PLUS: UNITED STATES MILITARY SECTION

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EXCEPTIONAL PARENT
PHYSICIAN • PATIENT • PEOPLE

EXCEPTIONAL PARENT
MAGAZINE
DECEMBER 2023
$14.95

INSIDE:

FINDING SUPPORT *from* THE COMMUNITY

AND:

THE UNCONDITIONAL LOVE *of* THERAPY DOGS

SPECIAL SECTION:

PARENTING MULTIPLE CHILDREN *with* SPECIAL NEEDS

EP's ANNUAL ISSUE:

Family & Community

ALSO:

ACCOMMODATING YOUR FAMILY DURING THE HOLIDAYS *and* BEYOND

EP MAGAZINE 1971 2023 52 YEARS CELEBRATES

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ON OUR COVER

Support from friends, family, professionals and community organizations is particularly important to individuals with special needs and the families that care for them. EP's Annual Family and Community Issue is filled with information and personal stories that are intended to help improve the lives of those with special needs and those that care for them. *Coverage begins on page 14.*

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Comfort and Joy

EP Magazine readers know how important family and community are when it comes to the care of loved ones with a disability.

Our year-end issue focuses on Family and Community, and no one is more aware than the readers of EP Magazine of how important having that support is when it comes to the care and development of loved ones with a disability. In this issue, we provide information and personal stories that are intended to help improve the lives of those with special needs and all those that care for them.

Our cover story, "The Unconditional Love of Therapy Dogs," details the work of Tosha Tharp-Gaitanis. After her son's autism diagnosis, Tosha included their pets while working with him at home. The results spurred her belief that pets could be an indispensable resource in the course of therapies for young people on the ASD spectrum and those with other disabilities.

> "Support from family and community is particularly important to help ensure childrens' inclusion and independence within the community."

Alondra Cabrera recounts how she was introduced to and became a forever friend of Lisa Brnicevic, a 59-year-old woman whose normal life was totally changed by a medical complication when she was 37. Alondra's account of Lisa's journey is a testament to how important family support, friendship and a positive attitude are for recovery.

Larry Landauer, Executive Director for Regional Center of Orange County, writes "As much as extended family and friends with typical children love and want to support parents of children with special needs, I hear it from parents regularly: 'They're terrific. I love them for wanting to be supportive. But they really just don't get it.'" His article outlines a wide array of national and local advocacy organizations and community groups that offer much needed support to parents of children with special needs.

Our December issue also includes a special section about the challenges that parents of two or more children with special needs face. "For parents with multiple children with disabilities," writes Kara Jolliff Gould, Ph.D, "support from friends, family and community organizations is particularly important to help ensure their children's eventual inclusion and independence within the community."

EP welcomes all comments, suggestions and feedback. We want to hear from you at **epmagazinevp@gmail.com**.

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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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1971 2023 52 YEARS

WHAT'S HAPPENING

BETTER HEALTH CARE ACCESS IS HELPING PEOPLE WITH DOWN SYNDROME LIVE LONGER

A new study suggests that adults with Down syndrome are more consistently enrolled in Medicaid and have higher costs and service use than people without developmental disabilities.

The publicly funded insurance program will have to respond to rising numbers of older adults with Down syndrome, researchers say.

"As more people with Down syndrome survive to older ages, the Medicaid system needs to be ready to serve this population with tailored, sensitive, and comprehensive care," study co-author Eric Rubenstein, an assistant professor of epidemiology at Boston University School of Public Health, said in a school news release.

The study authors noted that life expectancy has increased substantially for people in the United States who have Down syndrome, from a median age of 4 years old in the 1950s to 57 years old in 2019. The majority of this population is at high risk of developing Alzheimer's disease or related dementias and other chronic health conditions as they age.

VITAL LIFELINE: As more people with Down syndrome survive to older ages, the Medicaid system needs to be ready to serve this population with tailored, sensitive, and comprehensive care.

To see how Americans with Down syndrome utilize Medicaid services, the research team studied more than 120,000 adults with the genetic condition.

It's rare for people who have Down syndrome to be employed full time, so analyzing Medicaid represents nearly everyone with this condition, Rubenstein explained.

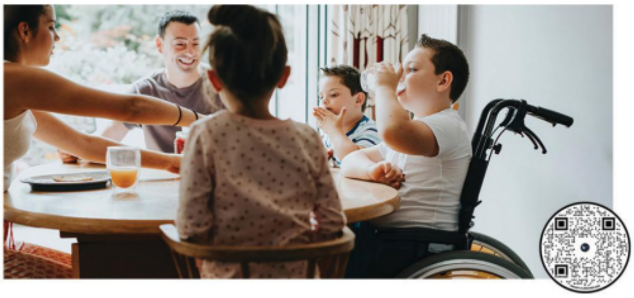
For the study, the researchers used federal health data to examine Medicaid enrollment, health care usage and costs. They also included 1.2 million adults with intellectual disabilities but not Down syndrome, and 6 million adults with no diagnosis of developmental disabilities, for a period from 2011 to 2019.

For people with Down syndrome, median enrollment in Medicaid was eight years and median health care costs were nearly four times those of people with no developmental disabilities, the findings showed.

The investigators found no substantial differences within these measurements among individuals with Down syndrome and those with different intellectual disabilities.

Most adults with Down syndrome are automatically enrolled in Medicaid through Social Security Insurance, a safety net insurance program, so they're unlikely to lose their coverage. But the study showed that Asian, Black, Native American and Pacific Islander adults with Down syndrome had lower Medicaid claims and costs than their white counterparts.

The authors said this suggests that barriers to health care still exist. "In our work, we see higher costs and claims among white enrollees, but less in-patient hospitalizations and fewer chronic conditions," Rubenstein said. "We think this points to white enrollees having better access to care, receiving more preventative health services and having additional Medicaid benefits such as home and community-based service waivers." The report was published recently in the journal *JAMA Health Forum*.



WHAT'S HAPPENING

MEDICARE EXPANDS THE ROSTER OF AVAILABLE MENTAL HEALTH PROFESSIONALS

BY JUDITH GRAHAM

Lynn Cooper was going through an awful time. After losing her job in 2019, she became deeply depressed. Then the covid-19 pandemic hit, and her anxiety went through the roof. Then her cherished therapist – a marriage and family counselor – told Cooper she couldn't see her once Cooper turned 65 and joined Medicare.

BROADER ACCESS: Regulatory changes have expanded Medicare's pool of behavioral health providers and will allow family therapists and mental health counselors to provide services.

"I was stunned," said Cooper, who lives in Pittsburgh and depends on counseling to maintain her psychological balance. "I've always had the best health insurance a person could have. Then I turned 65 and went on Medicare, and suddenly I had trouble getting mental health services."

The issue: For decades, Medicare has covered only services provided by psychiatrists, psychologists, licensed clinical social workers, and psychiatric nurses. But with rising demand and many people willing to pay privately for care, 45% of psychiatrists and 54% of psychologists don't participate in the program. Citing low payments and bureaucratic hassles, more than 124,000 behavioral health practitioners have opted out of Medicare – the most of any medical specialty.

As a result, older adults anxious about worsening health or depressed by the loss of family and friends have substantial difficulty finding professional help. Barriers to care are made more acute by prejudices associated with mental illness and by ageism, which leads some health professionals to minimize older adults' suffering.

Now, relief may be at hand as a series of legislative and regulatory changes expand Medicare's pool of behavioral health providers. For the first time, beginning in January, Medicare will allow marriage and family therapists and mental health counselors to provide services. This cadre of more than 400,000 professionals makes up more than 40% of the licensed mental health workforce and is especially critical in rural areas.

Medicare is also adding up to 19 hours a week of intensive outpatient care as a benefit, improving navigation and peer-support services for those with severe mental illness, and expanding mobile crisis services that can treat people in their homes or on the streets.

"As we emerge from the COVID-19 public health emergency, it is abundantly clear that our nation must improve access to effective mental health and substance use disorder treatment and care," Meena Seshamani, deputy administrator of the Centers for Medicare & Medicaid Services, said in a July statement.

Organizations that have advocated for years for improvements in Medicare's mental health coverage applaud the changes. "I think we are, hopefully, at a turning point where we'll start seeing more access to mental health and substance use disorder care for older adults," said Deborah Steinberg, senior health policy attorney at the Legal Action Center in Washington, D.C.

For years, seniors in need of mental health aid have encountered obstacles. Although 1 in 4 Medicare recipients – including nearly 8 million people under 65 with serious disabilities – have some type of mental health condition, up to half don't receive treatment.

Cooper, now 68 and a behavioral health policy specialist at the Pennsylvania Association of Area Agencies on Aging, bumped up against Medicare's limitations when she tried to find a new therapist in 2020: "The first problem I had was finding someone who took Medicare. Many of the providers I contacted weren't accepting new patients." When Cooper finally discovered a clinical social worker willing to see her, the wait for an initial appointment was six months, a period she describes as "incredibly stressful."

The new Medicare initiatives should make it easier for people in Cooper's position to get care.

Advocates also note the importance of expanded Medicare coverage for telehealth, including mental health care. Since the pandemic, older adults have been able to get these previously restricted services at home by phone or via digital devices anywhere in the country, and requirements for in-person appointments every six months have been waived. But some of these flexibilities are set to expire at the end of next year.

Robert Trestman, chair of the American

PHOTO COURTESY E+/GETTY IMAGES

Psychiatric Association's Council on Healthcare Systems and Financing, called on lawmakers and regulators to maintain those expansions and continue to reimburse mental health telehealth visits at the same rate as in-person visits, another pandemic innovation.

Older adults who seek psychiatric care tend to have more complex needs than younger adults, with more medical conditions, more disabilities, more potential side effects from medications, and fewer social supports, making their care time-consuming and challenging, he said.

> *"Although 1 in 4 Medicare recipients have some type of mental health condition, up to half don't receive treatment."*

Several questions remain open as Medicare enacts these changes. The first is, "Will CMS pay mental health counselors and marriage and family therapists enough so they actually accept Medicare patients?" asked Beth McGinty, chief of health policy and economics at Weill Cornell Medicine in New York City. That's by no means guaranteed.

A second: Will Medicare Advantage plans add marriage and family therapists, mental health counselors, and drug addiction specialists to their networks of authorized mental health providers? And will federal regulators do more to guarantee that Medicare Advantage plans provide adequate access to mental health services? This kind of oversight has been spotty at best.

In July, researchers reported that Medicare Advantage plans include, on average, only 20 % of psychiatrists within a geographic area in their networks. (Similar data is not available for psychologists, social workers, and psychiatric nurses.) When older adults have to go out-of-network for mental health care, 60 % of Medicare Advantage plans don't cover those expenses, KFF reported in April. With high costs, many seniors just skip services.

Another key issue: Will legislation proposing mental health parity for Medicare advance in Congress? Parity refers to the notion that mental health benefits available through insurance plans should be comparable to medical and surgical benefits in key respects. Although parity is required for private insurance plans under the 2008 Mental Health Parity and Addiction Equity Act, Medicare is excluded.

One of the most egregious examples of Medicare's lack of parity is a 190-day lifetime limit on psychiatric hospital care, a feature that deeply affects members with serious conditions such as schizophrenia, severe depression, or post-traumatic stress, who often require repeated hospitalization. There is no similar curb on hospital use for medical conditions.

An upcoming Government Accountability Office report examining differences between the cost and use of behavioral health services and medical services in traditional Medicare and Medicare Advantage plans may give Congress some guidance, suggested Steinberg, of the Legal Action Center. That investigation is underway, and a date for the report's release hasn't been set.

But Congress can't do anything about the all-too-common assumption that seniors feeling overwhelmed or depressed should "just grin and bear it." Kathleen Cameron, chair of the executive committee for the National Coalition on Mental Health and Aging, said "there's a lot more that we need to do" to address biases surrounding the mental health of older adults.

ABOUT THE AUTHOR:

Judith Graham writes the "Navigating Aging" column for KFF Health News. She has covered health care for more than 30 years. She's been an investigative reporter, national correspondent and senior health reporter at the *Chicago Tribune* and a regular contributor to *The New York Times*' New Old Age blog. Judith was the first topic leader on aging for the Association of Health Care Journalists. Her work has appeared in publications including Stat News, The Washington Post, and the Journal of the American Medical Association. She is a graduate of Harvard College and has a master's in journalism from Columbia University.

WHAT'S HAPPENING

ARTIFICIAL INTELLIGENCE IS MAKING A BIG DIFFERENCE FOR PEOPLE WHO ARE BLIND

New free technology tools are helping change lives.

National Industries for the Blind, the nation's largest employer of people who are blind, recognizes and celebrates the significant impact technology advances are having on everyday life for people who are blind. Advances in artificial intelligence are making an especially strong impact and allowing for greater access and inclusion.

Recently, Google rolled out new accessibility tools (**https://blog.google/outreach-initiatives/accessibility/making-daily-tasks-accessible**) designed to better assist people who are blind. Tools like Lens in Maps rely on artificial intelligence and augmented reality to allow users to orient themselves in unfamiliar surroundings and discover new places around them. Other accessibility features include auditory feedback and enhanced screen reader capabilities. The new version of Guided Frame uses a combination of audio cues, high-contrast animations, and haptic feedback to make it easier for people who are blind to take better photos and selfies. Google's Pixel camera has also upgraded its camera to include a Magnified tool that can zoom in on anything, just as one would with a magnifying glass.

A GLIMPSE OF THE FUTURE: Advances in AI are making a strong impact and allowing for greater access and inclusion in the workplace.

"Technology is rapidly growing, and many of the assistive apps have now incorporated artificial intelligence to give users who are blind or have low vision more detail," said Doug Goist, program manager of workforce development for NSITE, NIB's national talent management enterprise. Goist, who is blind, added, "I use these apps regularly and their capabilities just keep getting better and better. AI is a major game changer for employees who are blind or have low vision, and Google's recent announcement shows their continuing commitment to enhancing the lives of people who are blind, both in the U.S. and worldwide."

Google's tools are just one of the many options now available that improve accessibility through AI. For example, Microsoft's Seeing AI (**www.microsoft.com/en-us/ai/seeing-ai**) app provides a variety of free tools to narrate the world around people who are blind or have low vision. These include a currency identification component, a tool to read handwriting, and an app that allows users to recognize friends and describes the people around them in detail, including their emotional state.

NIB celebrated its 85th anniversary in 2023. It was incorporated on August 10, 1938, after President Franklin D. Roosevelt signed the historic Wagner-O'Day Act in June of that year. NIB is a central nonprofit agency for the AbilityOne Program, a small government program that provides employment opportunities for people who are blind or have significant disabilities.

Over the past eight decades, NIB has paved the way for people who are blind to build successful careers, realize dreams like higher education and home ownership, and achieve personal and economic independence.

"While our mission has remained constant, the means of achieving it have evolved," said Kevin Lynch, NIB president and chief executive officer. "In a future where opportunity is limited only by our imagination, NIB will continue to empower people who are blind to choose the preferred career path and chart their own journey to achieving the American Dream."

People who are blind have one of the highest unemployment rates – 70% of working age Americans who are blind are not employed. According to the Bureau of Labor Statistics, the jobless rate for people with a disability is about twice as high as the rate for people without a disability.

Many people who are blind and actively searching for jobs have advanced degrees and valuable professional experience, including many veterans. NIB works with potential employers and with job seekers who are blind, assisting both in finding the right fit. NIB launched NSITE in 2021, which provides award-winning training and professional development and empowers people who are blind to build successful careers.

While employers know that creating a diverse and inclusive workforce is important, they don't always know how to accomplish that, especially when it comes to people who are blind and visually impaired. "Technology is helping many employers easily create an inclusive workplace with an eager workforce," Goist added.

For more information on National Industries for the Blind, visit **www.nib.org** •

ABOUT NATIONAL INDUSTRIES FOR THE BLIND:

NIB
NATIONAL INDUSTRIES FOR THE BLIND

Incorporated in 1938, NIB is the nation's largest employment resource for people who are blind, and through its network of associated nonprofit agencies, is the largest employer of people who are blind in the U.S. NIB creates opportunities for people who are blind to become wage earners and taxpayers, reducing their reliance on government support and increasing engagement in their communities. The organization offers career training and assists employers and employees in developing mutually beneficial workplaces. NIB's vision is that blindness is not a barrier to employment. In 2021, NIB launched a national talent management enterprise known as NSITE. NSITE provides a continuum of employment services that connect employers with talented, dedicated people who are blind or visually impaired, including veterans. For more information, visit **www.nib.org** or **www.nsite.org.**

PHOTO COURTESY NATIONAL INDUSTRIES FOR THE BLIND

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Outing & Dinner
June 3rd, 2024
at Lake Mohawk Golf Club
in Sparta, NJ

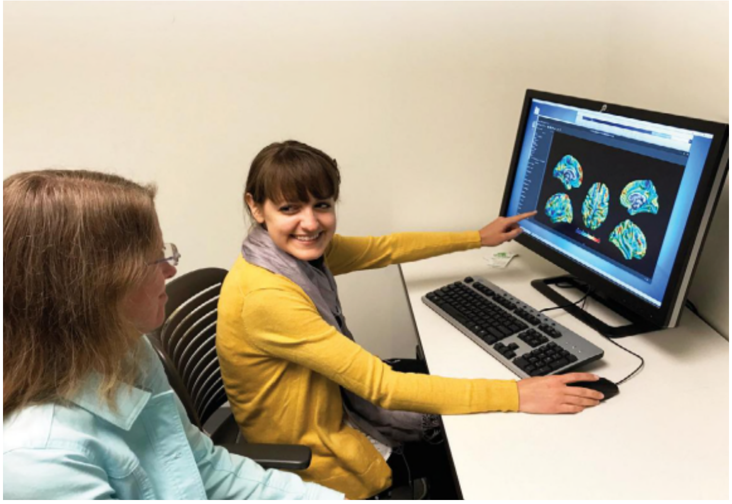
SUMMER FELLOWSHIPS

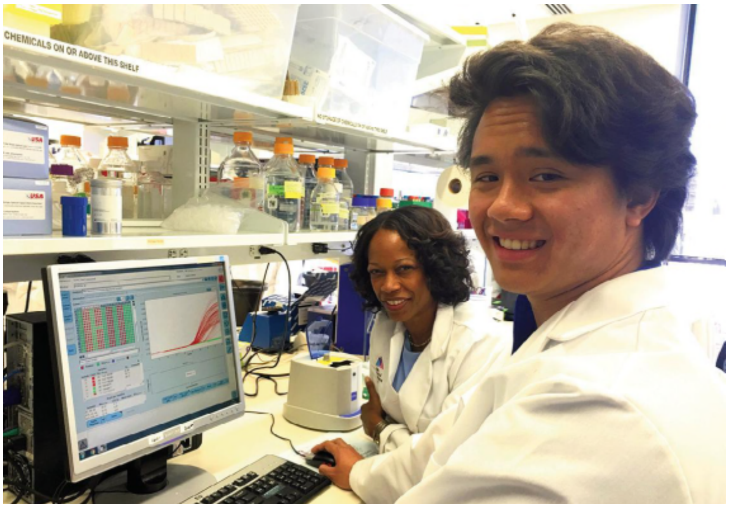
will resume

SPECIAL CELEBRATIONS IN 2024

The inspiration for our Foundation, Eric Simon would have been 100, as well as his wife and Foundation co-namesake, Irene.

2024 is also the 20th anniversary of Irene and Eric Simon Brain Research Foundation being announced.





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WHAT'S NEW

GOOD CHEER

MITZVAH MOOSE

Mitzvah Moose includes a storybook (*The Miracle of the Mitzvah Moose*) and an adorable plush moose doll. Cuddle up with Mitzvah Moose this Hanukkah and enjoy the inspiring 17-page story whereby Moshe, your favorite mensch, ends up encountering a Moose whose antlers won't glow. As Moshe and the moose begin to do good deeds, the candles begin to illuminate! Mitzvah Moose makes it even more exciting for your family to do good deeds this Hanukkah season. What good deeds will they accomplish? Will all the candles on the Moose light up? Join Moshe and Mitzvah Moose as they journey on their path of doing good deeds, together!

THE TOY INSIDER
www.thetoyinsider.com

TWIDDLEPUP ACTIVITY MUFF

The TwiddlePup Activity Muff provides comfort, warmth, and activity for those with diminished hand mobility, limited social interaction or anyone soothed by repetitive tactile motion. The TwiddlePup has 3 removable gadgets: a buckskin crackle pouch, a strand of textured ribbons, and a loop of colorful wooden beads. On the side is a soft, faux suede pocket for personal essentials and a Velcro pull patch to exercise hands. These multiple sensory activities provide an engaging, entertaining way to occupy the hands. Twiddles are ideal for home, therapy clinics, and ”safe spaces” at school and other group settings, as well as memory care and respite care facilities. Endorsed by AblePlay, these therapeutic sensory tools are recognized by the International Board of Credentialing and Continuing Education Standards (IBCCES) as a Certified Autism Resource.

THE WRIGHT STUFF
www.thewrightstuff.com

SANTA POP IT LIGHT UP GAME

This pop fidget toy is as practical as it is fun, with advanced features like multi-level play modes, high-scoring competitions, and handheld portability. With its bright design and giant pop fidget toy buttons, this toy is a hit with kids and adults alike. Specifically designed to stimulate children's minds and improve their motor skills, this pop fidget game machine is a fantastic way to encourage learning through play. It's suitable for children of all ages and promotes sensory development.

THE MOLLIFY STORE
www.mollifystore.com

WRIST FIDGET

The Wearable Wrist Fidget: Put it on in the morning, wear it all day. Use your finger to manipulate the spinning star topper clockwise or counterclockwise. Slide your fingers along the tactile bumps that are along the topper edges. Lightweight nylon band with hook-and-loop closure. Adjusts to fit most wrist sizes Comes with a standard 20mm Quick Release wristband for swapping out one band color for another to match your mood.

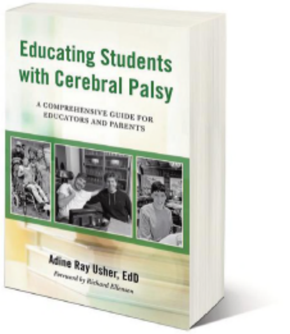
AUTISM PRODUCTS
www.autism-products.com

WHAT'S NEW

EDUCATING STUDENTS WITH CEREBRAL PALSY

Cerebral palsy is the most common physically disabling condition affecting school-age students. Why, then, are so many educators and parents confused by the multiple and often interrelated aspects of this group of disorders?

Using easy-to-follow, demystifying language, Educating Students with Cerebral Palsy details how the physical, medical, sensory, communication, cognitive and social-emotional elements of cerebral palsy can impact learning--and therefore teaching – both at school and at home. Author Adine R. Usher, EdD, and her contributors emphasize the need for collaboration between educators and families, and they spotlight the voices of students and parents living with the hopes and challenges of cerebral palsy each day.



Title: **Educating Students with Cerebral Palsy**

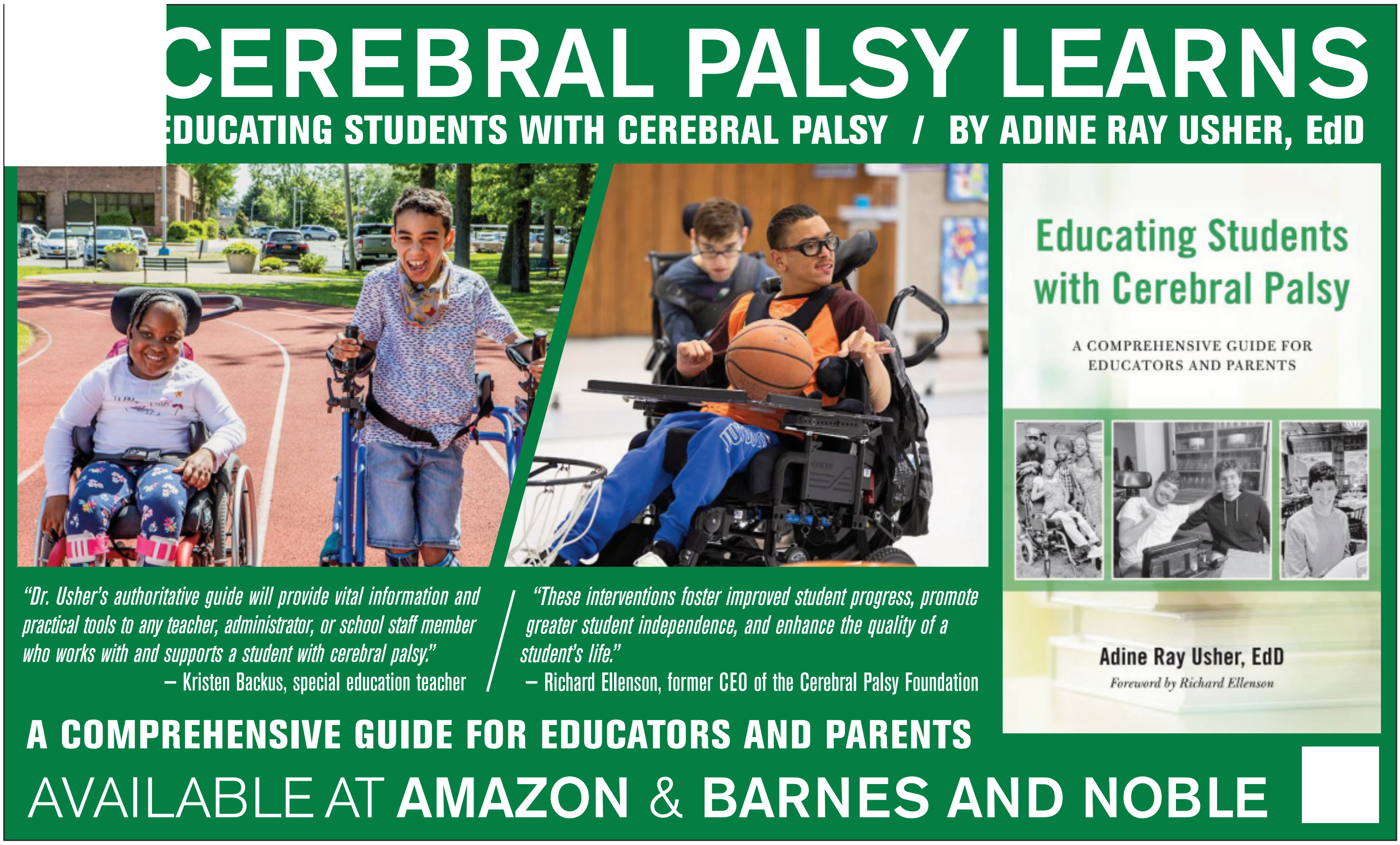
Author: **Adine R. Usher, EdD**

Publisher: **Small Batch Books**
Publication Date**: February 2023**
Paperback: **562 pages**
ISBN-13: **978-1951568290**
Available at: www.amazon.com and barnesandnoble.com

Carol L. Courtadon, special education advocate and parent, said of the book: “Having raised two children with cerebral palsy, both in general education settings and in my practice as an advocate, I have seen the importance of teachers’ access to effective support with respect to students with CP. This is an important book that will bring that support into the classroom within easy reach of every teacher: it will make a major difference in the lives of students with CP.”

During her sixty-year career, Adine R. Usher, EdD, has taught students with cerebral palsy and other physical disabilities, trained their teachers, and offered guidance to their families. Her national and international reach focuses on helping educators to understand and address the developmental barriers posed by cerebral palsy.

SMALL BATCH BOOKS
www.amazon.com, www.barnesandnoble.com



My goal remains the same: to help as many individuals as possible achieve those same successes as my son achieved, and realize their fullest potential through the unconditional love of Therapy animals.

THE UNCONDITIONAL LOVE OF THERAPY DOGS

BY TOSHA THARP-GAITANIS

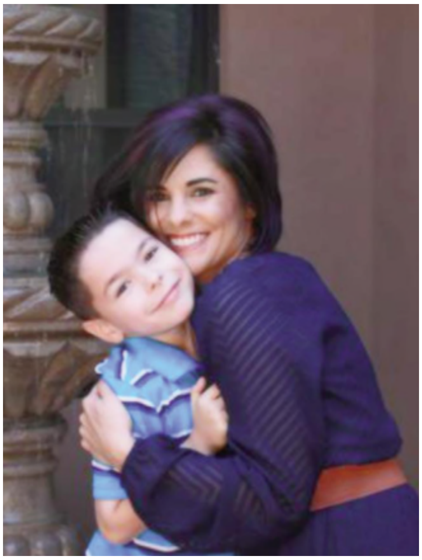
PHOTO PROVIDED BY TOSHA THARP-GAITANIS

POSITIVE VIBES: An elementary student with limited vision and mobility practicing walking with the assistance of her walker with Therapy Dog Finley; Pawsitive Friendships currently has over 110 Animal Therapy teams and 1,500 individuals with special needs enrolled in its programs – from clinics and special education schools to adults with developmental disabilities.

In life, we are often faced with and challenged by unexpected and difficult situations. The way that we react to and deal with them makes all the difference. Will we choose to be angry or seek someone to blame? Or will we take action and focus on the future, instead?

When my four-year-old son was diagnosed with Autism in 2012, I found myself in just such a situation. This was my crossroads. After running the entire gamut of emotions, from anger and sadness to depression. I ultimately emerged secure in my determination to dedicate all of my efforts towards helping my beloved son mature into a successful young man.

After receiving my son's initial diagnosis, we were referred for an Occupational Therapy evaluation. I was confident that all he needed was to work on some of his fine motor skills. After the therapist completed her assessment, she reviewed the results with me. I was stunned! My four-year-old son had the upper body strength of an 18-month-old and the grasping strength of a nine-month-old. He couldn't stack more than two blocks, had various sensory issues… the list of his deficits seemed endless.



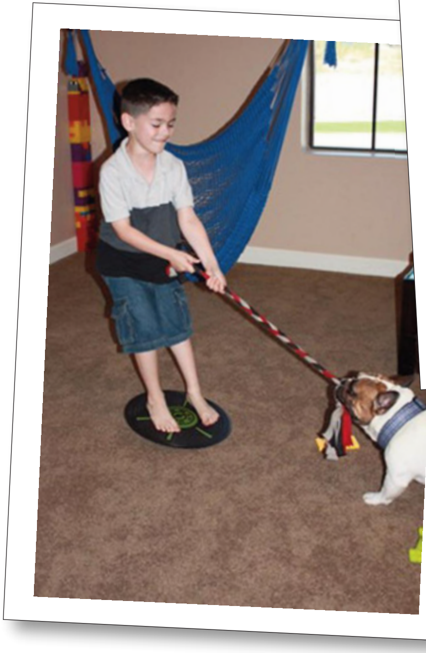
SHAKEN TO THE CORE: I was stunned after the therapist completed her assessment and reviewed the results with me. The list of my son's deficits seemed endless.

Shaken to the core, but more determined than ever to prepare him for school, I accompanied him to OT sessions twice a week, questioning the "why's" of everything he and the therapist did together. Then, I turned his playroom at home into an OT gym and tried to duplicate his exercises at the clinic. He had other ideas. Choosing his preferred – and familiar – activities, he would run away or hit, kick, and spit at me to avoid the exercises. One day, I decided to try something different by making my French Bulldog Zoe, who always sat next to me, the focus of his attention.

I began with the swing. I asked, if Zoe sat in the swing with him, would he stay in? He said "yes." We tried it and it worked! He stayed in the swing petting Zoe, and she loved the attention. Next up, wheelbarrow walks. I had Zoe "wait" on one side of the room. I told my son that I would place a small dog biscuit on his back that he would "walk" over to her, remove it and give it to her. Once he agreed and got into position, I grabbed his legs and placed the dog biscuit on his back. Although he was wobbly and the biscuit fell off, he excitedly said, "Put it back on!" I did and he eagerly, if somewhat shakily, wheelbarrow walked it over to Zoe. He gave her the biscuit and jumped up, saying, "Let's do it again!" I was elated!

Our small successes prompted me to incorporate Zoe into every exercise and activity he did. I then added my other Frenchie, Jacques into the mix, who was still a puppy and LOVED playing tug-o-war and catching balls and Frisbees. Jacques' upper body strength came naturally to him because of his large head and broad shoulders. He not only helped my son build up his upper body strength, he helped with his life skills as well. Since my son was still learning how to take a bath and have his teeth brushed, he was only too happy to "teach" Jacques the ropes.

I soon stopped attending his OT sessions, but one day while still taking my son to OT, as I waited in the lobby, I could hear children yelling in non-compliance inside other rooms. My immediate thought: they need a dog back there. Then it clicked. Why couldn't they have a dog back there? It works for us at home. I began researching Therapy dogs, what they are, what they do, how to become one, and started formal Animal Therapy training with Zoe. Then I began researching non-profit 501(c)3 organizations, including the many intricacies involved in setting one up. In early 2014, Zoe became an official Animal Therapy dog through a nationally accredited organization. By the end of 2014, Pawsitive Friendships had not only been formed, we received our official 501(c)3 status. We were ready to make a Pawsitive impact!



LEARNING THE ROPES: *(Left)* Early successes prompted me to incorporate Zoe into every exercise and activity he did. I then added my other Frenchie Jacques, who was still a puppy, into the mix; *(Above)* Jacques not only helped my son build up his upper body strength, he helped with his life skills, as well.

Zoe and I visited countless clinics, describing Pawsitive Friendships' structure, purpose and goals. Despite many disappointing rejections, in early 2015 we had a breakthrough with a single clinic. The administration allowed us to work with two clients and their therapists. The results of our sessions duplicated the results of the sessions with my son! I immediately began recruiting additional teams of registered Animal Therapy dogs and volunteer handlers, and by the end of the year, we had seven teams working at this particular clinic as well as at a private Autism school.

> Looking back, I'm still amazed that what was originally an in-home project with my son and two dogs, is now "pawsitively" impacting thousands of special needs community members across Arizona. Whenever I see our logo, comprised of my son and Jacques, I'm reminded of the struggles we worked through and the successes we achieved.

Working in a school differed from working in a clinic. There was no therapist facilitating the activities. Instead the teachers and para-professionals were focused on the students, and Pawsitive Friendships was supplying the activities. After that first school year, I drew up a list of ideas and put them into practice with my son. My next step was having speech and occupational therapists review our lessons and add the formal terminology to our activities. Pawsitive Friendships now uses a structured and copyrighted curriculum for all of our programs.

We started receiving requests for hypoallergenic dogs. Shortly after, I brought home a four-week-old potbelly pig named Penelope, who provided an entirely new level of learning and self-regulation to my son's progress. Because she was so young, she squealed incessantly and was extremely skittish. My son had to learn that if he didn't want her to squeal and run away, he would have to be calm in both his body language and voice. For her part, Penelope accepted my son's meltdowns and loud, sudden movements as "normal." Being someone who thrives on thinking "outside the box," I considered Penelope a potential substitute for a hypoallergenic dog and began training her in earnest! When she turned one, she started working as a Therapy pig, adding another dimension of sensory integration to our existing programs.

As we continued to expand, more students began asking about other animal species. This led me to investigate the possibility of carrying our own insurance, thereby allowing Pawsitive Friendships to conduct our own assessments of Therapy animals. Not only are we now an independent Animal Therapy Program with the ability to assess and utilize over 12 species within that program, we are also a registered organization with the American Kennel Club (AKC), enabling teams to earn their Therapy Dog titles through us. And our volunteers pay no annual membership fee to be part of Pawsitive Friendships.

It's been nine years since I founded Pawsitive Friendships, and I'm astounded by the speed at which we've grown. We currently have over 130 Animal Therapy teams and 1,600 individuals with special needs enrolled in our programs: from clinics and special education schools to adults with developmental disabilities. We've recently begun expanding within Arizona itself, targeting the Phoenix metro area and Tucson.

KID'S BEST FRIEND: *(Above)* An elementary student with limited vision and mobility cuddles with Therapy Dog Moosie on a gym mat; *(Right)* A preschool student at an ABA center gives Therapy Dog Dice love while practicing self-regulation and social skills.

Looking back, I'm still amazed that what was originally an in-home project with my son and two dogs, is now "pawsitive-ly" impacting thousands of special needs community members across Arizona. Whenever I see our logo, comprised of my son and Jacques, I'm reminded of the struggles we worked through and the successes we achieved. My goal remains the same: to help as many individuals as possible achieve those same successes, and realize their fullest potential through the unconditional love of Therapy animals. •

ABOUT THE AUTHOR:

Tosha Tharp-Gaitanis, a mother of an autistic son, has always loved animals and working with children. The daughter of a children's pastor, she never knew a time when there weren't at least two dogs in their family. She could not have known that someday her twin passions would merge and ultimately form a single entity: Pawsitive Friendships, founded in 2014.

HOW FAMILIES CAN FIND SUPPORT FROM THE COMMUNITY

BY LARRY LANDAUER

As much as extended family and friends with typical children love and want to support parents of children with special needs, I hear it from parents regularly: ***"They're terrific. I love them for wanting to be supportive. But they really just don't get it."***

That makes finding support in the community an absolute necessity for many parents. But where to start? Resources vary greatly across the globe, and in places where people with disabilities are not routinely included, this can be particularly challenging. Simply searching online for "support for parents of children with disabilities" may yield some great results. But here are several other options for parents to consider.

FIND YOUR LOCAL FAMILY RESOURCE CENTER

Throughout the United States and in many other countries, Family Resource Centers (FRCs) are mainstays of communities. Often funded by state or national governments, FRCs typically exist to connect families to local social services, public benefits and other support services that they may be eligible to receive. However, many can also refer parents to local parent-to-parent and sibling support groups, adaptive sports and recreation programs, as well as a multitude of other resources.

Many, such as Regional Center of Orange County's Comfort Connection FRC, provide their services free of charge to all families in the area, whether or not the children with disabilities are eligible for state-funded services and supports.

EXPLORE LOCAL CHAPTERS OF NATIONAL ADVOCACY ORGANIZATIONS

A number of national advocacy organizations, such as The Arc, which was founded back in 1950, have hundreds of state and local chapters supporting special needs families, in a multitude of ways. Depending on the chapter, this can include advocacy and actual service delivery, as well as recreational activities to facilitate social interaction, sibling resources, and more.

While The Arc focuses specifically on those with intellectual and developmental disabilities, you can find a similar range of supports and resources from well-established, specialist organizations such as Autism Speaks, the Autism Society of America, Epilepsy

A HAND UP: As much as family and friends want to support parents of children with special needs, sometimes they just don't get it.

Foundation, UCP (United Cerebral Palsy), National Down Syndrome Society, National Organization for Rare Disorders (NORD), and many others.

CONNECT WITH OTHER SPECIAL EDUCATION PARENTS

For parents whose children are school age, public schools can be an excellent avenue for making friends with other parents, and getting connected to local support networks. Of course, some school districts are more involved than others, but schools are often a locus of interaction for parents of children with special needs.

Not all parents will have the time and energy to get involved with their local Community Advisory Committee (which we have in California) or similar parent advisory groups, but doing so can be a great way to learn about local community support, and engage with others who share your concerns and can identify with your family challenges.

ASK SERVICE PROVIDERS FOR RECOMMENDATIONS

Professionals who work with your child, whether in therapy or other programs, are among the most knowledgeable about community supports. Most are also very caring individuals who will welcome the opportunity to share their knowledge about community resources, support groups, social and recreational outlets and the like.

REACH OUT TO FAITH AND SPIRITUAL COMMUNITIES

While you may find that not all faith and spiritual communities are as inclusive as we might like, many do have active programs or ministries specifically focused on the needs and interests of people with disabilities. For example, where my organization operates, in Southern California's Orange County, our local Catholic diocese operates several active ministries serving deaf and hard of hearing individuals, as well as those with developmental and physical disabilities.

SEARCH FACEBOOK GROUPS

While some of the options above likely offer mostly in-person support, many of the families have successfully used Facebook and other social media platforms to connect with other parents and interest groups. Sometimes these groups are strictly online forums for sharing and mutual support, but many are also conduits for events and activities for families to engage with one another and build friendships.

Another online resource many parents have found helpful is the Center for Parent Information and Resources (**www.parentcenterhub.org/rptacs**). It's an online resource library (offered in English and Spanish) that provides locations of local Parent Training and Information Centers, which can be an excellent place for parents to connect with each other. •

ABOUT THE AUTHOR:

Larry Landauer is Executive Director for Regional Center of Orange County, the private, nonprofit organization contracted by the State of California to coordinate lifelong services and supports for more than 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**

AN ACT OF KINDNESS LEADS TO FRIENDSHIP

BY ALONDRA CABRERA

PHOTOS PROVIDED BY ALONDRA CABRERA

A FEW YEARS AGO, LISA AND I CROSSED PATHS AT SHOPRITE, WHERE I WORKED. IT ALL BEGAN WHEN I STARTED ASSISTING HER WITH HER GROCERY SHOPPING. OVER TIME, OUR CONNECTION DEEPENED, AND OUR FRIENDSHIP FLOURISHED.

I looked forward to seeing her every Saturday. Time seemed to fly when we were together, as we shared our weekly stories and experiences. Our bond remains unbreakable, even though I moved on from that job. It started as a simple act of assistance that turned into an enduring friendship. I am here to share Lisa's incredible story.

Lisa Brnicevic is 59 years old and grew up in a small town in Stirling, New Jersey. Her fond memories include family vacations down the shore, talking about cars with her friends, and trips to Canada. She loved working in her family-owned restaurant as well as the bakery down the street. She even worked on her days off. Lisa enjoyed the simplicity of life. She had described herself as a "free bird," until something happened that changed her life forever.

At 37 years old, Lisa was prescribed antibiotics for a common cold, Lisa inadvertently mixed them with alcohol on the second day of the regimen. What seemed like a minor oversight led to a nightmarish sequence of events. She woke up in the middle of the night feeling very ill, she was uncontrollably throwing up to the point where she was rushed to the hospital. Lisa's health deteriorated rapidly, leading doctors to induce a coma for six weeks. They didn't know what was wrong and didn't want the condition to worsen. Lisa's battle for recovery was not easy, but her family was right by her side. She faced two near-death experiences during her coma. She doesn't recall anything in those six weeks, but she does remember her surreal encounter with an otherworldly realm. The vivid imagery of white clouds, bubbles, towering mountains, and an overwhelming sense of joy left an indelible mark on her consciousness. Lisa recalls the moment she lunged at one of these ethereal clouds, only to have them pull back. In an instant, everything turned completely black, marking the awakening from her coma. Lisa's journey to the edge of life and back was a profound and transformative experience.

INSEPARABLE: Lisa Brnicevic with the author; "Our bond remains unbreakable, even though I moved on from that job. It started as a simple act of assistance that turned into an enduring friendship."

When Lisa emerged from the coma, she faced a reality drastically different from the one she once knew. She was immobilized and connected to various medical devices. She found herself equipped with a feeding tube and a tracheostomy. She was perplexed by her surroundings at the hospital. A wave of unhappiness swept over her, yearning for the chance to return to that surreal tranquility. The aftermath of Lisa's condition was profound. She was unable to walk or talk and was stripped of her sense of taste and smell. Lisa's world was transformed.

MOVING FORWARD: Lisa works through a physical therapy exercise; Through persistent efforts in therapy, she's gaining the ability to walk again.

Her legs were so tight that the heels of her feet touched her behind. The doctors decided to surgically implant a baclofen pump on the side of her stomach. It released a muscle-relaxing liquid into the body every couple of hours. As Lisa grappled with her new reality, she fell into the depths of depression. The weight of feeling that she made a mistake, coupled with the nagging from her mother about making that mistake, added emotional layers to her already arduous journey. The inexplicable nature of her condition left Lisa and her family searching for answers, with no pre-existing conditions or family history to offer insight.

The challenges extended beyond the physical, Lisa was unable to talk for 15 years. Her medical team developed a unique way for her to communicate. She would wear a baseball cap with a flashlight attached to it that allowed her to point at a letter board to convey her words. She diligently used a plastic pump that would hang around her neck known as a spirometer which made her lungs stronger and eventually led to the return of her speech.

Lisa reflects on the societal separation that can occur, acknowledging that people treat disabled people differently. "It's like we have a whole planet with disabled people, and they don't want us to mix." She believes that understanding to be inclusive is crucial for breaking down these barriers. "People don't know how to address disabled people," Lisa shares, pointing out the awkwardness and fear that can accompany interactions. There's a clear hesitation to engage or even touch someone with a disability as if the condition itself is contagious. One prevalent misconception Lisa has faced is the assumption that people in wheelchairs or with disabilities have hearing problems. This assumption leads people to speak loudly to her, when in fact, her hearing has heightened due to the loss of her other two senses.

Despite facing significant adversity, Lisa found unexpected positives. She successfully quit smoking, a change that might not have occurred without her condition. The experience has also taught her profound lessons about respect and appreciation for what she has. As she puts it, "You have to look at the good side of something bad." Lisa is content with her life, even though it could be better. She resides in a group home with 10 individuals with diverse abilities who have become family, complemented by a dedicated team of four aides always ready to provide support and care. She acknowledges that her condition could have been worse and expresses gratitude for retaining some senses. Others with similar conditions faced even more significant challenges, such as loss of eyesight, speech, or the use of their arms.

Lisa considers herself fortunate. Over the years, she made significant strides in her recovery. Through persistent efforts in therapy, she's gaining the ability to walk again. The doctor was also able to take out the baclofen pump and she now takes the pill form instead. Lisa discovered her newfound passions in exercise, gambling, jazz music, and crocheting. Lisa's journey is not over, but she is determined to continue moving forward. While her life has been altered in many ways, she refuses to let it define her. Lisa passionately advocates for greater understanding, acceptance, and inclusivity, challenging stereotypes and fostering a more compassionate world. •

ABOUT THE AUTHOR:

Alondra Cabrera is a Senior at Montclair State University majoring in Communication and Media Studies. She is expected to graduate in Spring 2024 and eagerly anticipates working in her field of study. Alondra is glad to be a part of Exceptional Parent Magazine. She was introduced to EP Magazine through Hawk Communications, a MSU course that provides the opportunity for students to gain experience in public relations, social media, advertising, content creation, writing, and much more! Alondra loves learning, cooking, and trying new things. Find her on LinkedIn at **www.linkedin.com/in/alondracabrera**

THE BENEFITS OF ACCOMMODATING YOUR FAMILY DURING THE HOLIDAYS AND BEYOND

BY COREY BRISKEY, MPH

My kids were two and six months old when my husband and I packed our bags to drive from North Carolina, where we lived, to New York where most of my husband's family still resided.

I should have been excited, but I was stressed and tired from the past year. We had completed a six-week stint in the special infant care clinic after having a premature child. Weekly follow-up appointments and therapies were piling up. I was balancing the health needs of one medically complex child with the typical needs of an older sibling, who was still just a baby herself. I was drained, but I didn't want that to stop us from enjoying the holidays, like we always had in the past, with good food and family. As we piled into the car a few days before Thanksgiving, I offered to drive, knowing I wouldn't want to do it once it got dark. About half an hour in, I felt a familiar fog envelop my brain. My vision blurred, and my eyelids felt incredibly heavy. I made it another ten minutes before admitting I needed to switch. I had made it forty minutes out of a ten-hour drive. My husband drove the rest of the way.

I'd like to say the fog lifted at some point, but exhaustion followed me every waking moment of our visit up North. It was with me at 3:45 am when my child woke, screaming and arching in pain. It was with me when relatives chatted and visited. I slapped a smile on my face and made jovial conversation, while holding and rocking a fussy baby and balancing the needs of a toddler tugging at my sweater. The fog remained heavy during bedtime when my husband and I tag-teamed with a toddler that was upset at the unfamiliar environment, and an infant that needed to be bottle fed just perfectly so he wouldn't choke and sputter. It was with me when we ate our holiday meal, played outside with the kids, and finally said our goodbyes, before getting back in the car for the dreadfully long trip home. I didn't even bother offering to drive on the way back. I knew I didn't have it in me.

It was on the car ride back that my husband and I agreed, no more long holiday trips. If people wanted to see us, they could visit us. This admission of our limitations, while painful, was also freeing. Once we put down hard boundaries for ourselves, so much pressure was released. It wasn't just stressful for the parents to make these huge efforts to travel, it was stressful for our children.

ROAD TO WISDOM: "The admission of our limitations, while painful, was also freeing. It wasn't just stressful for the parents to make these huge efforts to travel, it was stressful for our children."

PEACEFUL PLACE: When the holidays come around and you have to set limits, remember you are doing a wonderful job of protecting your child and your own peace of mind.

As the years passed, we began to recognize all the places in which we had to limit ourselves to keep our lives manageable. It wasn't just during the holidays, but it was during the weekends when we couldn't leave the house after 4:00 pm, or it was during the week when only one of us could go for a walk while the other stayed back to watch the kids, instead of all going at the same time.

While these changes to our routines and traditions felt big, and were upsetting at the time, two things happened.

1. *I reframed my thinking enough to realize these weren't limitations, they were necessary accommodations. Accommodations for our family and our children that we ALL needed, to keep everyone happy and healthy.*
2. *I learned that those who loved us would accommodate us. It wasn't long before my in-laws asked us what location would be best for our family, and when. They show us every year how much they love us, by making sure our holidays stay as simple as possible, while still getting to be with family.*

As individuals, it's hard to accept large changes in routine because it feels like a self-sacrifice that you aren't ready to part with. But as a parent, it's what you do to help your child. Think about what the accommodation means to your child and what you are giving you child. Here is what you are doing when you accommodate your child during the holiday season and beyond:

1. *You are creating joyful memories. – Instead of stressful car trips and uncomfortable sleep environments, you are creating an ambiance of fun and joy. It is something they will feel and remember every time the holidays come around.*
2. *You are teaching them self-care and how to advocate for their needs. If you make accommodations for them, as they grow, and if they can communicate their needs, they will know just how to advocate for themselves when you aren't able to be there to do it, whether it be at school, in an adult care facility, or just with another parent or family member.*
3. *You are showing them that your love is unconditional. There is no greater way to show a child you love them, than by doing things for them without an expectation of anything in return. It is unbelievably hard to put our own needs aside, but it is sometimes necessary to prioritize what is most important in life. And with our families, with kids with disabilities, it's keeping things simple and stress-free.*
4. *You are bringing peace and happiness to a soul that otherwise might not be able to find it for themselves. You have made the ultimate sacrifice to raise a child, even when they don't have high support needs. But, when a child has high support needs, they need a constant advocate, and you will know you are doing it right, when your child is happy. When you do that, they will be eternally grateful, even if they can't communicate it to you directly. They will show it to you in the ways that they can. You will just know.*

So, when the holidays or other events or excursions come around and you have to set limits, just remember: those that love you will accommodate you, and you are doing a wonderful job at taking care of your family and protecting your child, their needs, and your own peace of mind. The joy that your children will feel looking back will be immense, because you gave that to them. Happy Holidays and a peaceful new year! •

ABOUT THE AUTHOR:

Corey Briskey, MPH is a mom of two wonderful children, one of which is medically complex and has disabilities. Corey is a writer, blogger, and a neurodiversity-affirming advocate for children with disabilities and their families. Corey has written a memoir, not yet published, centered around raising a child with disabilities, among the crushing pressures of society. She has a Master's degree in public health from the University of Buffalo and a bachelor's degree in psychology from The College at Brockport. You can follow Corey on Instagram (**@coreybriskey**) or view her website and subscribe to her blog at **coreybriskey.com**

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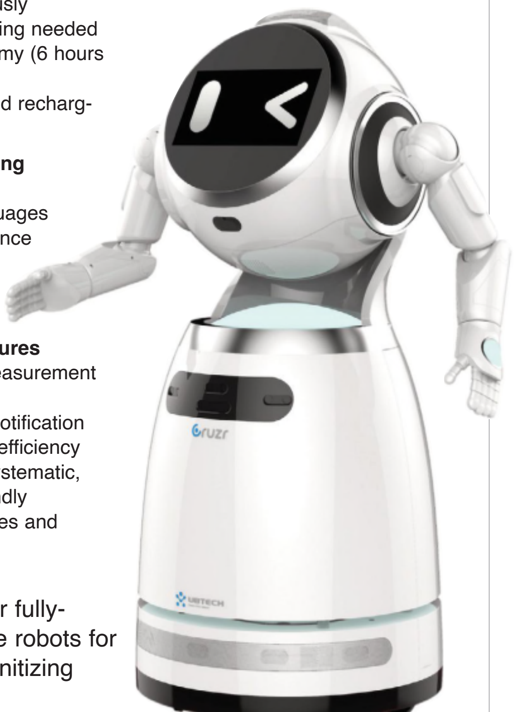

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Parenting Multiple Children with Special Needs

INFORMATION, TIPS, AND RESOURCES

COURTESY OF MASSACHUSETTS MUTUAL LIFE INSURANCE COMPANY (MASSMUTUAL) SPECIALCARE

Raising a child with special needs requires additional understanding, planning and considerations to ensure the best quality of life for years to come. For parents of multiple children with special needs, there are additional factors to consider. An ideal situation for one child might not be ideal for the other. So, it is important to consider each child individually. Planning can often seem overwhelming. That is why it is critical to work with experienced professionals to help put plans in place.

Two unique visions

Each child is unique; therefore, the vision for his or her future is also going to be unique. If possible, it is important to involve each child in the planning. In keeping with the concept of Person-Centered Planning, development of the vision should include all those that may impact the life of the individual with special needs. This could include siblings, extended family members, professionals involved in planning, recreational connections, religious connections, and educators, just to name a few. Careful consideration should be given to each child's desires, wants, and needs for the future. What are the thoughts on post-secondary education, employment, housing, etc.? These factors will be critical to building a vision for the future. This process is not static; it may change over time. Plans should always be fluid.

Understanding capacity

Each child's capacity and capabilities may be different. It is important to understand each child's strengths, interests, and need for assistance. How do these factors relate to each child's vision for their future? Resources are available through early intervention programs. Once the child is eligible to attend school, there will be additional resources through Individualized Education Programs (IEPs). There may be other community-based programs and supports.

Legal and financial considerations

Legal plans should be distinct. Eligibility and availability for resource-tested government benefits are important to understand, as well as, how they apply to each child. There are many legal and financial instruments that should be considered as part of the planning. As an example, Special Needs Trusts and ABLE accounts may be valuable tools in preserving eligibility for means-tested government benefits. They also provide the integration of legal and financial planning. In most states, once a person turns 18, they become an adult. Depending on the individual's capacity, guardianship or other considerations might be appropriate.

Creating a letter of intent

Creating a Letter of Intent document is also a good way to capture the needs, desires, and concerns for the individual currently and in the future. It also provides caregiving instructions to future caregivers, guardians, trustees, and advocates for both children. Each child should have their own Letter of Intent. The Letter of Intent will vary depending upon the unique situation for each child. Although not a legally binding document, the Letter of Intent will allow future caregivers to more quickly learn how to deliver the very best care.

Family meetings and communication

Having conversations and meetings regularly can help to identify needs, and assess plans and openness of existing and potential successor caregivers. Keep in mind that dynamics may change over time, as caregivers age and siblings grow up. Therefore, it is important to continue an open conversation with all individuals involved. Make sure everyone is aware that there are plans in place, and that they know where to find the information on each individual (legal documents, Letter of Intent, etc.).

Successor caregiving

The ages of the individuals with disabilities will be a factor when considering successor caregivers. A multi-generational approach should be considered. Who you identify as successor caregivers is a very important consideration. Communication is key. It is important to communicate plans and vision with the whole family, so that everyone is on the same page, and is informed as plans develop and change.

A CUSTOM FIT: Each child's capabilities may be different. It is important to understand each child's strengths, interests, and need for assistance.

Building resources

Building a resource network of professionals with expertise in special needs planning is essential. This includes attorneys, financial planners, tax professionals, non-profit disability organizations, and service providers. Connecting with other families can help, who offer information and insight, as well as encouragement. It can be difficult, but it is important to take time for yourself.

Creating a life-care plan will help provide a secure future for your children with special needs. Remember: the goal is to achieve and sustain the best quality of life for your loved ones with special needs and ensure they have the assistance they need in every aspect of their life. •

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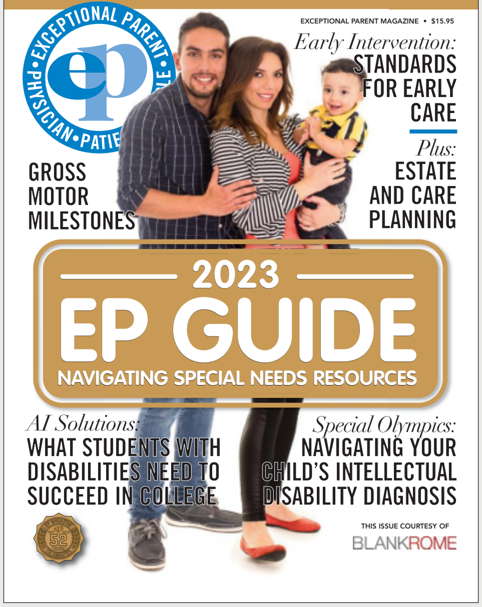

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EP MAGAZINE: THE JOURNAL FOR SPECIAL NEEDS FAMILIES AND PROFESSIONALS

A UNIQUE FOCUS: Eileen and family enjoying a picnic; "We've come to terms with the fact that we can't do things like most families do, but there are still awesome things we *can* do to connect as a family. These things are what we focus on."

WHEN MORE THAN ONE CHILD IN THE FAMILY HAS ASD

BY MARTA CHMIELOWICZ

Eileen Lamb, autistic advocate and mother of three, shares her experience parenting two autistic boys.

Charlie was almost 2 years old when he was diagnosed with level 3 autism. At 15 months, he stopped hitting his developmental milestones. His language began regressing, he started avoiding eye contact, and he began lining up his toys in neat rows, all hallmark symptoms of autism spectrum disorder (ASD).

At the time of Charlie's diagnosis, his mother Eileen Lamb, was pregnant with her second son, Jude. "When I was pregnant with Jude, I remember being terrified of the possibility of him having autism too," she says. "I was afraid I'd never hear the word 'mommy' from one of my sons. That thought was paralyzing."

Eileen and her husband monitored Jude closely for early signs of autism. By 15 months, their younger son started showing signs of developmental delay. Early speech therapy and occupational therapies helped Jude improve his speech and motor skills, but at age 5 he was diagnosed with level 1 autism – the opposite side of the spectrum from his brother.

PHOTOS PROVIDED BY LIGHT BY IRIS PHOTOGRAPHY

NAVIGATING A WORLD OF DIFFERENCES

Today, Charlie is 10, Jude is 8, and Eileen and her husband Willy have welcomed a third child into their family: Billie. While the past few years have brought many challenges, the family has learned to navigate their differences, finding ways to connect and support each other's unique needs.

Charlie's needs are the most complex. Because he is nonverbal, he struggles to communicate anything beyond his most basic needs, which he conveys using an iPad. He also engages in dangerous and self-injurious behaviors like pica, the compulsive eating of non-edible items. These behaviors require 24/7 supervision, impacting his ability to go to school without one-on-one support, which the family has been unable to acquire. Luckily, Charlie has been approved for 40 hours of applied behavior analysis (ABA) therapy, which has been helping him learn important communication and self-care skills while keeping him occupied during the day.

On the other hand, Jude is very talkative and inquisitive. He loves learning and being challenged at school but struggles with anxiety. Bullying only triggered his anxiety further, making him fearful of going to school and requiring him to transition to private school.

"They are very different from one another," says Eileen. "Their needs clash quite often, because Jude wants to play with his brother, Charlie, but Charlie likes to be alone. Charlie also likes to stim using Jude's toys, dropping them over and over, which creates issues in their interactions. There are moments when Charlie will be in the mood to play catch or tag with Jude, but these moments are very rare, only a few times a year."

These moments of rejection can be difficult for Jude, so Eileen has a weekly tradition where they spend quality time together one-on-one. Every Saturday, she and Jude go on an adventure, whether playing soccer at the park, going to get ice cream or buying Pokémon cards. Then, they get some fast food to bring home for the family.

"While it breaks my heart to see Jude sad when Charlie pushes him away, I also see all the amazing ways in which having Charlie as a big brother, has a positive impact on Jude," she explains. "Jude seems to accept differences in people in the most natural way. He's compassionate and always wants people around him to be happy. He's the kind of child who comes to you and asks if you're okay, if you look sad. Jude always sticks by Charlie."

BROTHERS IN ARMS: Charlie and Jude having a brotherly moment; "It took time for us to find our 'new normal' after Charlie's autism diagnosis. But we have our own little routine now that everyone seems to enjoy."

Community outings are often too overwhelming for Charlie, so Eileen and Willy prioritize quiet time for the entire family to be together. Often, that involves parallel play, with Charlie and Jude sharing space, but playing separately. When they do go out to a pumpkin patch or a birthday party, the family takes separate cars, so if something happens, one child can leave while the other stays.

"I've learned through my experiences raising a child with a disability, that you have to learn to adapt," Eileen says. "I'm constantly readjusting my expectations. It's all about finding the balance between not doing things at all, because they're too overwhelming, and forcing our kiddos to do things because that's what other families do. It took time for us to find our 'new normal' after Charlie's autism diagnosis. But we have our own little routine now that everyone seems to enjoy. We've come to terms with the fact that we can't do things like most families do, but there are still awesome things we *can* do to connect as a family. These things are what we focus on."

CARING FOR THE CAREGIVER

In a complex family situation where more than one child has a developmental disability, caregiving can be a heavy weight. It's important for parents to remember to take care of themselves and make space for their own needs and emotions.

"Work, in a way, is self-care for me. I know it sounds funny, but working while Charlie and Jude are at school and ABA, gives me purpose. It's also less stressful. At home, if I'm not looking, I have to worry that Charlie will swallow something and hurt himself. At work, I can relax," says Eileen. "I also like going to the salon to get

FIELD DAY: Charlie, Jude and Billie among the flowers; "Brothers and sisters of children with autism frequently face their own challenges. Much more may be expected from these siblings."

a pedicure or manicure. I make time for myself whenever I need to get out of the house, even for a few hours."

For parents and caregivers who are overwhelmed or struggling to find balance in their lives, these five self-care tips can help:

1. **Get going.** Get your children started in therapies and activities. If you know your children are engaged in meaningful activities, you can better focus on moving forward. It may also free up time to educate yourself, advocate for your children and take care of yourself. Getting started with therapies and interventions can help to build a team of people who care for your children and want to see them succeed.
2. **Ask for help.** Asking for help can be very hard, especially at first. Don't hesitate to use whatever support is available to you. People around you may want to help, but may not know how. Is there someone who can take your kids somewhere for an afternoon or cook dinner for your family one night? Maybe someone can pick a few things up for you at the store or do a load of laundry.
3. **Talk to someone.** Everyone needs someone to talk to. Let someone know what you are going through and how you feel. Someone who just listens can be a great source of strength. If you can't get out of the house, use the phone to call a friend.

   It may be helpful to listen or talk to people who have been or are going through a similar experience. Support groups can be great sources of information about services and providers available in your area. You may also want to consider getting your children involved in local recreational programs for children with autism. This may be a good way to meet other parents like you.
4. **Take a break.** If you can, allow yourself to take some time away, even if it is only a few minutes to take a walk. If it's possible, getting out to a movie, going shopping or visiting a friend can make a world of difference. If you feel guilty about taking a break, try to remind yourself that this break will help you feel renewed for the things you need to do when you get back. If you are getting regular sleep and taking time to recharge, you will be better prepared to make good decisions, be more patient with your children and more able to deal with the stress in your life.
5. **Keep a journal.** Some parents find a journal to be a helpful tool for keeping track of their children's progress, including what is working and what isn't, as well as their own feelings and day-to-day experiences.

Read more about supporting your children after an autism diagnosis in the *Autism Speaks 100 Day Kit for Newly Diagnosed Families of Young Children*[1] or *School Age Children.*[2]

SUPPORTING YOUR OTHER CHILDREN

For parents of autistic children, so much focus and attention is placed on the autistic children that there is often less time and energy if you have other children that do not have autism. Brothers and sisters of children with autism frequently face their own challenges. Much more may be expected from these siblings. They often need help understanding the emotional reactions they are experiencing as a result of the many changes occurring in their lives. This support is essential to their future well-being.

- **Help your other children understand autism and what is going on with their siblings.** Talk with them early, often and in age-appropriate ways. Many books and other resources are available to help them to understand this diagnosis, including Autism Speaks' *Siblings Guide to Autism.*[3]

- **Help your children learn how to play and form relationships with their siblings with autism.** There are a few simple things that you can do that will help with this, including teaching your other children how to get their siblings' attention and give simple instructions. It's also important to praise all your children when they play well together.

- **Find a sibling support group.** Support groups can help children build friendships and relate to other peers who have siblings with autism. Don't hesitate to consult a professional if you feel your children are internalizing most of their feelings or beginning to act out. The earlier you address this, the better.

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[1] www.autismspeaks.org/tool-kit/100-day-kit-young-children

[2] www.autismspeaks.org/tool-kit/100-day-kit-school-age-children

[3] https://www.autismspeaks.org/tool-kit/siblings-guide-autism

FLEXIBLE FRAMEWORK: Jude and Eileen walking back from the market; "I've learned through my experiences raising a child with a disability, that you have to learn to adapt. I'm constantly readjusting my expectations."

BUILDING MOMENTUM : KEEP ON LEARNING

Interested in learning more about how to support your children with autism? Autism Speaks offers two free programs for parents and caregivers looking to build their skills:

CAREGIVER SKILLS TRAINING (CST)

Developed by the World Health Organization (WHO) and Autism Speaks, CST teaches caregivers how to use everyday play and home routines as opportunities to build your children's communication, engagement, positive behavior and daily living skills. CST is now available for free online and in-person. Learn more at autismspeaks.org/CST

FAMILY ECHO: AUTISM

Autism Speaks and Nationwide Children's Hospital are partnering to offer a virtual learning program that brings autism experts right to your screen. In a series of 75-minute sessions, engage with clinicians and other families to learn more about sleep, challenging behaviors, transition to adulthood and more. Learn more at autismspeaks.org/FamilyECHO

ABOUT THE AUTHOR:

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

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PARENTING ONE CHILD WITH DISABILITIES CAN BE DAUNTING

PARENTING TWO OR MORE IS OVERWHELMING

BY KARA JOLLIFF GOULD, PH.D.

A parent's wish is that their child grows to be an independent, productive member of their community. Parents hope that their children will grow to be independent, productive members of their community. For parents with multiple children with disabilities, support from friends, family and community organizations is particularly important to help ensure their children's eventual inclusion as well as independence within the community.

MORE THAN 1 CHILD WITH SPECIAL NEEDS

Having multiple children with special needs means never being able to concentrate on just one child for long. Parents are always busy, bouncing from one set of diagnoses to another. They are researching possible treatments and haggling with insurance, all while teaching their children to cope with their own challenges, and to recognize and understand those of their sibling(s). With work and other obligations, it's nearly impossible to find enough time to rest and recharge before the next crisis or medical procedure.

As the parents of twins, my husband and I have navigated multiple diagnoses for our children over the years, including: SPD, APD, OCD, anxiety, ADHD, and the most enigmatic, PANDAS (a type of autoimmune encephalitis that can cause both physical and neuropsychiatric symptoms). I could not imagine surviving physically and emotionally without the support we had from grandparents and a handful of friends, as well as some community groups. Still, there were many times when we needed more support, but didn’t tell anyone. We couldn’t imagine that they would understand.

Kimberly Eallonardo has a daughter with kidney and autoimmune disease, and another with multiple diagnoses including autism. On social media, she writes, “Unless you live it, breathe it, tend to it day in and day out, hour after hour, second after second, individuals are blissfully unaware of the complexity and difficulty of a special needs parent’s life. They are blissfully unaware of the isolation, the broken heart, the mental effort, and the sleepless nights.”

> “Unless you live it, breathe it, tend to it day in and day out, hour after hour, second after second, individuals are blissfully unaware of the complexity and difficulty of a special needs parent’s life.”

Annie Parsons Camacho’s experience is similar. She is mom to three children, two of whom have been diagnosed with PANDAS. “My children were diagnosed at the ages of 15 and 12, about a year apart. Initially, we had zero support. Our family and friends just didn’t understand. There isn’t enough awareness about PANDAS, even in the medical field, and it made it impossible for people to understand what we were dealing with.”

This theme is echoed by another parent of children with disabilities, Sarah Norwood, who writes, “I grew up with a close group of friends and they have not been supportive. It’s almost as if they don’t realize the severity."

That’s very likely. Whether the issue is autism, PANDAS, ADHD, or a physical disability such as cerebral palsy, friends and family members often don’t know how to help. And many parents can be hesitant to explain what help they need.

Camancho began by seeking out support groups, both online and in-person. Those interactions helped her realize that if she wanted significant help when returning to work after family leave, she would need to ask for it, and be very specific.

“I knew I had to ask for help,” she recalls. “I sent a message to our parents and siblings. I was direct about what we needed. We needed meals, someone to stay with our son doing homebound instruction. I was going to need help with the housework, all of it. I knew if I didn’t ask, I wouldn’t get what I needed. Everyone immediately jumped into action! We created a schedule that we could all share and it is working wonderfully. Although our journey isn’t over, we are doing much better. My biggest advice to other parents is this: don’t be afraid to ask for help. People want to help, they just don’t always know how.”

TWIN CHALLENGES: “As the parents of twins with multiple diagnoses, there were many times when we needed more support, but didn’t tell anyone. We couldn’t imagine that they would understand.”

Our experience with our children’s grandparents bears this out. While we could have asked for more help than we did, when we made specific requests, they were usually happy to help. They would feed, pick up from school, or entertain one child, or both. They had limited energy, but they did help us periodically to take a break, finish work, or keep our own doctor or dentist appointment.

Not everyone has extended family members nearby, or ones who are able to help. Another parent of children with disabilities, Sarah Marie, puts it succinctly: “Families like mine need support: emotional, physical, and mental.” The care of children with disabilities, whether visible or invisible, can be exhausting.

Community organizations, patient outreach programs, and religious groups can provide some support for weary parents. When our children were little, the YMCA, a local children’s gym, and various churches offered parent’s night out programs. Some were free, some were not. Others offered movie nights for kids on the weekends, craft classes, musical activities and more. While not all such programs are set up for children with special needs, many will accommodate if made aware of the situation. If your child’s needs can’t be met by any existing programs you know of, your local health care provider or advocacy organization may be able to help.

Other parents in your area can serve as great resources also. If you don’t have time to meet in person, a Facebook search will reveal parent groups for almost every disability and/or childhood condition, and many are local to specific cities, states, or countries. Parents can exchange information on community support, doctors, therapists and treatments.

Caring for multiple children with disabilities can be isolating. It can be hard to make friends when you are in a constant state of crisis. But even online friends can help ease that feeling of isolation. Parent groups on social media can connect parents in a way that helps them feel supported. Telehealth options may help you squeeze in an appointment with a therapist who can help you cope with stress.

When friends and family ask how you are and what you need, consider answering openly, honestly and in detail. Confiding in others can be difficult, but many times when people ask, they actually want to know. And the more they know, the more they can help. •

ABOUT THE AUTHOR:

Kara Jolliff Gould, Ph.D. is Assistant Professor of Journalism, School of Journalism and Strategic Media, University of Arkansas in Fayetteville, AR. She and her husband are parents of two young adults.

BUILDING RESILIENCE IN FAMILIES OF CHILDREN WITH DISABILITIES

BY LAUREN AGORATUS, M.A.

Looking at family strengths and building on them, families can advocate for their own child and later for other families on systemic issues.

STRENGTH VS. WEAKNESS

Parents of children with disabilities may feel the need to be strong. However, even if they don't feel as strong as they might like, their lived experience is invaluable in creating change. Parents have unique experiences in medical systems, schools, special education, and family support programs. Families need to know that they are the experts on their child. One mother of a daughter with a disability said she had her M.O.M. degree. There are family support programs such as Strengthening Families, Parents Inc., or Parent-to-Parent *(see Resources)*. Often, families who are helped find they later want to give back and help other families.

HOW FAMILIES CAN CREATE CHANGE

"Nothing about us without us!" Families and self-advocates are stakeholders and must be involved in all levels of program creation. This includes even the initial stages of research and data collection, so the end product will be what families need, not what someone else thinks they need. For example, CYSHCNet (Children/Youth with Special Health Care Needs Network) links families of children with disabilities to researchers in partnership in their Emerging Investigator Program. CYSHCNet has recently expanded this to recruit families and other experts for their Advisory Committee. Maternal Child Health programs have families testify at their block grant hearings. Families in NJ serve on school district Special Education Parent Advisory Groups *(see* https://spanadvocacy.org/programs/start/county). Parents can attend State Interagency Coordinating Councils for early intervention or State Advisory Panels for special education and can provide public comment at meetings, and even be appointed to serve on these important groups. Families and self-advocates can attend board meetings of disability specific organizations or Centers for Independent Living and again offer input or even serve on Boards.

WHAT IS FAMILY ENGAGEMENT?

Family engagement involves an equitable partnership with professionals to ensure best outcomes. Family Voices has a toolkit on how families can create systems change. The four domains of family engagement are:

- ✔ *Representation (all families)*
- ✔ *Transparency (information access)*
- ✔ *Impact (changes were due to families)*
- ✔ *Commitment (family engagement at all levels)*

It is essential that all families, including diverse and underserved families, are at the table.

FOUR DOMAINS OF FAMILY ENGAGEMENT IN SYSTEMS

REPRESENTATION

- Reflect the diversity of the community (race, ethnicity, language, income, education level, and geography)
- Partner with family-led and community-based organizations

TRANSPARENCY

- Provide access to relevant knowledge
- Practice partnership in all parts of the process

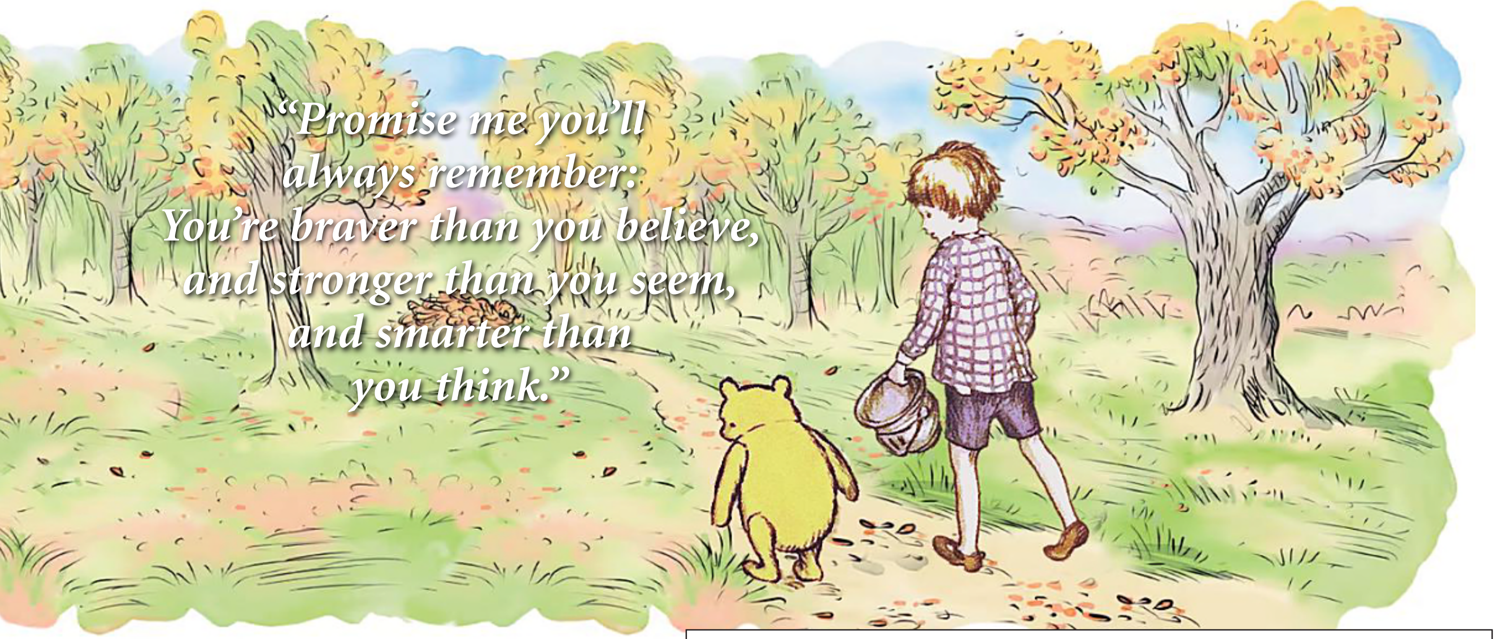
IMPACT

- Identify what has changed and what the organization or system of care is doing differently because families were involved

COMMITMENT

- Promote engagement as a core value
- Establish engagement at all levels, in all systems of care

IMAGE COURTESY DISNEY/A.A. MILNE



“Promise me you’ll always remember: You’re braver than you believe, and stronger than you seem, and smarter than you think.”

OVERCOMING BARRIERS FOR FAMILIES TO BE ENGAGED

Families must not just be invited to the table, but their voices need to be heard. The two biggest barriers for family participation are childcare and transportation. Organizations can:

☐ *Hold meetings at times convenient for families, including working families*
☐ *Provide sufficient notice of meetings for families to make arrangements*
☐ *Have meetings in accessible locations, perhaps near public transportation*
☐ *Provide parents with stipends for childcare*
☐ *Provide equitable compensation for their time*

Who better to influence policy change than parents and self-advocates through family engagement? •

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 two 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.

BUILDING RESILIENCE : FAMILY ENGAGEMENT AND ADVOCACY

FAMILY SUPPORT PROGRAMS

Strengthening Families Foundation

STRENGTHENING FAMILIES
https://strengtheningfamiliesfoundation.org/program-overview

PARENTS ANONYMOUS
https://parentsanonymous.org

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

EXAMPLES OF FAMILY INVOLVEMENT

CYSHCNET
https://cyshcnet.org

SPAN PARENT ADVOCACY NETWORK
Special Education Parent Advisory Groups (required for all school districts in NJ)
https://spanadvocacy.org/programs/start/groups

IDEAS THAT WORK
State Interagency Coordinating Councils/State Advisory Panels
https://osepideasthatwork.org/resources-grantees/sap-sicc

HOW TO ENGAGE FAMILIES

FAMILY VOICES
Family Engagement in Systems toolkit
https://familyvoices.org/familyengagementtoolkit

CENTER FOR HEALTH CARE STRATEGIES
Engaging Community Members: A Guide to Equitable Compensation
www.chcs.org/resource/engaging-community-members-a-guide-to-equitable-compensation

DIVORCE
AND THE SPECIAL NEEDS CHILD

BY DAVID BULITT

Divorce in and of itself is an emotional, challenging and life-changing process. Individuals going through divorce experience higher rates of cancer, heart disease, diabetes and other chronic ailments. Mental illness, substance abuse, insomnia and depression also increase during the course of and subsequent to a divorce. And that is just the adults. The statistics for children of separation and divorce are staggering – increased depression, anger, anxiety, loneliness, impulsive behaviors and acting out – just to name a few.

For children with Attention Deficit-Hyperactivity Disorder ("ADHD") and/or other behavioral and emotional challenges, the difficulties increase. Kids with these types of special needs frequently struggle with executive functioning difficulties, they are often disorganized, they lose things – like homework assignments, backpacks, lunches and clothing. For a special needs child who is now tasked with moving back and forth between two homes, the demands of staying connected with friends and keeping up in school can be overwhelming. Even wearing clean clothes, getting up in the morning or taking a bath are often daunting exercises.

ADHD is a very common neuro-developmental childhood disorder. While ADHD symptoms generally start in children before age 12, they can be noticeable as early as 3 years of age. Parents who are in the midst of a divorce often disagree on some of the basic tenets of parenting: bedtimes, sleepovers, exercise, how much time to watch TV or play video games. When those parents have a child who exhibits ADHD, behavioral or other mental health symptoms, there is often conflict over their child's diagnosis and any appropriate treatment, as well.

My wife is a family therapist with expertise in diagnosis and treatment of children and adults with ADHD. One of our daughters was diagnosed with ADHD at a very young age and that led to a series of evaluations, doctors, medications and other protocols. It also led to years of fighting over the appropriate way to help our daughter. Our marriage survived, but the disagreement remains. Had we separated and divorced, however, it is certainly possible that our divergent views of how to manage and treat our daughter may have ended up inside a courtroom for someone wearing a black robe to decide.

For couples with a special needs child who are facing separation and divorce, the potential for continued divisiveness and conflict remains a constant. If the divorcing couple is willing to see the other parent's perspective – whether they agree with it or not – and not just be willing, but dedicated, to find a way to communicate and work through those differences, they can minimize the adverse effects of the divorce on their children.

While divorce is a difficult and stressful transition in anyone's life, it can also be an opportunity for parents of children with special needs to communicate and work together in a way that best serves the interests of their family. Combined with sound legal counsel and support from others in the community, such as therapists, family and friends, parents can take the right steps to ensure their special needs child's future and emotional stability. •

ABOUT THE AUTHOR:

David Bulitt is a shareholder in the suburban Maryland law firm of Joseph, Greenwald & Laake. He is regularly listed among the DC area's top divorce lawyers and was selected by the Maryland Daily Record as a Leader in the Law. David published two novels in 2015 and 2017. He and his wife Julie, a family and couples' therapist, are the authors of two books on marriage and relationships: The newly released *Secrets of Strong Couples* and the award-winning *Five Core Conversations for Couples* in 2020. Read more about David at **www.davidbulitt.com** and contact him at **dbulitt@jgllaw.com**.

CO-PARENTING FROM DIFFERENT HOUSEHOLDS : NAVIGATING THE COMPLEXITIES

Here are just a few tips designed to assist parents in navigating the complexities of co-parenting a special needs child from different households:

RECOGNIZE AND ACCEPT THAT YOU WON'T AGREE ON EVERYTHING. If you did, you might not be separating or getting a divorce in the first place.

GET SUPPORT. Consider having the entire family – parents and kids alike – get support from mental health professionals who have experience working with families going through separation and divorce. For parents with a child with special needs, this is particularly important.

DON'T LOSE SIGHT OF THE OTHER KIDS. As parents, most of us will focus a great deal of our energy on that child with the special needs, while the other more mainstreamed children take a back seat. Their needs and desires are often minimized or even forgotten about entirely.

PRESENT A UNITED FRONT. In other words, if it is not okay to have friends sleep over twice in one weekend at one parent's house, then the same rule should apply in the other parent's house. Maintain consistency between the homes.

COMMUNICATE REGULARLY. Keep each other informed as to any problems, behaviors, other issues or symptoms that are observed, particularly with a child who may be on medication. Never exhibit anger toward the other parent in the presence of the child.

CHOOSE A LAWYER THAT HAS EXPERIENCE WORKING WITH SPECIAL NEEDS FAMILIES. Someone who understands the intricacies and challenges that your family faces will be better able to develop a Parenting Plan that is more sensitive to your family's needs and, if necessary, understand how to appropriately advocate your position should you end up in court.

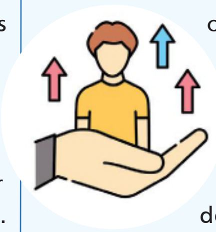
Be realistic in terms of the amount of time that you are able to solely parent. For example, if you are a full-time worker with travel obligations during the week, it is not likely that you will be able to manage a week on - week off access schedule for the children, and you may need to consider other practical ways to maximize your off time with them.

REMEMBER THAT YOU ARE HUMAN. These kids take up enormous amounts of work, diligence and energy. Tack that on top of full-time work and maintaining a household on your own, and a parent can be overwhelmed. Self-care is a must. Make time for yourself.

TRY TO ESTABLISH ACHIEVABLE AND UNDERSTANDABLE SCHEDULES AND ROUTINES FOR YOUR CHILDREN. If possible, both parents' households should include comfortable spaces for the children that they consider "theirs." Many kids with autism disorder or behavioral issues need to have a safe space.

TALK TO YOUR CHILDREN ABOUT THE SEPARATION IN A WAY THEY WILL UNDERSTAND. Tell them you love them.

WHEN IT COMES TO THE PARENTING PLAN, work with your lawyer to establish a firm procedure that allows for significant decisions to be made without undue delay or harm to the children. In other words, where the two of you have agreed to "joint custody" be sure to address how decisions are to be made when there is disagreement. Does one parent have tie-breaking authority? Do the parents work with a mediator to decide or consult with an expert in the area of dispute? There are any number of ways to handle this process, but it most definitely needs to be discussed and should be included in the parenting plan.



FINALLY, YOUR PARENTING PLAN SHOULD BE MALLEABLE. Children are not static creatures. They grow and change as do their needs and their desires. With special needs kids, this is an even more acute issue. Today it might be best for a child to live primarily with one parent, but in three years, there may have been changes in the family dynamics and that child would be better served by living primarily with the other parent. What about care or medications or schools? Your parenting plan should include provisions that anticipate and plan for these possible changes.

WHAT TO KNOW BEFORE AND AFTER YOUR CHILD'S SURGERY

TIPS FROM LEADING PEDIATRIC SURGEON KATHRYN BASS

Your child needs surgery. This sudden reality can cause any parent to feel unsettled, concerned, and just as scared as their child. Those fears compound when your son or daughter has physical, developmental, behavioral, emotional, or sensory-impaired disorders.

Because structure is crucial to children, especially children with special needs, surgery can make them and their parents feel out of control. And for some kids, their special needs can make it difficult to even understand what is happening.

Every patient and operation is unique, but there are practical tips that can help parents feel more comfortable and better equipped, as they support their child from pre-surgery preparation through post-surgery recovery.

It is important that the doctor takes every child and their parent through the preparation leading up to surgery, rooted in honesty, comfort, and meeting the parents and child where they are, and customizing the approach based on the child's needs.

BEFORE SURGERY

Pre-Op Visit: The surgery begins in the pre-op visit, where the doctor should speak with parents to understand their expectations. According to Dr. Bass, "parents with special needs kids are some of the savviest people" she has ever met. "They are superhuman, consuming as much healthcare knowledge as they can, taking full advantage of all resources available, to become their child's greatest advocate helping to make their child's way in the world," she continued. The advice Dr. Bass offers complements the vast knowledge many parents of special needs children already have.

Not All Hospitals Are Equal: Parents should remember that not all hospitals operate similarly. While many of the tools outlined in this article are widely available at children's hospitals, this may not be the case at community hospitals that do not discriminate by age, nor at systems without pediatric-specialized services. There are children-focused hospitals within hospital systems and free-standing hospitals that solely serve children. Most children's hospitals are incredibly competent in catering to children with special needs.

Focusing On the One Child: It is best that parents of multiple children do not bring their other kids to the appointments leading up to the surgery or surgery day itself, if possible. The child being operated on needs to be the focus, and, as parents know, it is hard to focus on one kid when the others are there.

Making a Medication Plan: When preparing for surgery for your special needs child, one of the biggest things to remember is to discuss their medication schedule with their medical team.

Special needs children often take medication on a strict schedule and often the medication must be taken with food or water. In surgery, strict rules exist around when a child can eat or drink before the operation. Medication and feeding schedules need to be discussed and managed, so that the child gets the medications needed, at the correct time. In those cases, pediatric surgeons create a specific schedule for what will occur on the day

STEPS TO PREP: The mental realities of preparing for surgery can be just as challenging as the physical, sometimes even more so.

of surgery and communicate it with the anesthesiologists, who are very used to such things. For example, many medications can be taken on the child's schedule with a sip of water. Other times, the child will take additional medication during anesthesia. Depending on the drug, this may be an extra dose of steroids during the surgery.

The Waiting Time: When coming in for surgery, you will need to come in early enough to check in with different people. Come prepared to have some downtime in between meetings with the specialized members of staff that all play a crucial role in the operation. The surgeon and OR team will take as much time as necessary to safely guide your child to their intended surgical destination. Though it may test your nerves, take comfort in that fact as you wait.

Making the Child (And Parent) As Comfortable As Possible: Many children are frightened during the appointments before surgery, because depending on their age and development, some believe the surgery is happening that day in the office. It is important to always reassures them that the surgery is not taking place. Remind children of this on their way to the appointment to help, as much as possible, with the child's nerves. In those pre-op appointments, the doctor might help to emotionally prepare the child by asking the child to think about a favorite dream, so that on the day of surgery, the child is ready to think about this dream in the seconds when the child counts down to their "nap" (being sedated for the operation).

The mental realities of preparing for surgery can be just as challenging as the physical, sometimes even more so. Bring a go-to comfort object, like a favorite stuffed animal or blanket for the child on the day of surgery, to help calm and soothe. This is particularly important for children with special needs. It is also recommended that the parents bring something interactive, like a beloved puzzle or another interactive toy. Parents should bring something to distract themselves during the waiting period, like a book, an iPad, or Sudoku.

Most children's hospitals have child life specialists who distract the child leading up to the surgery with various interactive, age and development-appropriate activities. These individuals are exceptionally versed in working with kids with special needs. The child life specialist is critical for children with special needs, because they play a huge role in getting the child comfortable, engaged, distracted with something, and helping them to communicate.

While most operating rooms in community hospitals do not allow a family member to be present, children's hospitals often permit a parent to stay in the operating room until their child is sedated. Parents should ask their doctor way before the surgery, to prepare mentally. The parents may expect to hold their child's hand throughout the surgery, which is never the case.

AFTER SURGERY

Waking Up: After a surgical procedure, parents meet their child, as they rest in the recovery room. Parents should not be alarmed if their little one is still sleepy, disoriented, upset or if they do not immediately recognize or respond to them or other family members. Kids wake up in a sterile room with bright lights and beeping noises. For many children, especially those without an intellectual or emotional understanding of the event, this can be terrifying. They usually just need a few moments to re-adjust and be comforted by their parents and medical team.

The First Meal: Many parents want to reward or perk up their children after surgery with some of their classic favorite comfort foods especially those children who may be struggling. The first post-surgery meal should steer clear of things like pizza, ice cream, or French fries to avoid an upset stomach, and furthering the child's discomfort. The child should first consume liquids and then advance to something simple. After being able to keep down fluids, simple carbs, such as, pancakes and scrambled eggs tend to go down easier, and what child doesn't get excited about breakfast for dinner?!

Recovery: The length of the recovery process will generally depend on the child's age and the type of surgery. Just like in adhering to pre-surgery guidelines, it is extremely important that parents follow the surgeon's instructions for post-surgery care, including monitoring the child's pain levels and administering prescribed pain medication as directed.

It is also essential to monitor for signs of infection, such as fever, redness, or swelling at the incision site. Parents should be mindful of any activity restrictions and specific restrictions related to any areas of incision. Additionally, children and their parents should manage any dressing well by keeping it dry. Dressings can sometimes be taken off at home, but other times, an appointment is required.

All pediatric surgeons know surgery is scary and that parents have a million questions, and will sometimes need to ask them multiple times.

Like any post-surgery patient, children may feel tired or have a decreased sense of appetite, but they should gradually return to their regular spirits and energy levels, as they recover from their operation. Nevertheless, parents and caregivers should reach out to their medical provider for any specific questions that might be unique to their child, or just for reassurance as they help their child recover.

CONCLUSION

Surgery is scary, and all pediatric surgeons know this. They have chosen to work with a more vulnerable client base and are very much aware that parents have a million questions, and will sometimes need to ask them multiple times, which is OK and even encouraged.

At the end of the day, parents of special needs children are the ultimate experts on their children, equipped with abundant medical knowledge, because they have had to arm themselves with information for their child's whole life. Parents are encouraged to work very closely with their child's healthcare provider, lean on them as a resource, and lean on their close friends and family as resources, too. •

ABOUT DR. BASS:

Dr. Kathryn Bass serves as Section Chief of Pediatric Surgery at Carilion Clinic and Professor of Pediatric Surgery at Virginia Tech Carilion School of Medicine. She is triple board-certified in general surgery, pediatric surgery, and wound care. In her more than two decades as a surgeon, she has held many leadership roles, including Director of a Level 1 Pediatric Trauma Center and Co-Director of a Pediatric Wound Care Center. Her peers have recognized Dr. Bass as one of the nation's leading pediatric surgeons, and she was honored as a "Top Doctor" in Western New York from 2010 - 2019. Dr. Kathryn Bass is a pediatric surgeon of over 20 years, who works with children with special needs daily in her practice – ranging from small children to young adults who continue to receive care from their parents.

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MILITARY

SECTION

MILITARY LIFE

BOOK EXCERPT 12TH OF A SERIES

OUR JOURNEY IN CAMO

ARMY
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WHAT'S NEW WITH THE EXCEPTIONAL FAMILY MEMBER PROGRAM

A FRESH PERSPECTIVE: EFMP & Me can help you and your family member with special needs overcome challenges and thrive in military life. The more families understand how EFMP works across these three parts, the better their experience can be.

The Department of Defense Office of Special Needs is committed to helping families with special needs thrive in military life. The Exceptional Family Member Program does this through Identification and Enrollment, Assignment Coordination and Family Support. The more families understand how EFMP works across these three parts, the better their experience can be.

The following enhancements are designed to improve the family experience through greater understanding of the role of each component within EFMP while expanding EFMP Family Support resources.

STANDARDIZING EFMP ACROSS THE SERVICES

There has been a continual focus on creating consistency to benefit the entire community. The following changes to EFMP have been implemented across the services:

Respite care services: Eligible families are allotted a standard number of monthly EFMP respite care provider hours. Also, respite care now covers care for adult dependents. It no longer covers sibling care. Families have the ability to request additional services based on exceptional circumstances.

EFMP Family Support: Provides greater clarity on the Family Support services and establishes the requirement for EFMP Family Support providers to complete at least one annual personal contact to each family assigned to their caseload and every family using the respective service's respite care program.

Identification and enrollment: There is greater transparency and communication regarding the identification and enrollment process.

Assignment: The service member has up to 14 calendar days from the date of the original assignment notification to request a second review and submit updated medical or educational information.

Disenrollment: The disenrollment process is more transparent. Families are told what constitutes disenrollment and how to disenroll.

EFMP & ME TOOL

EFMP & Me is an online tool to provide families direct access to information and resources (https://efmpandme.militaryonesource.mil)

- Offers 24/7 access, at home or on the go, through a digital application.
- Provides family members with a tailored, streamlined and supportive digital experience to locate guidance and information when and where needed.
- Gives service providers and military leaders an additional information source to use and to recommend to families.

IMPROVED COMMUNICATION WITH FAMILIES

EFMP Family Support continues to focus on sharing information with families to better support them and help them improve their self-advocacy skills.

- **EFMP Family Support Feedback Tool:** Provides a mechanism for families to give feedback about their recent experience with installation EFMP Family Support. This feedback will help OSN and the military services with program improvement and policy development. https://apps.militaryonesource.mil/MOS/f?p=EFSS
- **EFMP brand toolkit:** Provides helpful tools and resources for service providers and leaders to get the message out to families about EFMP. https://apps.militaryonesource.mil/MOS/f?p=EFSS
- **EFMP/SPECIAL NEEDS** provides additional tools and information for service providers and leaders who support military families with special needs. www.militaryonesource.mil/leaders-service-providers/efmp-special-needs/

EXCEPTIONAL ADVOCATE NEWSLETTER

The Exceptional Advocate (www.militaryonesource.mil/epublications/the-exceptional-advocate-enewsletter-archives) is a newsletter for military families with special needs and those who support them. Published quarterly, *The Exceptional Advocate* focuses on updates and information from EFMP.

OFFICE OF SPECIAL NEEDS EFMP PODCAST SERIES

Tune in to this podcast series (www.militaryonesource.mil/resources/podcasts/efmp) from the Office of Special Needs, where subject matter experts share information and resources of interest to military families with members who have special needs. Listen at your convenience to a range of topics including education, PCS moves, long-term and financial planning, deployment and much more. Get to know EFMP & Me and how it can help you and your family member with special needs overcome challenges and thrive in military life.

Learn more about the EFMP & Me tool and other program highlights to help your family or to share with other families with special needs at www.militaryonesource.mil/benefits/exceptional-family-member-program-family-support. Contact your nearest installation EFMP Family Support provider (https://installations.militaryonesource.mil/search?program-service=16) or contact Military OneSource special needs consultants (www.militaryonesource.mil/specialty-consultations/military-onesource-special-needs-consultants) for free and confidential special needs consultations to help you navigate services for your family. You can schedule appointments 24/7 by calling 800-342-9647. •

– Military OneSource

U.S. MILITARY ★ BOOK EXCERPT 13TH OF A SERIES

THE RESILIENT WARRIOR

SELF-SOOTHING WITH BUBBLE BATHS

BY CAROL GEE

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

Utilize a bubble bath to de-stress and unwind. "Ahh," I sighed as I slid into a bathtub of hot water full of frothy bubbles. Leaning back against the padded rubber bath pillow, I exhaled as the hot water covered my entire body.

In my mind's eye, I could still hear the blip, blip, blip, of the various machines hooked up to my husband. The sounds seem to pulsate throughout my entire body every time they sounded. While under the tangle of tubes and wires and oblivious to everything around him, my husband slept. "Heart attack" the doctor said, walking into the Cardiac Intensive Care Unit with my husband's chart in hand, and asking me how old he was, all seemingly in the same breath.

As I told him his age, I remembered thinking, 44 years old seemed way too young for something so serious to have happened. Standing by, I felt helpless, a feeling that I absolutely detested.

As the female half of a two-military servicemen couple, both long retired from two successful careers. All my life I've had to use skills honed in the military to resolve problems. For the past 27 years, my husband has battled one chronic health issue after another. Married without children and no immediate family in the area, it has always been just me as his caregiver. Every time I have sat in the 'family' waiting room of a hospital, I have felt much like Alice, tumbling down the rabbit hole, feeling nervous, frightened… alone.

Unknowingly, this same feeling would be repeated over and over, throughout the years. Although each instance (two heart attacks, a small stroke, diabetic foot wounds) initially scared me to death, addressing each in a step-by-step methodical manner has helped me get through all of them. With each new diagnosis, I would immediately go into warrior mode.

Once we had received the diagnosis, I sought next steps. My husband is a quiet man, so this includes my asking questions, tons of questions about his care. Are there more tests? What are the procedures such as hospitalizations, surgery? What about aftercare? What can I do to ensure my husband gets the best prognosis for the future? Focusing on each incident step by step, makes me feel like I have some control, and am part of the solution.

Telling myself to take a deep breath, I force myself to let the hot, sudsy water do its thing. This particular day, I had added a few caps full of eucalyptus and spearmint foaming bath gel.

I am a fanatic of lovely scents. Adding black raspberry vanilla soap to my washcloth, I washed away the fears of that day. You see, bubble baths have always been my way of dealing with stress. While most folks take showers for a quick refresh (and I typically do so in the mornings), science states that a bubble bath is better for one's mental health than showers. A bubble bath forces you to slow down. Submerging in hot water can also help with pain, inflammation and one's circulation. Lastly, a bubble bath allows you to take a few extra minutes to simply exhale.

THOUGHT BUBBLE: "A bubble bath forces you to slow down and allows you to take a few extra minutes to simply exhale."

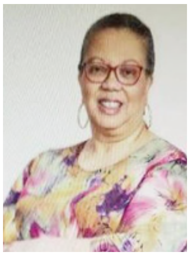
For me, turning off the lights, adding a candle, and shower gel, leaves me, my bath water and even the entire bathroom smelling fabulous. Smoothing a body lotion of the same scents afterward, guarantees the scents last long after my bath.

Alas, when people think of men and women serving in the military, or those of us who previously served, they picture someone hard, tough. For example, when folks learn I served, they say, "I wouldn't have thought you were ever in the military. You look too soft, too feminine." (Do they think all servicewomen look like brawny men)? To which I reply that aside from my love of smelling good, and all things pink and girlie, I am tough. After all, life has demanded that I be. However, even the toughest person you know needs to find a way to promote self-care, to unwind, to decompress. Some find it through working out, running, or jumping out of planes. (Are those folks nuts)? Others find it through painting or some other outlet.

So, if bubble baths are your thing, or you think taking them will help you relax, as it does me, you can typically find bubble soap or bath gels at local stores.

The Air Force changed my whole life's trajectory. It also inspired fearlessness. As such, I'm unafraid of changes, be it new ideas, locales, or situations. In my heart, I am still a warrior. Always have been. Always will be. •

ABOUT THE AUTHORS:



Carol Gee, M.A, served nearly eight years on active duty. With an active-duty spouse, (long retired) wanting to continue play a role in the military, she joined the Air Force Reserves, serving fourteen years before retiring as a Technical Sergeant, E-6). Nine years ago, she retired again after twenty-eight years in higher education at the university level, to become a published author and freelance writer, **www.VenusChronicles.net**. She and her spouse of fifty years live in an Atlanta suburb.

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

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

Friends in Scary Places

In my mind I have grabbed the back of my friend's shirt and I'm inching forward as she clears the path. I lean my head into her back, hoping that she helps me get to where we need to go.

I have a friend who has a son that is 22 years old with severe autism. I lean on her more than she realizes. The feeling is almost like having an older sibling. She must do everything before I do, so I watch her carefully. I'll ask her, "If you could do it over again, what would you do?" Once she reflects, I'll take a mental note and write it down, so I don't forget. I don't have an older sibling, but that seems to be the only way I can describe the relationship I have with her. The landscape parents who raise children with severe autism maneuver through is thick, intimidating, and confusing. I picture my friend with a weed whacker and power saw tearing down anything in front of her. If she needs to change direction, she will back up, reassess the situation and then start again. In my mind I have grabbed the back of her shirt and I'm inching forward as she clears the path. At times, my head is down too tired or overwhelmed to look ahead, so I lean my head into her back, hoping that she helps me get to where we need to go.

JOY RIDE: Broden enjoys his ride to his clinic with his Dad for a change; "Severe autism is a unique landscape with challenges that are difficult to explain to those who do not care for those with the diagnosis. Mark and I remind each other that we need to comfort one another, because it's ok to be scared."

"We left our son alone at home tonight! Gosh, I never thought we'd get to this point. He's 22 years old and he's successfully home alone tonight." Wow. I couldn't believe it myself. My friend asked, "Do you look forward to that happening some day for you?" I shook my head in disbelief. I did tell her that Broden continues to change and grow. It's the little things right now. He's got this thing for cashew milk ice cream. He'll pick out what flavor he wants in the grocery store and throws it in the cart. He'll then wander over to the candy aisle and grab a bag of candy that he can eat and tosses it in the cart. He remembers what ice cream he bought. I'll catch him in the kitchen ripping the top off the ice cream container, opening the silverware drawer to grab a spoon, and shove a few spoonfuls of ice cream in his mouth. We're still working on him closing the freezer door, closing the silverware drawer, and not putting the dirty spoon back with the clean spoons. Mark and I are still confused about the bag of candy he grabs during each grocery trip. He wants to buy candy but won't eat it. We have about six bags of candy stacked in our pantry unopened.

After I told my friend about the changes and progress Broden has made, I said, "It's funny. I'm still amazed at what Broden continues to do, because 15 years ago, we were told that the window for Broden to make great strides would start to close around 6 or 7 years old. In the beginning of Broden's life, each birthday was almost like a funeral. That was one more year that my son wasn't meeting the milestones like his peers did. My friend smiled and nodded, "Me too. I did the exact same thing. I was so stressed, and you're right. I was sad each year my

PHOTO PROVIDED BY SHELLY HUHTANEN

son got older." I don't know. Maybe the medical field was generalizing people with autism. Maybe Broden's pediatric team didn't know enough about autism to truly assess his capabilities and what to expect 15 to 20 years down the road. I don't know if we really know now.

A few days ago, I Googled "What happens when your child with autism turns 21 years old?" I was curious what the search would provide, and frankly, in some twisted way I was hoping that "Fortune Teller Google" would be as lucrative in information as "Dr. Google" is every time I have an ache or pain. Well, "Fortune Teller Google" was as predictable as a real-life fortune teller. The search didn't tell me anything new. In a nutshell, the smart thing to do is to plan. Mark and I need to plan financially for Broden's care, plan for Mark and me to die, and find a group home or family member to take care of him after we die. I laughed, "Oh ok, sounds pretty straight forward to me." The thing is, it sounds easy, but it's not.

Alone, it seems scary, and I become filled with anxiety and worry. Then I remind myself that I have grabbed the back of my friend's shirt while she whacks away at the intimidating and overwhelming forest of uncertainty that lay before us. I am not alone as we edge closer to this cliff, where there are no answers, no services, and no ABA insurance coverage. Severe autism is a unique landscape with challenges that are difficult to explain to those who do not care for those with the diagnosis. As Mark and I tread through the swamp of guardianship and applying for Medicaid, we remind each other that we need to comfort one another, because it's ok to be scared. Mark asked me last week, "How much is a lawyer going to cost to help work through all this paperwork for us to apply for Medicaid?" I just shook my head, "I don't know." Honestly, I'm getting comfortable with not knowing much these days.

After chewing on the idea of starting the application process for Medicaid, we sighed and knew that we are behind the curve. Since we are a military family, we usually aren't in a state long enough to start the Medicaid process, and honestly, not until recently did we truly know that we could retire here. There was still a slight possibility that we would have one more move. Now we know we can start the process. If we could do it all over again, we should have started this process around three years ago.

> "All I can do is tell a friend with a younger child with autism is to grab the back of my shirt, 'Hang on. It's scary, but I'll do my best to help you plow a way forward.'"

We don't have time to play the "what if" game. We must keep pushing through, planning and deciding what our next move is to ensure Broden is cared for with appropriate supports in place. In my mind, I'm holding Mark's hand tight in the darkness and I'm grabbing a hold of the back of my friend's shirt. All I can do is tell a friend with a younger child with autism is to grab the back of my shirt, "Hang on. It's scary, but I'll do my best to help you plow a way forward." It's the least I can do, because in the end it's the village around us that will help us get there. •

OUR JOURNEY IN CAMO

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

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