukushima shrine in Japan. *(Right)* Jane and her mother Sara before their departure to Poland; "Jane's sensitivity to sensory input, like certain noises and foods, and the occasional need to decompress, influenced their decision to go with Global Volunteers."

TASTE FOR ADVENTURE: Colton Treadwell in front of a Domino's Pizza in Tbilisi, Georgia. "Colton's experience in Georgia forced him to be more resourceful and gain useful skills. He found opportunities to feel like he was contributing to society and being more independent."

CONCLUSION

Whether volunteering or studying abroad, international education can be a great way for young people with and without disabilities to develop personally and professionally. It can also be an activity that kids and parents can experience together. To learn more about how to study or volunteer abroad with a disability, visit **www.miusa.org** or write us at **clearinghouse@miusa.org** •

The National Clearinghouse on Disability and Exchange is a project of the U.S. Department of State's Bureau of Educational and Cultural Affairs, designed to increase the participation of people with disabilities in international exchange, between the United States and other countries, and is supported in its implementation by Mobility International USA. Resources and services are free of charge.

ABOUT THE AUTHOR:

Justin Harford (he/him/his) is a Program Coordinator with the National Clearinghouse on Disability and Exchange, working to increase the participation of people with disabilities in international exchange by providing information and resources to both individuals with disabilities and higher education professionals. Previously, Justin worked for two years in disability community organizing and policy in the foothills of Northern California. He received his Bachelor of Arts in Latin American History and Spanish Literature from University of California, Berkeley. He studied abroad at the Pontifical Catholic University in Santiago Chile, where he researched and wrote a thesis on the history of the blind in Chilean society. In 2008, he spent 10 weeks immersing himself in the culture and language of Michoacan, Mexico.

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

FOLLOW YOUR HEART

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

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.

FUEL UP RIGHT

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

CATCH SOME ZZZ'S

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

TAKE CARE OF YOUR MENTAL HEALTH

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

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FUN WAYS TO PREVENT THE SUMMER READING SLIDE IN DYSLEXIA

BY GEORGIE NORMAND, M.A.

Eight-year-old Alec was a very motivated student during his daily dyslexia intervention at school. He had been diagnosed with dyslexia six months earlier when still reading at kindergarten level. When he was told this was the source of his reading problem, he felt better. He now understood that he was as smart as his classmates and simply needed a specialized approach to reading instruction.

His twice weekly after-school tutoring sessions were also building his reading skills. He was looking forward to a time when he could pick up a book and read it fluently. As summer approached, Alec told his mother that he wanted to take the summer off from all lessons. She was justifiably concerned that some of his hard-earned gains would be lost over the summer break.

SUMMER LEARNING LOSS

Although the summer slide can impact all students, with or without dyslexia, there is no consensus about how much learning is lost. One recent study found that the average student lost 17-34% of the prior year's learning gains (reading, math, and other subjects) during the summer, and that those who lost ground in one summer are likely to lose ground in subsequent summers.

An earlier study found that achievement scores declined by one month's worth of school-year learning, with declines being greater for math than for reading. Another study suggested that the degree of loss depends on many factors, including household income. Some experts say that the summer slide issue is far from settled, but surveys do show that the average teacher finds it necessary to spend the first 3-6 weeks of school re-teaching content from the previous year.

For dyslexic students, when there is no summer intervention in place, the slide can be more dramatic and consequential.

SUMMER SLUMP: Without ongoing cumulative review and lots of repetition with newly introduced reading skills, progress can stall or the student may regress.

Reading skills are much more difficult to acquire and retain, compared to their non-dyslexic peers. Without ongoing cumulative review and lots of repetition with newly introduced reading skills, progress can stall, or worse, the student may even regress. In dyslexia, multiple inefficiencies in the brain's reading circuit interfere with the critical processes involved in learning to read. Overcoming these inefficiencies requires such an intense effort, that any interruption in instruction can result in learning loss.

THE PLAN

Remembering how even a short two-week holiday break had impacted Alec's progress, his mother was worried that a summer break could create a significant setback for Alec. She discussed the situation with his tutor.

The decision was made to work out a compromise with Alec. Instead of two tutoring sessions per week, they would only do one during the summer, with the caveat that Alec would complete assigned work from the tutor, twice a week. His mother would need to supervise this work to address another feature of dyslexia - a weak error-detection mechanism in both reading and spelling. Every component of a dyslexia intervention requires supervision, so that errors are not overlooked.

Since fluency is especially impacted during tutoring breaks, Alec's tutor gave his mother 30-minute fluency drills each week, to use for his supervised work. These drills were based on the instructional content from their weekly tutoring session. Alec could do all 30 minutes at one time or break it into two 15-minute drills. This plan would at least maintain the momentum he had established during the school year. It was also possible that he would even make gains with this plan.

Studies have found that a focus on fluency during dyslexia interventions can actually accelerate gains in every reading measure –

GET A GRIP : TEN TIPS TO PROTECT YOUR DYSLEXIC CHILD FROM THE SUMMER READING SLIDE

1. Avoid changing the tutoring schedule that was in place during the school year, if at all possible. If the intervention only took place in school, you could still follow
Tips 2-10.

2. Add 30 minutes of supervised fluency drills (as described above), at least 2 days per week. Record the time it takes to complete each repeated task. Make it a game, encouraging your child to "beat" their previous reading and handwriting rates.

3. Keep it fun! Waterproof the writing paper, word lists, and sentences so that the drills can be taken to the beach, pool, waterslide, and other enjoyable activities. You may want to save the handwriting drills for the kitchen table.

4. Set a goal of adding 45+ Words Correct per Minute (WCPM) over the summer and reward your child with a small prize for achieving that goal or even coming close to it. You can use an online Words Correct per Minute (WCPM) reading calculator to make this easy.
https://calculator.academy/wcpm-calculator/#f1p1
Or use the following formula: *To calculate WCPM, subtract the number of mistakes made from the total number of words read, then divide by the total time in minutes.*

5. Let your child track their own WCPM progress on a chart.

6. Don't neglect the handwriting component of the fluency drills. It's just as important as the reading component, in terms of building the reading circuit in the brain.

7. Encourage your child to listen to self-selected audiobooks to build vocabulary and comprehension, and to foster a love for books.

8. Find decodable readers for your child to read in their spare time. Talk to their teacher/tutor about decodable readers that would match their current phonics skills. This will usually prevent the word-guessing habit, but it's still wise to listen in, to monitor for accuracy.

9. Let your child select books for reading aloud (you do the reading). Minimize unsupervised reading, unless your child is far advanced in their intervention.

10. Create a special space in the house just for your child to listen to audiobooks.

not just fluency. When done the right way, fluency activities improve connectivity in the reading circuit and provide a shortcut to reading gains. For connectivity to improve, the research tells us that these activities must "push" Alec out of his comfort zone in both reading and handwriting rates.

Alec's tutor recommended that the fluency drills involve repeated timed reading of the assigned word lists and groups of sentences, in addition to writing these words and sentences (from dictation). She explained that each time he completed a timed reading or writing task, he should repeat the task multiple times, with the goal of increasing his speed each time. During the school year, the tutor had set a goal with Alec of increasing his reading fluency rate by 20 words correct per minute (WCPM) every month. She encouraged Alec's mother to do the same, explaining that goal setting is a very important part of making gains in dyslexia. She suggested that some small prize could be awarded to Alec for reaching the goal or getting very close to it. She also gave Alec a fluency chart, so he could track his own progress.

Lastly, she alerted Alec's mother to the possibility that he may try to skip the handwriting component as he had attempted to do during the school year. This was the only part of the intervention he didn't enjoy. She shared the results of neuroimaging studies which found that handwriting, by itself, plays a major role in rewiring the reading circuit, especially timed handwriting activities. In fact, handwriting fluency facilitates reading fluency.

These fluency activities had been included in Alec's sessions throughout the school year. He especially loved the game of beating his own time, competing with himself instead of other students, and seeing his fluency improve, week after week. Even though he enjoyed this challenge during the school year, his mother knew that she had to integrate the drills into a summer-fun environment. She tucked the writing paper, word lists and sentences into clear plastic pocket sleeves to make them waterproof for trips to the beach, nearby pool, and waterslide. She also included them in the backpack they took when the family went hiking. Stopping to snack was the perfect time to do a 15-minute drill. Once they were back on the trail, Alec never gave it another thought until their next stop. Sometimes they saved the handwriting drills for the kitchen table.

Audiobooks were another recommendation from the tutor, because they are a great way to build vocabulary and comprehension, over the summer. His mother repurposed a comfortable and quiet space in the house for him to listen to these books. Alec also selected books from the library for his mother to read aloud to him.

Each week the tutor sent him home with "decodable" readers that he could read somewhat independently in his spare time. Decodable readers are books that use phonics skills that have already been explicitly taught to the student. This usually prevents the word-guessing habit, so common in dyslexia, but it's still important for accuracy to be monitored by a tutor or parent, while reading. When matched to the student's current phonics skills, decodables can provide practice, enjoyment, and a sense of accomplishment.

Alec used the fluency chart to track his own progress over the summer, and he, his tutor, and his mother were excited to see monthly gains. He had almost met the goal that was set for the summer. When he returned to school and was tested, these gains were confirmed. His mother was relieved to learn that he had avoided the summer reading slide and had even made gains in several other reading measures. Most importantly, embedding the fluency drills into some all-day summer-fun activities made the work seem almost effortless to Alec.

COMPARING APPLES TO ORANGES

When summer tutoring for dyslexic students is dropped, the reading slide can be far more substantial than the summer slide experienced by other students. The activities that would prevent a reading slide for Alec's non-dyslexic classmates, such as lots of independent reading, would not be sufficient for Alec and could even create problems for him. For example, depending on how much time a student has already spent in their intervention and how much progress they've made, unsupervised reading activities could reinforce dyslexia-related reading behaviors, such as word-guessing.

The first step in preventing the summer reading slide in dyslexia is to recognize that these students need much more specialized help than their classmates •

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ABOUT THE AUTHOR:

Georgie Normand, M.A. holds a Master's degree in Reading Education and has spent many years working with students with dyslexia. She is the founder of Early Literacy Solutions and the author of the Orton-Gillingham based Fluency Builders Dyslexia Program (**www.earlyliteracysolutions.com**). Designed for parents, tutors, and teachers, the Fluency Builders program utilizes the latest neuroscience in dyslexia. These new studies found that dyslexia is not a one-size-fits-all learning disability. Georgie has also developed the Certified Dyslexia Practitioner Program, a professional learning program that trains teachers and tutors to identify and succeed with multiple dyslexia profiles. Contact her at **georgienormand@earlyliteracysolutions.com**

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Summer fun&travel

TIPS ON TRAVELING WITH EPILEPSY

FLY RIGHT: Knowing where to find help if you were to have a really bad siezure can provide confidence during your trip.

BY PHIL GATTONE

1. Look up hospitals and epileptologists located in your destination. Knowing where the hospitals and doctors are located in your destination provides confidence in knowing where to find help if you were to have a really bad seizure.

2. Develop a plan for what to do if there is an emergency and you need to travel home. You can prepare a plan by looking up your airline's flight change policy and being aware of what other flights travel between your home and destination. Knowing this information can allow you to worry less about having a seizure and can provide peace of mind when traveling.

3. Always have emergency contact information available so you have someone to contact in case you have a really bad seizure. You may also want to let your doctor know you are traveling and ask if you can call them when on your trip.

4. I would recommend building an online support group at FriendsWithEpilepsy.com. You can connect with others all over the world and connect with them while traveling.

5. Enjoy your trip! It's easy to be overly cautious about having a seizure and worry about what might happen. This mindset can prevent you from enjoying your trip so try not to worry and focus on enjoying your trip.•

ABOUT THE AUTHOR:

Phil Gattone is the creator of an online epilepsy community called **FriendsWithEpilepsy.com**. Phil's motivation for creating Friends With Epilepsy stems from his personal experience with epilepsy. Phil was diagnosed with epilepsy when four years old, has had thousands of seizures, two brain surgeries, and knows the social struggles that come with epilepsy. However, with the help of his family, friends, teachers, and mentors he was able to overcome epilepsy and now runs a digital health startup, called Neurish (**https://www.neurish.me**), that empowers patients and caregivers to better manage epilepsy and reduce the limitations caused by epilepsy.

To Travel or not to Travel

BY PAMELA AASEN

Travel always involves extra considerations when you have a child with a disability. It may be dietary needs, mobility issues, need for frequent stops, equipment, accessories, extra parts that need to be remembered, or numerous other scenarios that you may need to be prepared for. Sometimes, the thought of going away may feel like it is not worth the effort, but we must have joy in our lives, and summertime and travel can be huge parts of that.

PHOTOS PROVIDED BY PAMELA AASEN

Our family loves to pick up and go somewhere for a weekend, make a day trip, or turn disability related activities into a vacation. However, we can't just pack a bag and go. In many ways, it is like preparing to travel with a baby or toddler

For my sons, Ethan (21) and Gavin (18), who have Usher syndrome type 1b, there are still several considerations for travel, because of their needs. They were born with profound sensorineural hearing loss with no residual hearing, have retinitis pigmentosa (causing tunnel vision and eventual blindness), and vestibular dysfunction. Along with the necessary accessories and extra parts, there are so many other considerations that sometimes it can feel too exhausting and easier to stay at home.

JET SET: *(Above left)* Ethan and Gavin, with their cochlear implant processors visible, check out the view from their plane seats; *(Above right)* Ethan and Gavin, without their processors, enjoy the beach in St. Maartens in 2015.

Early Years

There were plenty of trials and tribulations in the early years, as we adjusted to our children's technology needs. Like most mothers, I was too hard on myself; taking all the blame when something went awry. When Ethan was a baby/toddler and we were adjusting to having a child with cochlear implants, I was terrified that I wouldn't have enough batteries and his processor would die, leaving him without access to sound, during that crucial time for learning listening and spoken language. One time, we were getting ready to board an international flight when it hit me that I left Gavin's processors on the counter at home. He was about 18 months old. Needless to say, that was not a fun flight. Tears were shed as I thought what a horrible mother I was, and how could I do this to him. Luckily, we left a key with the neighbor, who I contacted once we arrived at our destination. She gathered the forgotten equipment and, at great cost to us that we couldn't really afford, she priority shipped them to us. Even when I brought them, it never failed, whether it was a short or long trip, one of the boys' processors would stop working and need to be replaced, then programmed. This was back when it meant a trip to the hospital/cochlear implant clinic when we returned, and a vacation without sound, because each had only one cochlear implant or reduced access, once they were both bilateral. Today's technology allows processors to be programmed remotely and shipped directly.

> "There were plenty of trials and tribulations in the early years. Like most mothers, I was too hard on myself; taking all the blame when something went awry."

Considerations

Depending on the disability, there are plenty of factors that families must take into account when traveling. For us, it includes lighting and the environment. For now, Ethan and Gavin are resisting using their canes, so we need to remember flashlights or headlamps. These days they tend to use their phones, but we always have backups. We make a point of providing them with visual descriptions of unfamiliar environments, so they are aware of obstacles at their feet or with low contrast that would make them hard to see, and put them in danger of tripping over or walking into them. If it's a beach vacation or just a day at the beach, they often choose not to wear their processors, so we would have to let the lifeguards know that they have two children/teens in the water with low vision and who can't hear, so they would need help getting their attention.

Amusement parks are always a fun destination for my family. When you have two children without a working vestibular system, that means they do not get dizzy. They can ride all day long without breaks. This of course, increases the danger of lost processors, so they either take them off so they don't fly away, or use accessories (see resources for ear gear) that will keep them safely attached. But, there are no guarantees! When Ethan was around eleven, he was on a ride at Canada's Wonderland and his processor went flying. We thought it was gone forever, but some eagle eye rider saw something on the track and we got a smooshed processor returned to us. That was easier and less expensive to replace than a lost one. A dilemma for us has always been the use of the accessibility pass. We know that at first glance, our children, now young adults, do not look like they have a disability, and we have felt the stares of others wondering why we have the pass. We have even had angry comments directed our way from those who felt we didn't deserve the pass, but most people have genuine compassion. I always want to shout from the rooftop and let people know that I would do anything to stand in line for hours with everyone else, but since my children's lives are challenging enough, I am going to take anything that makes life a little easier for them.

Family Vacations vs Vacations to See Family

Many years ago, we lived near my husband's family. After Ethan was born and first diagnosed with hearing loss, we made the decision to move to Canada for the health care system. We lived briefly near my family, but after Gavin was born, we made the decision to move to Toronto, to be closer to the Hospital for Sick Children. Now, we live in New Jersey, so Ethan and Gavin have never lived near their extended family, which means that most vacations are to visit family. Often, that means staying with family members. This is not a bad thing for us. During the summer, we plan a visit to the east coast of Canada to visit my family and in the winter, we make plans to visit my husband's family in the Dominican Republic. Regardless of whether we are staying with friends/family or if it is a hotel room, it takes preplanning, as we know we are going to need lots of electrical outlets. In this rechargeable world, what is available does not always match demand. It takes a lot of electricity to run my family, when you have rechargeable battery-operated children. We have to take into consideration that they need to charge their processors and accessories, as well as their iPhones and iPads. Traveling with extension cords and outlet extenders is a must. Wherever we stay, everyone needs to be aware that they will trip over anything laying around, and that pets can also pose a danger. As young adults, Ethan and Gavin have taken the lead in helping others be aware of their needs.

When staying with family and friends, there is a little more forgiveness. They will help you out as much as they can. Sometimes you think you made the perfect plan, but, it doesn't always work out that way. On a past weekend trip, despite traveling with extension cords and extenders, there was not enough outlets for everyone to 'plug in.' Ethan was recently traveling,

ON THE MOVE: *(Above left)* Ethan, Gavin, and Carlito head to their gate at the Miami airport in 2010; *(Above right)* Ethan and Gavin with Erickson, their companion dog, at Six Flags Amusement Park in 2017.

> *"It takes a lot of electricity to run my family, when you have rechargeable battery-operated children. Traveling with extension cords is a must."*

staying in a hotel independently, and forgot his travel alarm clock shaker. He missed his return flight, because he had nothing to get him up on time. No matter where we go, a processor can get lost. We have spent hours searching in children's play areas, fields, parks, driveways, cars, beaches, and once even a sewer drain! My husband is an expert "finder" at this point, but there are times when it's not possible. For instance, when a processor is blown off your child's head into a lake or falls out of your child's hand into the crashing waves, even my husband cannot find it. My brother-in-law even found a diver to search for the processor in the lake, but to no avail. There was no point in even trying to find it in the ocean.

planning and organization is key. For trains, they need to be aware of the time and number of stops, because they might not hear the announcements. They embrace opportunities and recently have traveled abroad, This comes with the added challenge of needing an adapter (depending on the country) for charging their cochlear implants.

As Parents

As parents, we want to show our children as much of the world as we can. Dealing with a disability should not stop that. It makes it more challenging, even quite frustrating at times, but we all need what family vacations give us. It is a time to make memories and bond over shared experiences. It provides memories we can look back on, when our children are older. As any parent of child with a disability has learned, we need to be planners, we need to be well organized and structured in our day to day lives and to always expect the unexpected. That is even more important when we travel, so all can go as smoothly as possible. I have even learned to remember that I did the best I could, and try to be a little more forgiving of myself when things go wrong. I have learned over the years that a 'go bag' helps when planning travel. This has had many iterations over the years, but about 5 years ago, I finally settled on a large photo storage container with smaller photo boxes on the inside to help organize. I did not come up with this myself. I think I saw it in a Facebook group. I use one of them to store extra parts for travel, so we can just grab and go. As Ethan and Gavin got older, it was important to transition to them grabbing and packing the extra parts on

SAVVY TRAVELERS: *(Above left)* Ethan gets ready to board his train to Baltimore in 2019; *(Above right)* Ethan and Gavin at Rochester Airport, about to fly home for Thanksgiving 2022.

Planes, Trains and Automobiles

Ethan and Gavin are in college now, so our family road trips are not as frequent. Recently we had to go to Boston for their appointments at Mass Eye and Ear, so we decided to make it a long weekend and take the opportunity to check out the city. I am happy to say that I was not involved in their packing Though old habits die hard, so there may have been a few reminders (and I was the one who brought the outlet extender). They are already confident travelers, used to any type of transportation, and comfortable staying in different environments. I am certain that we have given them the tools they need to be prepared. They have flown independently and are comfortable using preboarding, because they are able to get to their seats with fewer people around them. We have taught them to talk to the flight attendants and let them know that they are deafblind, and that it is necessary to touch their arm to get their attention. They have been on a cruise and understand that

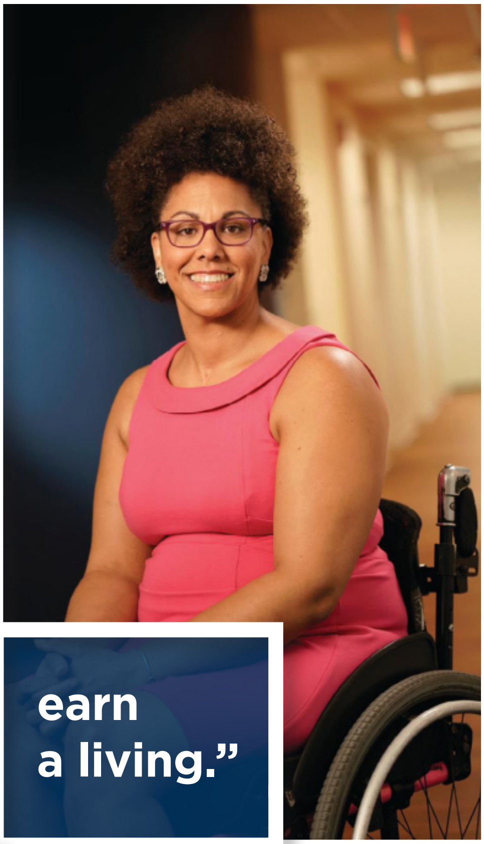
> "As any parent of child with a disability knows, we need to be well organized planners, structured in our day to day lives, and to always expect the unexpected."

GOOD TO GO: *(Above left)* Photo storage containers, with Ethan's designated travel container, laying on the table. *(Above right)* A cruise portrait from 2015, *(left to right)* Pam, Ethan, Gavin and Carlito.

their own. Now that they are in college, I bought them each smaller versions. They each have their own organized photo box with a designated "travel" container to take with them when they come home, or for a weekend trip with friends. We will certainly continue to take trips as a family, but their travel is mostly independent now. They certainly don't put limits on themselves just because it takes a little extra work or planning. •

ABOUT THE AUTHOR:

Pamela Aasen is the parent of two adult sons with Usher syndrome. She was a Special Education Teacher for 25 years and most recently was the Early Hearing Detection and Intervention (EHDI) Mentoring and Family Engagement Project Director for the SPAN Parent Advocacy Network from 2017-2022. She is the Education Advisor for Ava's Voice and a Volunteer Ambassador for the Usher Syndrome Coalition.



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FAIR PLAY

How playgrounds are becoming more inclusive for kids with vision and hearing disabilities

BY JILL MOORE

When kids go to a playground, they do more than just play. They learn how to interact with others. They enjoy moments of freedom from their parents. And they build key developmental skills. But if you're the parent of a child with vision or hearing disabilities, you know these opportunities to play and grow aren't the same for everyone. Because for too long, playgrounds – even those deemed accessible – have focused mostly on orthopedic disabilities.

Author's note: *In recognition of the varying language preferences across the disability community and experience, throughout this article I've used person-first language (i.e. children with disabilities) and identity-first language (i.e. disabled children) interchangeably.*

The good news is, that's changing. Thanks to the work of inclusive-play advocates and greater use of inclusive design practices, playgrounds are evolving to better meet the needs of the greater disabled community. Now, more kids with vision and hearing disabilities can play like – and with – everyone else.

PHOTOS PROVIDED BY LANDSCAPE STRUCTURES

ON A ROLL: *(Above)* Two young girls holding hands take a ride down the Rollerslide, which delivers a cool, sensory experience to kids of all abilities; *(Opposite page)* A young boy points to a picture on the Symbol Communication Sign, which allows individuals who are nonverbal or early learning to communicate with friends and caregivers.

RETHINKING INCLUSIVE PLAY

The Americans With Disabilities Act (ADA) is often seen as the driving force behind making spaces more accessible. However, the focus when designing a playground tends to be on including access for those with mobility disabilities.

According to the National Center for Education Statistics, the number of students ages 3 to 21 who received special education services under the Individuals with Disabilities Education Act (IDEA) was 15% of all public-school students. And of that 15%, only 1% is attributed to orthopedic disabilities. If a playground is only focused on orthopedic disabilities, it may not address the needs of people with other disabilities, such as vision and hearing.

Certainly, many communities and schools do try to address the needs of disabled groups in play spaces. But too often, the intent is greater than the impact. A good example is when braille signs are used in a playground. It's a thoughtful step. But today, due to a shortage of braille teachers and an increase in assistive technology, only about 1 in 10 blind children are literate in braille.

Fortunately, the focus on inclusive play today is more holistic and intentional. Now, kids with vision or hearing disabilities have spaces where they can not only play, but also feel comfortable accessing, getting oriented and moving around in.

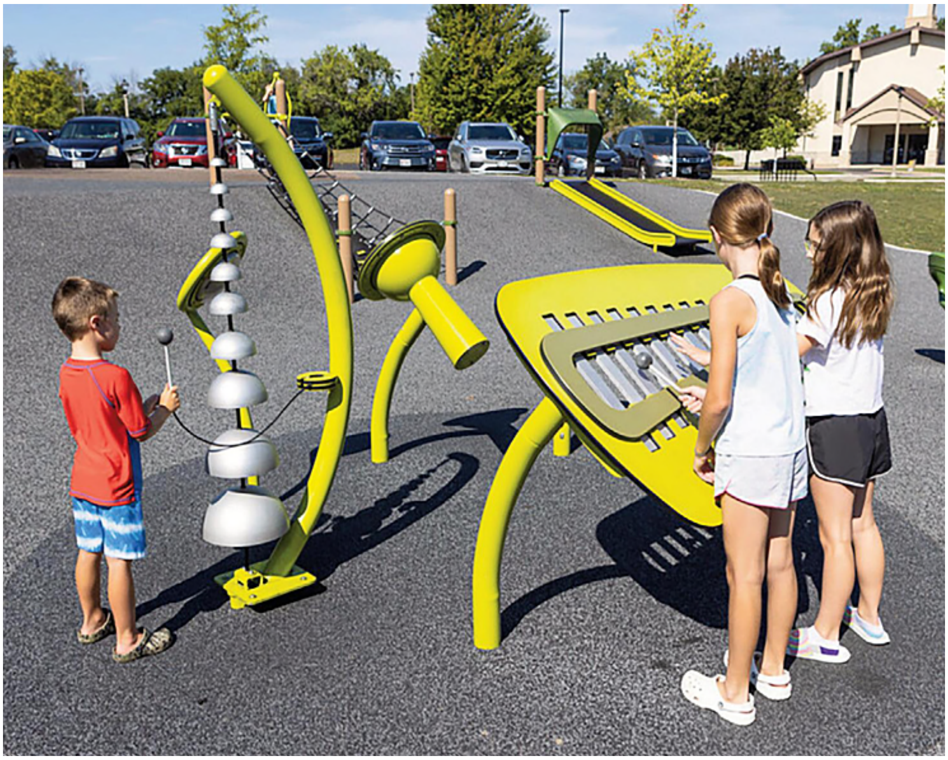
WHAT'S CHANGING

Modern, more inclusive playgrounds accommodate kids with vision and hearing disabilities in many ways.

If you have a child who is blind or has low vision, for instance, you may notice greater use of color and contrast at playgrounds. This can help children better perceive and differentiate playground features.

Steps on the playground may use color cues. This can help kids spot changes in elevation and know how far they need to climb. A balance beam may contrast in color with the ground below. This can inspire a kid with limited depth perception to see it and walk it. And solid or tightly perforated surfaces like the deck of a playground structure can help a low-vision child more easily identify it as walkable than surfaces with large perforation.

Subtle additions can also help blind and low-vision kids better orient themselves on play spaces. Tactile maps can help them mentally map the area. Sound elements like musical play panels or outdoor musical instruments help alert users to where they are. And elements like colored walkways, ground texture changes and guide ropes can help them get around.



PLAY BY EAR: A group of children play with Rhapsody® outdoor musical instruments. Many children who are deaf or hard-of-hearing are drawn to musical play features and use their other senses to enjoy them.

More thought is also being put into how deaf and hard-of-hearing kids experience playgrounds.

Open spaces and wide walkways, for example, make it easier for kids who are deaf to communicate with sign language, which typically requires more space than spoken language. An open layout and easy-to-reach high point that overlooks a playground can also give kids with hearing disabilities greater spatial awareness of the area and help them "read" activities.

If your child wears a cochlear implant, you're probably used to going out of your way to protect it. At playgrounds, that means avoiding plastic slides, which generate static that can damage the expensive device. But with a roller, concrete or stainless-steel slide, your child can enjoy going down a slide without worrying about static buildup.

> "By working together, you'll engage more of the community and get more dedicated resources to create an inclusive space."

Some inclusive play elements for kids with hearing disabilities may even surprise you. For example, deaf and hard-of-hearing kids can be drawn to musical play features like bells. The kids may not hear the bells ring, but they can enjoy them with their other senses, like watching them shake or feeling them vibrate.

HOW YOU CAN HELP

So, how can you make your local playgrounds more inclusive for kids with vision and hearing disabilities? The best thing you can do is be a good advocate.

That begins by being informed about inclusive play. Think about who will use a playground and what inclusion means for them. For example, get local ability demographics. They can help you understand your local disabled community so a playground can be designed to their unique needs.

Inclusive play features should also be woven into a playground in an intentional way. Otherwise, kids with disabilities can end up alone in isolated areas of play. What's nice about features like colorful stairs, roller slides and musical devices is that they can be integrated throughout a playground. They make play more inclusive for everyone. But they can be enjoyed by anyone.

Finally, use the power of positivity. Work with your city officials to inform them of your child's unique needs and offer your help. By working together, you'll engage more of the community and get more dedicated resources to create an inclusive space.

A group of students at Glen Lake Elementary School in Minnesota are a shining example of what a little initiative can do. The students wanted their fellow classmates with disabilities to be able to play on the school's playground just like them. They raised funds however they could and not only hit but exceeded their goal of raising $300,000 to make the playground more inclusive. And now, they've set a goal to make more school playgrounds in their community inclusive.

PLAY FOR ALL

On the playground, innovation can be an invitation – to play, to learn, to grow. To have the same experience as everyone else. By continuing to evolve playground designs to address the needs of kids with vision and hearing disabilities, playgrounds can be what they should be – places where every kid can have fun. •

ABOUT THE AUTHOR:

Jill Moore is a Inclusive Play Specialist at Landscape Structures. She uses her lived experience as a wheelchair user to help inform intentional design practices to create truly inclusive playgrounds including sensory diverse environments, designing for the blind–low vision–deaf–or hard of hearing child, and retrofitting existing playgrounds for adaptive recreation. She brings the voice of the disabled community and inclusive design practices into the product-development process at Landscape Structures. With a specific focus on merging lived experience with universal design principles, Jill promotes and educates audiences on the importance of integrating inclusion in play and bringing people with disabilities into the conversation. As an accredited educational presenter – both in the classroom and the playground – play has become her full-time role. During her lifetime, Jill has represented Team USA as a multi-sport athlete, bringing perspective on the importance of recreation and how imperative equitable access to play is for all.

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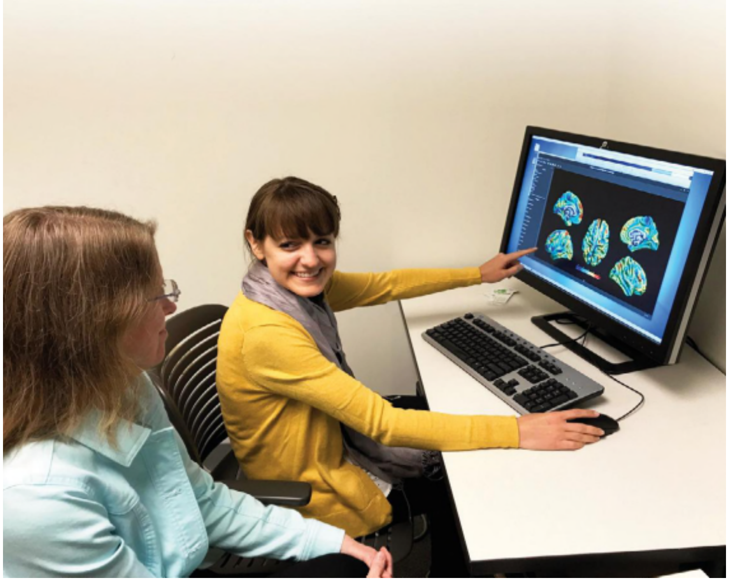

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HOW TO EVALUATE RECREATION PROGRAMS FOR A CHILD WITH SPECIAL NEEDS

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

Social and recreational programs can greatly enhance every child's quality of life year-round, but these activities often take center stage in the summer, when school's out. Without the structure, predictability, and daily interactions with peers that school offers, children with disabilities can lose ground, especially with the social skills that can be a challenge for many. Summer recreation programs can help fill that gap, while broadening a child's interests, skills and social circle.

HAPPY CAMPERS: In the United States, all programs are legally required to serve those with disabilities. Nonetheless, locating programs that are a good fit for a child with special needs can be a challenge.

Some years ago, “adaptive” summer camps, social, sports and recreation programs – geared specifically for those with physical and intellectual disabilities – were a family’s only option. While these specialized programs can still be a good option for many, it’s important for parents to understand that in the United States, all programs are legally required to serve those with disabilities. Nonetheless, locating programs that are a good fit for a child with special needs can be a challenge.

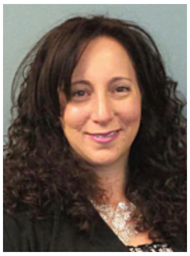
For example, those on the autism spectrum may have difficulty with stressful social interactions which could make team sports like basketball, football or field hockey. uncomfortable, while individual sports like golf, horseback riding or swimming could be ideal. That same individual might also enjoy and have greater opportunity to build social skills in a more low-key group setting, such as art classes or a computer or coding camp.

Whether exploring adaptive or fully-inclusive programs, here are some tips for parents looking to evaluate social and recreational options for their child:

- **Tap Your Network.** Other parents are often the best sources for identifying disability-friendly programs, but also think about consulting school staff and other professionals, and asking for their insights and suggestions for social and recreation options.
- **Inquire in Advance.** Whether you approach a program in person, over the phone, by email or online form, it can be helpful to explain that you are inquiring on behalf of someone who has special needs, and that you would like to ask a few questions about the program. This makes it more likely that you’ll connect with someone in a position of authority, who can answer your questions and, if applicable, discuss any necessary accommodations to serve your child.
- **Work Collaboratively.** Parents can better ensure their children have a good experience, if they approach programs and organizations with a collaborative mindset that seeks to find sensible solutions for overcoming possible barriers to inclusion.
- **Ask Questions.** Every family’s situation is unique, so think through the specific types of challenges your child might encounter with a given program. Here are just a few examples:
  - *Do you currently serve any individuals with physical or intellectual disabilities that you know of at this time?*
  - *What is your adult-to-student ratio for classes and/or activities offered?*
  - *Can you provide the additional support my child needs, such as toileting and feeding? Share examples of any specific assistance your child might need.*
- **Scout the Location.** This is particularly important if your child uses a wheelchair, has other mobility challenges, or tends to wander or be drawn to potentially unsafe features, such as pools and ponds. You’ll want to make sure the environment is both safe and conducive to your child fully participating in program activities. It can also be a good idea to visit the location with your child ahead of time, to help ease potential anxieties from unfamiliar sounds and smells, and get acquainted with staff or instructors.

Finally, if you find a program that seems otherwise ideal for your child, but is unable to provide all of the additional support your child needs to participate, don’t give up. Help may be available through your local disability services agency. At Regional Center of Orange County, where I work, we regularly assist families in securing disability-related accommodations, as well as one-on-one aides that can enable full inclusion for those with special needs, in traditional social and recreation programs.•

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 nearly 25,000 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**

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."

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.

HELPING PEOPLE WITH DISABILITIES LIVE IN THEIR COMMUNITIES – RATHER THAN INSTITUTIONS

BY LAUREN AGORATUS, M.A.

Sometimes individuals with disabilities end up in nursing homes or other institutional settings, even as young as in their teenage years. There are alternatives to institutional care, and supports to help keep people in their homes and communities.

An 18-year-old young man was hospitalized and his family asked for an NG (nasogastric) tube, as he was having trouble eating. The hospital discharged him without it and against the family's wishes, sent him to a nursing home, where he got aspiration pneumonia and died.

There are other options. One determined mom, Julie Beckett, fought against having her child institutionalized. It was actually determined more cost effective to keep her daughter at home and the Katie Beckett waiver was created under Medicaid (Julie was named a Hero Advocate by *Exceptional Parent Magazine;* see https://reader.mediawiremobile.com/epmagazine/issues/207309/viewer?page=31).

Years ago, some states created settings for people with disabilities, who were not helped before. However, although innovative at the time, it later resulted in segregating people with disabilities. Medicaid was originally paying for care in these separate facilities. Later, Home and Community Based Services (HCBS) was seen as better and mutually beneficial. To Medicaid, it was cost-effective, and it allowed Medicaid enrollees to stay in their homes and communities, with appropriate supports. These supports included help with personal care, activities of daily living, and even nursing.

Now with the Olmstead decision against segregated discrimination of people with disabilities, Medicaid Home and Community Based Services (HCBS), Managed Long-Term Services and Supports, and "Money Follows the Person" (MFP) programs, there are better options.

YOUNG PEOPLE WITH DISABILITIES IN INSTITUTIONAL CARE

Sadly, the proportion of younger people with disabilities in nursing homes has actually increased, even as admissions for

COMMUNITY CARE: There are state variabilities in the provision of Home and Community Based Services, and these should be expanded to defer institutional care.

those over 65 decreased.[1] Demographic characteristics showed health disparities in black and Hispanic families, and males, making up the younger population. In addition, the younger population resided in facilities with lower "star" designations from the Centers for Medicare and Medicaid. This is despite funding increases on HCBS and MFP ("Money Follows the Person"), so more work needs to be done in this area. Although, there has been some improvement for people with developmental disabilities, this is not true for other disabilities, particularly mental health. As expected, there were state variabilities in the provision of HCBS, and these should be expanded to defer institutional care. Medicaid and other insurance case managers should identify which of their members are at risk of institutionalization. Further, case managers should contact consumers if they enter institutional care, to determine steps to return to the community.[2]

COMMUNITY BASED SUPPORTS

How can self-advocates and their families become aware of these options? Every state has a Governor's Council on Medicaid where initiatives are discussed *(see Resources)*. There is also a Governor's Council on Developmental Disabilities. Another great resource are Centers for Independent Living, which helps with independent living skills and institutional diversion. The National Council on Independent Living also has resources. In addition, families and self-advocates can contact their state office on disability and some even have an Ombudsman.•

ABOUT THE AUTHOR:

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

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[1] https://doi.org/10.1377/hlthaff.2022.00548

[2] https://clpc.ucsf.edu/publications/managed-long-term-services-and-supports-contract-provisions-related-transition-and

NO PLACE LIKE HOME : KEEPING PEOPLE WITH DISABILITIES IN THEIR COMMUNITIES

IN THE NEWS

ALJAZEERA

YOUNG, DISABLED AND STUCK IN A NURSING HOME FOR THE ELDERLY

http://america.aljazeera.com/articles/2013/10/2/young-disabled-andstuckinnursinghomes.html

npr

A NEW NURSING HOME POPULATION: THE YOUNG

www.npr.org/2010/12/09/131912529/a-new-nursing-home-population-the-young

McKnights Long-Term Care News

AS SENIORS' PRESENCE IN NURSING HOMES DROPS, YOUNG PEOPLE WITH DISABILITIES STUCK WITH FEW ALTERNATIVES: STUDY

www.mcknights.com/news/as-seniors-presence-in-nursing-homes-drops-young-people-with-disabilities-stuck-with-few-alternatives-study/

Medicaid.gov Keeping America Healthy

STATE MEDICAID CONTACTS

www.medicaid.gov/about-us/beneficiary-resources/index.html

HOME/COMMUNITY BASED SERVICES

www.medicaid.gov/medicaid/home-community-based-services/index.html

MONEY FOLLOWS THE PERSON

www.medicaid.gov/medicaid/long-term-services-supports/money-follows-person/index.html

MACPAC

MANAGED LONG TERM SERVICES AND SUPPORTS

www.macpac.gov/subtopic/managed-long-term-services-and-supports

COMMUNITY RESOURCES

ACL Administration for Community Living

DEVELOPMENTAL DISABILITY COUNCILS

https://acl.gov/programs/aging-and-disability-networks/state-councils-developmental-disabilities

NCIL National Council on Independent Living

CENTERS FOR INDEPENDENT LIVING

www.ilru.org/projects/cil-net/cil-center-and-association-directory

Institutional Transition & Diversion

www.ilru.org/topics/institutional-transition-diversion

ABCs of Nursing Home Transition

www.ilru.org/abcs-nursing-home-transition-orientation-manual-for-new-transition-facilitators

Resources on Institutional Transition & Diversion

www.ilru.org/resources-institutional-transition-diversion

usa gov

STATE OMBUDSMAN/STATE OFFICE ON HUMAN SERVICES OR DISABILITY

www.usa.gov/disability-services

seen

cool.

BY KIMBERLEE MCCAFFERTY

It happened so quickly, if I hadn't been paying attention, I would have missed it. This week I took my eighteen-year-old profoundly autistic son to the dentist, where he is reliably wonderful. He waits appropriately for the appointment, gets right into the chair, and lets the professionals do all sorts of uncomfortable things to him for a good twenty minutes. Part of his compliance, I'm sure, is maturity and part of it is that, this is just part of his twice yearly routine and he knows he has to get through it. Sometimes, the waiting room is the hardest part because it's small, and perhaps, he just wants to get the dentist over with. Don't we all?

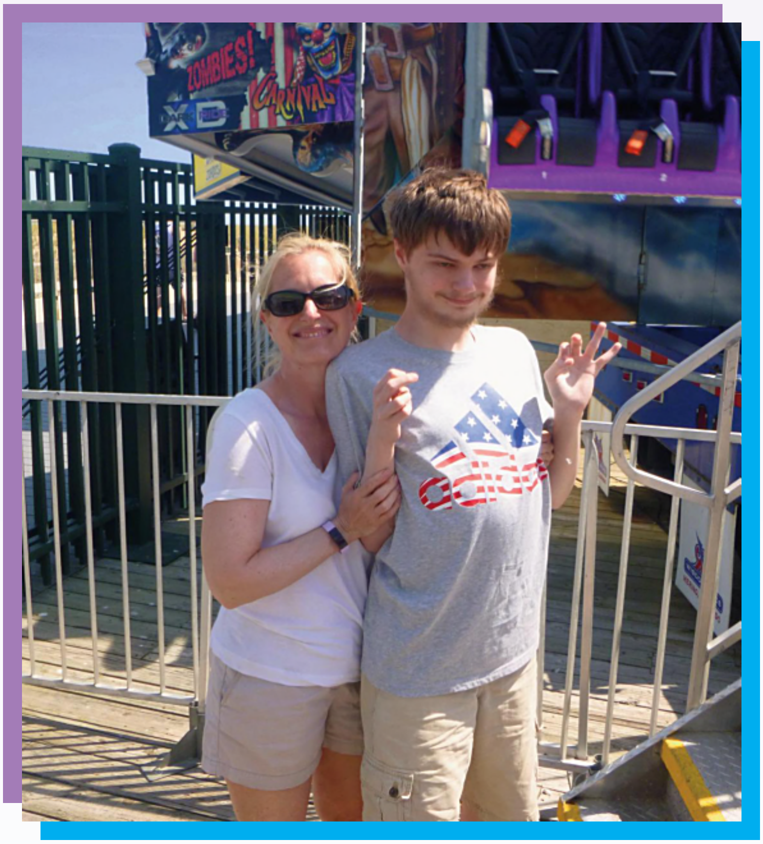
Several days ago, my boy and I sat in our respective chairs, and he started with his loud vocals and rocking back and forth in his chair. Three kids who looked to be middle school age were doing homework, and I noticed they all were flat out staring at him. Sometimes, I let things go (if I'm really tired), but more often than not, I like to address the issue and spread some awareness around. So, I chose who I thought was probably the oldest one, looked him in the eyes and said, "he's okay, he's autistic." Without skipping a beat, he replied "cool," and all three kids resumed their homework. Justin got a "cool."

Many years ago, I would probably not have been greeted with "cool" by a middle schooler, but rather a blank stare. When Justin was little, people thought he was adorable, no matter what he was doing, but by the time he was a "big" kid, some of the looks were not so kind. I haven't seen any of that in years, and as an adult, if anything, he's become more vocal and stimmy as he's gotten older. Nobody seems to mind. A huge win, especially for parents just trying to get through the day.

I've said this before, but I think we need to move on from awareness to acceptance. Not only acceptance of autistics as a valued part of society, but all the degrees of autism, as well. Some autistics grow up to attend college, find love, have kids and careers, and that's wonderful. Some however, have lifelong struggles with even the most basic forms of communication and have behaviors, and are profoundly affected. There are many degrees of autism. It's called a spectrum for a reason.

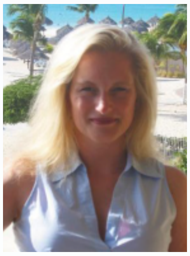
So, if we're moving forward to acceptance, then I say this. I want acceptance for all autistics, no matter how mild or severe. I want to see the entire community accept my son's challenges and acknowledge his worth. I want them to know that he has value equal to any individual not following a neurodivergent path, and equal value to any of his mildly autistic peers.

I want him to be seen. And this week, he was seen and accepted by the future generation, and I couldn't be happier about that.•



READY, STEADY GO: The author and son Justin last summer at Jenks boardwalk in Point Pleasant Beach, about to go on their first ride. They were implementing a visual schedule to try to get Justin to go on more rides during their day at the beach.

ABOUT THE AUTHOR:



Kimberlee Rutan McCafferty is mother to two sons on the autism spectrum, and an Autism Family Partner at the Children's Hospital of Philadelphia (CHOP). Kim is also the author of *Raising Autism: Surviving the Early Years,* which is on sale at Amazon. **https://autismmom-mytherapist.wordpress.com/me-and-my-blog**

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EP MAGAZINE: THE JOURNAL FOR SPECIAL NEEDS FAMILIES AND PROFESSIONALS

ORAL HYGIENE FOR AUTISTIC INDIVIDUALS WITH SENSORY CONSIDERATIONS

BY SCOTT RUVO, DDS

Maintaining good oral hygiene is crucial for overall health and well-being. For individuals on the autism spectrum, it is essential to address their unique sensory sensitivities and communication challenges, when it comes to dental care. By understanding and adapting oral hygiene practices to suit their needs, we can help autistic individuals achieve optimal dental health, while ensuring a positive and comfortable experience. In this article, we will explore some practical strategies and tips to promote effective oral hygiene for autistic people.

BRUSHING UP : MAINTAINING OVERALL HEALTH AND WELL-BEING FOR INDIVIDUALS ON THE AUTISM SPECTRUM

SENSORY CONSIDERATIONS:

Many autistic individuals have sensory sensitivities that can make dental care challenging. The sounds, tastes, and sensations associated with brushing, flossing, and dental visits can be overwhelming. To ease discomfort and encourage cooperation, consider the following:

Use a soft-bristled toothbrush with softer bristles to minimize sensory stimulation and potential discomfort.

Experiment with flavors and textures. Offer a variety of toothpaste flavors to find one that is more appealing. Some individuals may prefer milder tastes or non-mint flavors. Additionally, explore different toothpaste textures, such as gels or foams, which can make the experience more comfortable.

Gradually desensitize. Introduce oral care activities gradually, starting with short sessions and gradually increase the duration, as the individual becomes more accustomed to the sensations.

Provide sensory toys. Fidget spinners, textured balls, etc. can help relax the individual during a dental visit.

VISUAL SUPPORTS AND SOCIAL STORIES:

Visual supports and social stories can be effective tools for teaching and reinforcing oral hygiene routines. These tools help autistic individuals understand the steps involved and what to expect, reducing anxiety and promoting independence. Consider the following:

Create visual schedules or step-by-step guides, using pictures or written instructions to illustrate the oral hygiene routine. This visual support can help individuals follow the steps independently and understand the sequence of activities.

Develop social stories that describe the dental care experience in a narrative format. Include information about what happens during a dental visit, the importance of oral hygiene, and positive outcomes resulting from regular dental care. These stories can help reduce anxiety and increase cooperation.

POSITIVE REINFORCEMENT AND REWARDS:

Positive reinforcement and rewards can motivate autistic individuals to engage in oral hygiene practices consistently. Tailor the rewards to their specific interests and preferences. Consider the following:

Token systems: Implement a token or reward system, where individuals earn tokens or points for completing each step of their oral hygiene routine. Accumulated tokens can be exchanged for preferred rewards or activities

Visual progress charts: Create a visual chart to track their progress over time. Mark each successful completion of oral care activities, providing a visual representation of their achievements.

By understanding the sensory sensitivities and unique needs of autistic individuals, we can develop tailored strategies to promote effective oral hygiene and make dental visits less anxiety producing. Employing sensory considerations, visual supports, and positive reinforcement can make oral care and dental visits more sensory-friendly, comfortable and engaging. With patience, consistency, and a person-centered approach, we can empower autistic individuals to maintain optimal oral health. •

ABOUT THE AUTHOR:

Scott Ruvo, DDS graduated from University of Illinois Chicago Dental School and has been in private practice in Sparta NJ for over 25 years. Dr. Ruvo is an attending at the Morristown Hospital Dental clinic where he enjoys teaching residents. He is an active member of the American Dental Association and is a Trustee in the New Jersey Dental Association. Dr. Ruvo grew up and lives in Sussex County, where he enjoys fishing, hiking, biking and photography, with his wife and two children.

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WHERE THE HEART IS: In-home care offers convenience – everything you need is already there, and you don't have to worry about transportation. Your family member may feel more comfortable being home, too.

RESPITE CARE SERVICES
FOR FAMILIES WITH SPECIAL NEEDS

Taking care of a family member with special needs can be more than a full-time job. As a parent and/or caregiver, it's natural to want to give your all to your loved one, but everyone needs a break, whether that's to go to an appointment, run errands, or just have time for yourself.

Respite care provides that temporary break by putting your family member in someone else's care. It can be hard to leave your child, teen or other family member with special needs, but taking time away from caregiving duties is essential to your well-being and benefits your loved one as well.

WHAT IS RESPITE CARE?

Respite care provides short-term relief for primary caregivers — anywhere from a few hours to a few weeks. Respite care can be arranged daily, weekly or as needed.

Care may be provided:

- *In the home through an agency or from a caregiver you find and train yourself*
- *In the caregiver's home*
- *In a facility, such as a hospital or residential facility*
- *At an adult day center, school, camp, faith-based or volunteer agency*

Consider what's best for you and your family member when deciding where respite care will take place. In-home care offers convenience – everything you need is already there, and you don't have to worry about transportation. Your family member may feel more comfortable being home, too.

Respite care outside the home can offer your loved one more stimulation by exposing them to new people, experiences, and surroundings. It may also be a good choice if you want to stay home yourself during your time off from caregiving responsibilities.

WHERE CAN I FIND RESPITE CARE?

As a military family, you may qualify for respite care for your child or teen through Child Care Aware. This organization has partnered with the military services to provide respite care to families with children up to age 18 who have special needs and are enrolled in the Exceptional Family Member Program. Families enrolled in EFMP receiving respite care within their service branch must meet eligibility requirements and follow program regulations about the location and hours.

Other places to look for information and respite care options for children and adults include:

- Your state's Lifespan Respite Program, if available. Lifespan Respite Programs are run by state agencies to provide community-based respite for family caregivers; https://archrespite.org/lifespan-programs
- The National Respite Locator. This online tool can link you to information on respite funding and caregiver supports in your state; https://archrespite.org/respitelocator/respite-locator-service-state-information-map
- State Respite Coalitions. These membership organizations represent people with disabilities. Some of these organizations provide training and respite vouchers; https://archrespite.org/state-respite-coalitions
- Nonprofit organizations related to your family member's condition may be able to refer you to respite services in your community.
- A "co-op" in which you and other families take turns watching each other's loved ones. Family support groups are a good place to meet others interested in forming a respite care co-op.

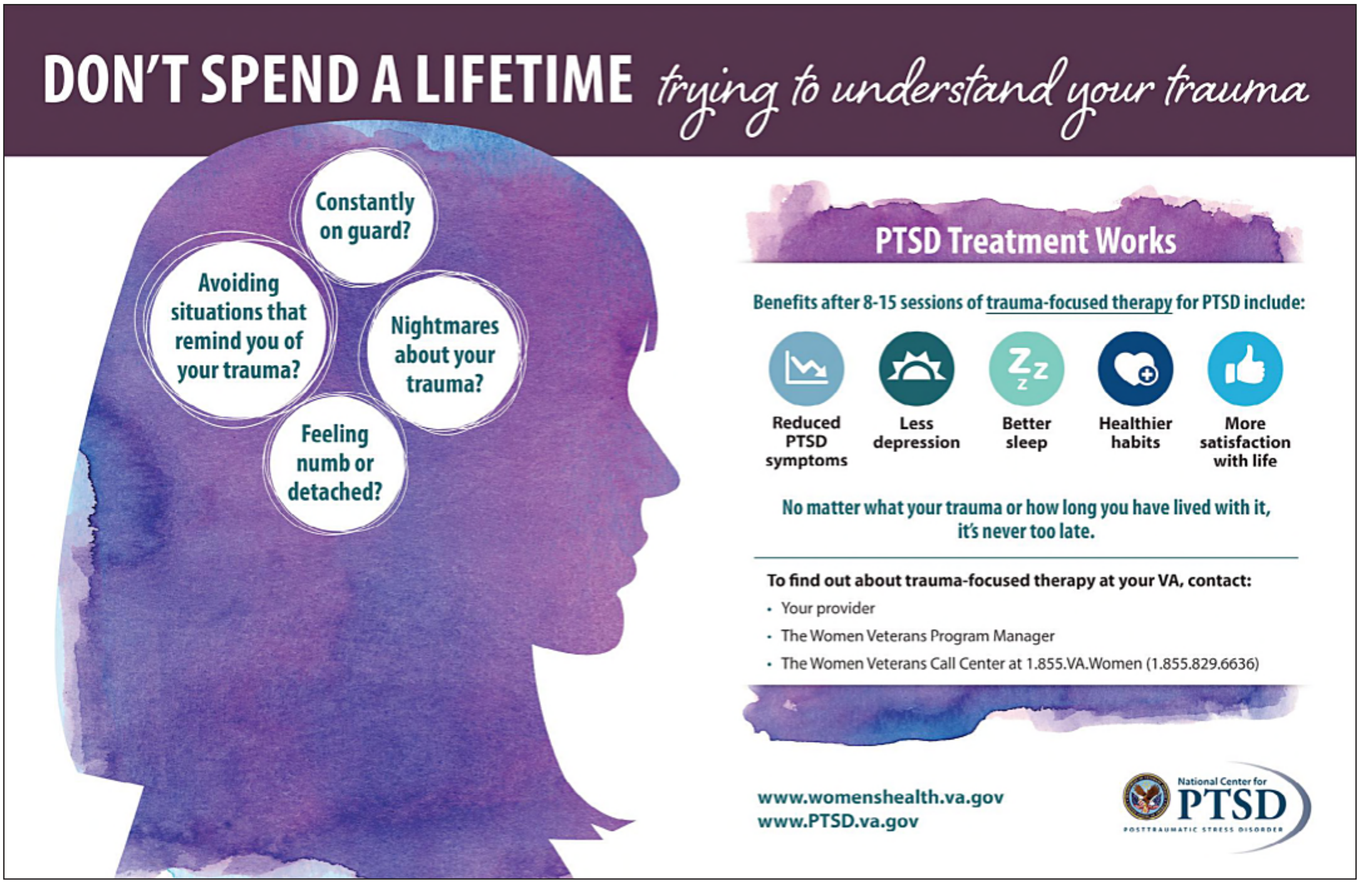
WHERE CAN I FIND HELP PAYING FOR RESPITE CARE?

There are several options where you may find help paying for respite care.

- Child Care Aware provides respite care to children of eligible military families enrolled in EFMP; www.childcareaware.org/fee-assistancerespite
- TRICARE Extended Care Health Option offers a respite care benefit to eligible military families; www.tricare.mil/Plans/SpecialPrograms/ECHO/EHHC
- Medicaid waivers cover the cost of respite care if your family member qualifies. Check with your state's Medicaid office to learn more; www.militaryonesource.mil/family-relationships/special-needs/support-for-families/medicaid-waivers-for-military-families/

Your installation's Exceptional Family Member Family Support (https://installations.militaryonesource.mil/?looking-for-a=program/program-service=16/focus=program) can help you with many aspects of caring for a family member with special needs, including navigating respite care. You can also schedule a special needs consultation 24/7 by calling 800-342-9647 or through live chat. If you're overseas, view international calling options.•

– Military OneSource



U.S. MILITARY ★ BOOK EXCERPT 7TH OF A SERIES

THE RESILIENT WARRIOR

SLEEP HYGIENE

BY HEIKE SOMMER

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 seventh in a series that EP Magazine has featured over the last several months.*

Make sound and healthy sleep a priority. I think of sleep as a pillar of mental health. Sleep deprivation is a torture method for good reason. Oftentimes, we contribute to sleep deprivation ourselves. Add in PTSD, from real torture and combat, or vicarious trauma to the mix, and sleep becomes a far-fetched, seemingly impossible notion.

The obvious do's and don'ts to improve sleep: Laying off the screen time at least two hours before bedtime (More, if you can.) This gives your brain time to unwind and settle down before sleep. No alcohol in the evening. Alcohol turns into fat and sugar, and has a short half-life, meaning it will wake you up in the early morning hours. No cannabis. The use of cannabis might help you relax, but will not help you stay asleep.

Physical activity is important. Help your body to be tired by exercising in the earlier parts of the day and go for another walk after dinner.

Respect your sleeping space. Bedrooms are for sleep only. If you must work from home, do not use your bedroom if you have any sleep issues at all.

Investigate health concerns. Investigate any health concerns that might be affecting your quality of sleep. If you snore and wake up gasping for air, please get a sleep consultation with a specialist to rule out sleep apnea.

Meditation is great. If you can manage to be in the moment, there is no anxiety – anxiety happens in the past or future. Not everyone likes sitting meditations. it can be fun to meditate with family and friends. Movement meditations are another option.

Other tips: There are great apps for sleep, such as the Cognitive Behavioral Therapy app called CBT-I (among many others). Try natural sleeping solutions. Medications can be a good temporary solution for chronic insomnia. Sometimes, people develop anxiety about not sleeping, and it becomes a vicious cycle that needs to be broken. Natural solutions are a good first choice, like melatonin, valerian root, and ashwagandha. However, in cases with serious symptoms of PTSD, it might be a good idea to talk with your health care provider about a good and non-habit-forming sleeping medication, or even a hypnotic for the short term, if you are struggling with

BODY AND MIND: Physical activity is important. Exercise in the earlier parts of the day and go for a walk after dinner.

intense nightmares and flashbacks. Ask your doctor about an alpha blocker that can be helpful in suppressing nightmares.

Have a sleep ritual. Transitioning into sleep can be easier with rituals, not to mention how the burden of going through your daily schedule can be eased by instituting structure.•

ABOUT THE AUTHORS:

Heike Sommer PMHNP is a highly trained mental health nurse practitioner with a versatile background. She has practiced nursing in three different countries and many different areas, including: the emergency room, internal medicine, oncology and the past ten years in acute inpatient and geriatric psychiatry. Heike is currently working in her private practice in downtown Portland, where she sees adults ages 18-65. Her expertise includes assessment, diagnosis and treatment of acute and chronic mental illnesses by varies modalities of therapy and psychopharmacology.

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

PUZZLES & CAMO SHELLY HUHTANEN

Bane of My Existence

It's very difficult for Broden to understand that when things aren't working, he needs to be patient and he needs to do without. In his world, that cannot be an option.

I'm a creature of habit. After I drop Broden off at his ABA clinic and if my schedule allows it, I'll head over to a local gym in town to blow off some steam. Like any gym, I've started to pick out the regulars and over time, I've exchanged smiles, head nods, or a casual "hello". A few weeks ago, while I was walking the track, an older fella named Earnest called out to me. "Hello! I'm Earnest. What's your name? I have to make it to 10,000 steps. Can you walk and talk with me until I reach my goal?" I agreed to the challenge. We talked about what I do for a living and how he was a Navy vet. As weeks passed, if I happened to be walking the track, Earnest would catch up with me and ask how I was doing, and check on Mark and the boys. A few days ago, he asked me "What's autism anyway? I really don't understand what it is. Can you explain it to me?"

As I took a deep sigh, I turned my head away from him and looked down the track, "Well Earnest, the easy, straightforward definition is that it's a developmental disability that affects how one communicates. They may show repetitive and rigid behaviors, and social situations can be difficult." He nodded to me as he was processing my definition and then said, "Ok, I think I understand." I then said, "Ya know, autism is so much more. I would need more time to build a better definition for you. I can't describe how many facets of life autism seeps into. Not just Broden's life, but our family's life as well." I gave him an example of our trip to Huntsville, so he could understand.

Last week, Mark, Broden and I drove to Huntsville, Alabama to pick Hayden up from college and move him back home for the summer. Mark and I know how to pack when travelling with Broden. If we have his iPhone and his iPad working, with back up battery phone chargers and a detailed itinerary to follow, Broden can be a great traveler. If one of those things is missing, we are in for a bumpy ride. iPhones and YouTube can be a gift and a curse. I scoff every time I relive the moment when I was told that I should get Broden an iPad because of all the great apps for autism that were being created. Now, electronics are the bane of my existence. Electronics are like an umbilical cord to Broden, and I have no idea how to find anything that competes with the joy and comfort they give him. I guess this is something he has in common with the rest of us, but there is a difference. The difference is the dependence on electronics for someone with autism, because it is very difficult for Broden to understand that when things aren't working, he needs to be patient. Sometimes, there are things out of our control and we have to do without. In Broden's world, that cannot be an option.

POWER PROBLEM: "Electronics are like an umbilical cord to Broden, and I have no idea how to find anything that competes with the joy and comfort they give him."

The first few hours of our trip to Huntsville were smooth. I looked over at Mark, "We should be in Huntsville by 6 pm or so. I'm texting Hayden that we can head to dinner when we get there." Mark agreed. As we started our way into Atlanta, traffic started to pick up. As our lanes started to multiply, and we wondered where all the cars and trucks came from, Broden shoved his purple iPhone into my shoulder and said, "I need help." The screen was black, so I grabbed one of the chargers and plugged it in, "Broden, it needs to charge. You have to be patient." Broden started to get more upset and the screen stayed black. I tried to restart it. Nothing happened. Then I started to panic, "Mark, we need to pull over. I can't figure out what's going on with Broden's purple iPhone. I will not drive though Atlanta with Broden screaming. Find an exit." As Broden started to scream more, his juice spilled and soaked the floorboard of our car. I clenched my face in frustration, as Mark sped into the first gas station he saw, "Go in there and see if there are some paper towels. I don't know if we have enough in the car to clean this mess up. I'll see what's going on with his purple iPhone." I ran into the gas station and found generic paper towels. They were probably the least absorbent paper towels I had ever seen. I ran out to the car as I tore the plastic off, and shoved the wrapping in my pocket, "Here, this is all they had." Broden was now banging his knees together due to his frustration, and I knew they were going to bruise. I shoved blankets between his knees to keep him from hurting himself. Mark turned to me defeated, "I can't figure it out. I think his purple iPhone died. We're going to have to buy him one in Huntsville." I told Mark there was only one way I knew that would possibly work to get through Atlanta, and it was going to be painful for us, but it would calm Broden. Mark gave Broden another iPhone, "This is not yours, but it has all of your videos and music on it." He took it begrudgingly and then I went to my music list and started to play "Don't Stop Believin'" by Journey, "Broden, I'll choose a song by Journey and then you choose a song." Mark counted. We listened to "Don't Stop Believin'" thirty-three times.

> "I scoff every time I relive the moment when I was told that I should get Broden an iPad because of all the great apps for autism that were being created."

On the other side of Atlanta, Mark stopped at another gas station to take a break. I headed to the bathroom, so I could stand in a bathroom stall and silently scream to myself. I walked back to the car and slowly sat in the passenger's seat to resume my position. I turned to Mark and he was sitting there grinning from ear to ear, "Shelly, I figured out the problem. Broden had dimmed the brightness of the screen so low that we couldn't see it. I had to shove the phone under the seat away from the sun to figure it out." I looked over at Broden and he was smiling, listening to music on his purple iPhone again, acting like nothing had happened.

Once we got to Hunstville, we bought Broden a new iPhone. The fear of his iPhone dying on a road trip was too much to bear. It was waiting for us on the front porch when we got home from our trip. I took Broden to the local Apple store and grabbed every phone case that would fit his new phone and laid them all out in front of him, on the table, "Which one do you want Broden?" He picked out the one I knew he would choose. It was a blue case, one of his favorite colors. I put everything together for him. As we walked out to the car I said, "Look at your new blue I-phone! Isn't it the coolest!?" He turned to me and said, "I want purple iPhone." •

PUZZLES & CAMO

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

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