PLUS: UNITED STATES MILITARY SECTION

EXCEPTIONAL PARENT • PHYSICIAN • PATIENT • PEOPLE

EXCEPTIONAL PARENT
MAGAZINE
DECEMBER 2022
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EP's ANNUAL HOLIDAY ISSUE:

TIPS TO HELP YOUR CHILD MANAGE HOLIDAY STRESS

PLUS:

SHOPPING *for* KIDS WITH SPECIAL NEEDS

IN THIS ISSUE:

NEVER STOP ASKING *for* HELP

THE HOLIDAYS
FAMILY & COMMUNITY

ALSO INSIDE:

SAFETY *for* THE ELDERLY POPULATION DURING *the* HOLIDAYS

AND • SPECIAL ED STUDENTS:

54 SKILLS *to* INCLUDE WHEN WRITING FUNCTIONAL IEP GOALS

EP MAGAZINE 1971 2023 51 YEARS CELEBRATES

Justin McCafferty

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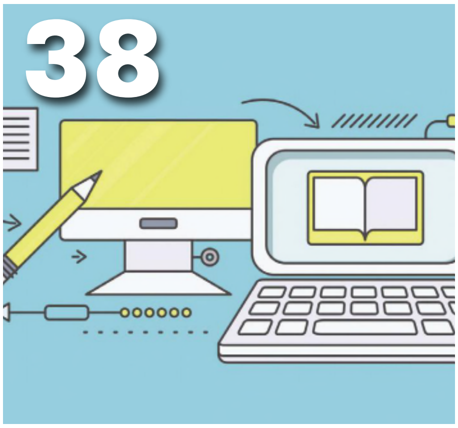

ON OUR COVER

Justin McCafferty, a 19-year-old with autism, gets ready for the holiday season; His mother Kimberlee writes about how important it is to build a support network to enable a family to make it through sometimes stressful parts of the year like the holidays. Her article and many others contain valuable tips and guidance as we approach what can be a joyous, but challenging, end of the year. *Coverage begins on page 18.*

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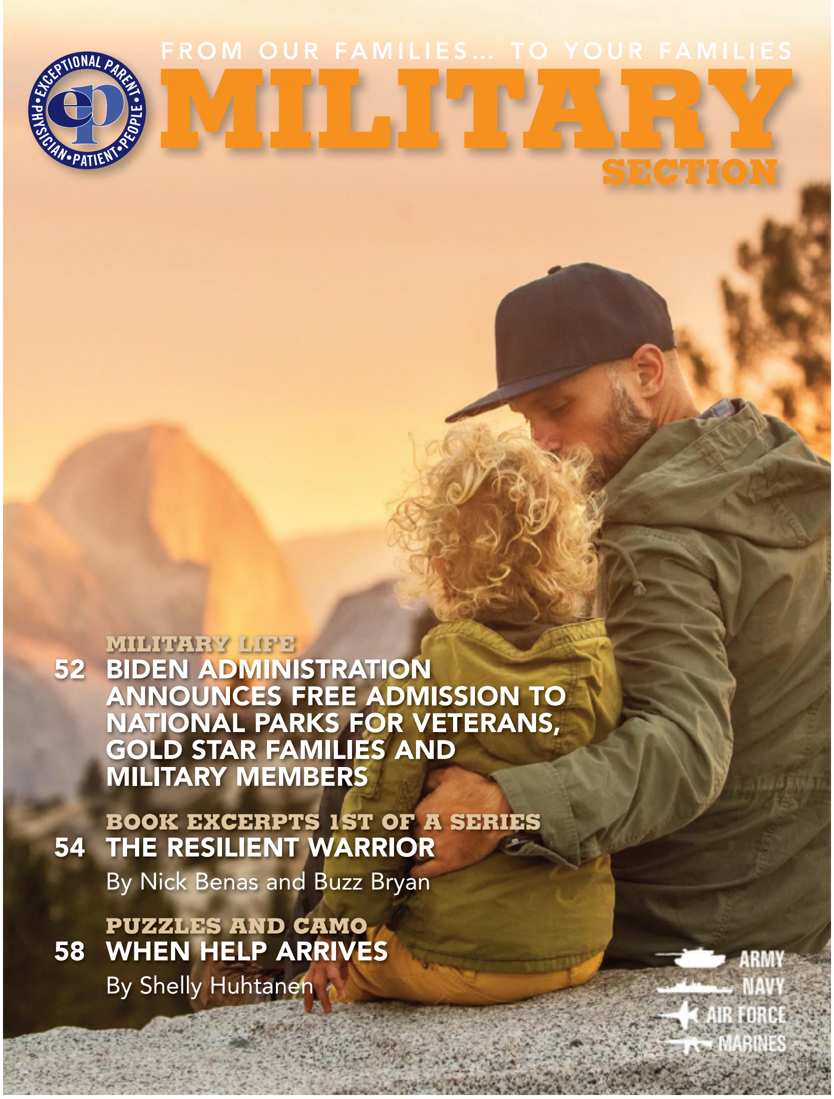

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Glad Tidings

We wish all of our readers a joyous, peaceful and healthy holiday season!

The gift-giving season is upon us, and many among us have come to realize that respite is among the most cherished gifts we can receive. To highlight EP's Annual Holiday Issue, two of our most senior contributors address the concept of *asking for help*. Kimberlee McCafferty advises readers to be bold enough to ask others for much-needed support, just as she has done in caring for her nineteen-year-old son with autism. Shelly Huhtanen, military spouse and our long-time Puzzles and Camo columnist, writes about the process of enlisting her mother and father to care for her autistic son Broden while she and her husband fly to Montana to visit her husband's aging parents.

> "Our December issue is filled to the brim with tips, advice, expert counsel - and good cheer!"

Our December issue is filled to the brim with tips, advice, expert counsel – and good cheer! It contains suggestions for managing holiday stress, shopping for kids with special needs, and keeping the home environment safe for elderly family members during holiday visits and throughout the year.

In addition, Jenn Adams offers valuable guidance on how to keep lines of communication open between parents and teachers during holiday breaks as well as throughout the school year. Joshua Fishkind, J.D., MBA returns with his second installment offering detailed advice on creating a holistic estate plan for your loved one with special needs, while Jean Budd, LPC, NCC, IMH E® and Corinne G. Catalano, Ph.D., IMH E® advocate for the increased use of self-statements to enhance inclusion in the classroom and parent/teacher involvement.

Also, The SPAN Parent Advocacy Network presents the second article in a series of six that highlight updates to its National Children's Mental Health Family Guide.

As we look toward the new year, please be on the lookout for our all-new 2023 EP Guide. Our longest issue of the year will feature an impressive amount of invaluable content that you will refer to throughout the entire year.

It's easy to subscribe and receive "EP for Free" – just visit **www.epmagazine.com** and click Subscribe! Please share our publication with anyone (family members, colleagues, etc) who would benefit from our great monthly coverage of information and resources for the special needs community. While you're at it, please share our Instagram feed at **instagram.com/epmzine** and be sure to like us on Facebook at **facebook.com/exceptionalparentmag** .

We here at EP wish you all a joyous, peaceful and happy holiday season!

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

VOLUME 52 ISSUE 12
ESTABLISHED 1971

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Exceptional Parent (ISSN 0046-9157) is published monthly 12 times per year including the special January EP Guide - Navigating Special Needs Resources by Exceptional Parent Magazine, 1360 Clifton Avenue, Ste. 327, Clifton, NJ 07012 Internet address: www.epmagazine.com. All rights reserved. Copyright ©2022 by Exceptional Parent Magazine,. Exceptional Parent™ is a registered trademark of Exceptional Parent Magazine. Postmaster: Please send address changes to: Exceptional Parent,1360 Clifton Avenue, Ste. 327, Clifton, NJ 07012. Any applicable periodical postage paid at Clifton, NJ and additional mailing offices (USPS 557-810). Basic annual subscription for EP Digital is free. Limited edition print subscription $95.00. Subscriber Service: Direct all inquiries & address changes to: Exceptional Parent, 1360 Clifton Avenue, Ste. 327, Clifton, NJ 07012 08758. Customer Service/New Orders: E-mail: fsimon@epmagazine.com or call (973) 726-6218. Back issues incur a charge of $10.50 each with shipping, (January issue $12:50 when requested) and depend upon availability. Call (973) 726-6218. Agreement #1420542

WHAT'S HAPPENING

LOIS CURTIS, ARTIST AND ADVOCATE WHOSE LAWSUIT SECURED DISABILITY RIGHTS, DIES AT 55

The woman known as the "godmother of the disability rights movement in Georgia" and one of the plaintiffs in a landmark civil rights Supreme Court case has died.

POWERFUL PICTURE: Lois Curtis presents President Barack Obama with a self portrait of herself as a child in June 2011.

Artist Lois Curtis, of Clarkston, GA, died of pancreatic cancer on November 3 at age 55. Curtis was named one of the plaintiffs along with Elaine Wilson in the 1999 *Olmstead vs. L.C.* Decision.

Curtis and Wilson had developmental disabilities and were voluntarily admitted to the psychiatric unit in the state-run Georgia Regional Hospital. After receiving medical treatment, medical professionals deemed each was ready to move to a community-based program. However, they were never moved and spent several years in the hospital after their initial treatment concluded.

"She fought for the freedom to live independently. When she was a young woman, she reached out to an attorney at Atlanta Legal Aid repeatedly to have her voice heard," a news release from GCCD said.

The Supreme Court upheld that unjustified segregation of people with disabilities constitutes discrimination and violates the Americans with Disabilities Act.

The decision helped spark policy change, with Curtis paving the way for people with mental, developmental and intellectual disabilities to leave institutional settings and live within their communities. It also upheld that public entities must provide community-based services to such individuals under federally determined circumstances.

The Supreme Court ruled in 1999, in a decision delivered by Justice Ruth Bader Ginsburg, that Curtis, her co-plaintiff Elaine Wilson and other people with disabilities had a right – under the Americans with Disabilities Act – to live in a "less restrictive setting."

The landmark civil rights case gave disabled and elderly people a right to seek long-term care services in their own home, instead of in an institution like a nursing home or a psychiatric hospital. Curtis "created a sea change in what our service systems look like," says Alison Barkoff, the top federal official for aging and disability policy.

> *"Lois Curtis' tireless advocacy and vision transformed the long standing right to live in the community into a reality for millions of Americans"*

"We went from a system in 1999 that the only places that most people with disabilities and older adults could get services were in institutions like nursing homes and psychiatric hospitals, to systems that are primarily focused on supporting people with services in their own homes," says Barkoff, the acting administrator and assistant secretary of aging at the Administration for Community Living at the U.S. Department of Health and Human Services.

"People often say that the Olmstead decision is the Brown vs Board of Education for the disability community because it opened doors for people to live in their communities, to have freedom, and to work. Advocacy was her life. She was amazing," Lee Sanders said. Sanders, a career specialist at Briggs and Associates, had worked with Curtis and had known her since 2005.

Although Lois never forgot her difficult years in institutions, she emerged as an empowered advocate who walked up the Supreme Court steps to hear her case argued as she was surrounded by supporters. After winning her struggle for independence, she lived a fulfilling life as a beloved community member in Atlanta and as a successful and renowned artist. She has been honored personally in the White House, by a host of disability and legal organizations, during Black History Month, and by the National Women's History Museum. The Association of People Supporting Employment First (APSE) created the Lois Curtis Award in her honor. The award recognizes an individual's personal achievement in advocating for inclusive, individualized, community-based employment and/or independent living.

PHOTO COURTESY PETE SOUZA / OBAMAWHITEHOUSE.ARCHIVES.GOV

WHAT'S HAPPENING

SUPREME COURT CASE ON INDIANA PUBLIC NURSING HOMES COULD SHARPLY LIMIT DISABILITY RIGHTS

A case going before the U.S. Supreme Court could severely threaten the rights of millions of people who rely on Medicaid, SNAP, CHIP and other government programs.

The question before the court is whether beneficiaries of programs like Medicaid have the right to sue state and local governments if their civil rights are violated, or if they have any form of recourse at all.

Gorgi Talevski was living with dementia and receiving care at Valparaiso Care and Rehabilitation, a state-run nursing facility in Indiana. His wife, Ivanka Talevski, filed a lawsuit on behalf of her husband alleging that Valparaiso Care failed to provide Gorgi with adequate medical care, used psychotropic medications as unnecessary chemical restraint, and improperly discharged and transferred him, among other practices, in violation of the Federal Nursing Home Reform Act (FNHRA).

The case, known as *Talevski v. Health and Hospital Corporation of Marion County*, was brought by the estate of Gorgi Talevski, who has since died, alleging that he was chemically restrained and medicated so that he would go to sleep instead of being treated for his dementia while living in an Indiana nursing home.

ROLLING BACK RIGHTS: Medicaid is the primary source of health care for people with intellectual or developmental disabilities, the vast majority of whom want to live with dignity in their homes and communities.

> ***"The implications of this case reach far beyond Talevski and nursing home standards of care. Safety net programs have been a lifeline for millions of people, especially people with disabilities."***

The United States Court of Appeals for the Seventh Circuit determined that Talevski's estate could sue under the Nursing Home Reform Act provisions of Medicaid, but the Health and Hospital Corporation of Marion County, or HHC, appealed to the Supreme Court arguing that nursing home residents shouldn't be able to bring suit in federal court.

On Nov. 8, *Talevski v. Health and Hospital Corporation of Marion County* will be heard by the Supreme Court. The implications of this case reach far beyond Talevski and nursing home standards of care. Safety net programs – such as Medicaid, the Supplemental Nutrition Assistance Program (SNAP), the Children's Health Insurance Program (CHIP) and Temporary Assistance to Needy Families (TANF) – have been a lifeline for millions of people, especially people with disabilities. A negative ruling will leave them without any legal recourse if they face mistreatment or abuse or their benefits are taken away or denied. This happens more often than you may think.

"With Talevski, the Supreme Court could cut off the right to go to court if state officials unlawfully deny, reduce or terminate benefits guaranteed by federal law," a petition from the Bazelon Center for Mental Health Law and a handful of organizations in Indiana that are pushing back against HHC reads. "This would make it nearly impossible to hold state and local governments accountable for violating the rights of those depending on federally funded safety net programs."

The impact would be far reaching, advocates say, affecting millions of people who rely on everything from Medicaid to the Supplemental Nutrition Assistance Program, the Children's Health Insurance Program, Temporary Assistance to Needy Families and more.

Disability advocates say the case could also influence the right to sue under Title IX of the Education Amendments of 1972, which bars discrimination based on sex, as well as Title VI of the Civil Rights Act, which speaks to discrimination based on race, color or national origin, and Section 504 of the Rehabilitation Act, which prohibits disability discrimination.

"This case is a large-scale assault on disability rights around the country," said Peter Berns, CEO of The Arc. "Medicaid is the primary source of health care for people with intellectual or developmental disabilities, the vast majority of whom want to live with dignity in their homes and communities. Protecting their right to private action when such rights are violated would ensure they aren't unnecessarily institutionalized and prevent the unraveling of anti-discrimination progress set forth by the ADA for over 30 years."

In recent weeks, advocates are pressuring HHC to drop the case. More than 20 amicus briefs supporting the Talevski estate have been filed by groups including the Bazelon Center, The Arc, the American Association of People with Disabilities, AARP and top Democrats in Congress.

Jalyn Radziminski at the Bazelon Center said more than 13,000 people have emailed HHC and Marion County elected officials urging them to withdraw the matter. Meanwhile, an amicus brief from a long-term care industry group as well as one filed by Indiana and 16 other states are backing HHC.

Jane Perkins, legal director at the National Health Law Program, which filed an amicus brief along with 42 other legal organizations supporting Talevski. said "This case is no joke. An adverse decision will have huge implications for government program beneficiaries and for holding governments accountable."

WHAT'S HAPPENING

CARILION CLINIC PEDIATRICIAN REITERATES CALL FOR TOY SAFETY THIS HOLIDAY SEASON

With the holidays right around the corner, pediatricians remind consumers to keep safety at the top of mind.

In 2021 there were more than 152,000 toy-related, emergency department-treated injuries to children younger than 15 years of age, including two deaths. The fatalities involved choking on a small part of a toy and suffocating on a soft toy in an unsafe sleep environment. Many of the incidents were associated with, but not necessarily caused by, a toy. For children younger than 15 years old, non-motorized scooters continued to be the category of toys associated with the most injuries. Males accounted for 58 percent of all of the injuries. Once the gifts are open, remember to immediately discard plastic wrappings or other packaging on toys before they become dangerous playthings.

SAFE AT HOME: Kids will have new toys to play with over the coming holidays, but it's important that safety always come first.

Dr. Kathryn Bass, Section Chief, Pediatric Surgery at the Carilion Clinic in Roanoke, VA, urges parents to prioritize safety when shopping for and giving gifts this holiday season. "Stay away from small objects that can fit in a toddler's mouth or fist – even something that can come apart in small pieces. I've taken countless small toys out of the GI tract and airway. Because it's very typical for children to put small things into their mouths, they likely won't be able to help themselves.

"The big thing we've tried to work on in pediatric surgery over the past few years is magnets. I urge you not to give magnets to kids," says Bass. "Even bigger kids ages seven and eight ingest magnets, especially those in objects meant to construct and build things. These rare earth magnets are powerful to have enough pull to engage each other and, if ingested, create bowel perforation and peritonitis. If this is untreated, it can be devastating – but the good thing is, this is all very preventable. We want everyone to have a fun but safe holiday season."

IMPENDING INTERGENERATIONAL CRISIS: AMERICANS WITH DISABILITIES LACK LONG-TERM CARE PLANS

BY SAM WHITEHEAD

Thinking about the future makes Courtney Johnson nervous.

The 25-year-old blogger and college student has autism and several chronic illnesses, and with the support of her grandparents and friends, who help her access a complex network of social services, she lives relatively independently in Johnson City, Tennessee. "If something happens to them, I'm not certain what would happen to me, especially because I have difficulty with navigating things that require more red tape," she said.

Johnson said she hasn't made plans that would ensure she receives the same level of support in the future. She especially worries about being taken advantage of or being physically harmed if her family and friends can't help her – experiences she's had in the past.

"I like being able to know what to expect, and thinking about the future is a bit terrifying to me," she said.

Johnson's situation isn't unique.

Experts say many people with intellectual and developmental disabilities do not have long-term plans for when family members lose the ability to help them access government services or care for them directly.

Families, researchers, government officials, and advocates worry that the lack of planning – combined with a social safety net that's full of holes – has set the stage for a crisis in which people with disabilities can no longer live independently in their communities. If that happens, they could end up stuck in nursing homes or state-run institutions.

"There's just potential for a tremendous human toll on individuals if we don't solve this problem," said Peter Berns, CEO of the Arc of the United States, a national disability-rights organization.

About one-quarter of adults in the U.S. live with a disability, according to the Centers for Disease Control and Prevention. Nearly three-quarters of Americans with disabilities live with a family caregiver, and about one-quarter of those caregivers are 60 or older, according to the Center on Developmental Disabilities at the University of Kansas.

But only about half of families that care for a loved one with disabilities have made plans for the future, and an even smaller portion have revisited those plans to ensure they're up to date, said Meghan Burke, an associate professor of special education at the University of Illinois in Urbana-Champaign.

"Engaging in it once is good, right? But you can't only engage in it once," she said. "It's a living document, because things change, people change, circumstances change."

FRAUGHT FUTURE: Courtney Johnson's grandparents and friends have helped her access social services, but she says she doesn't have plans in place to ensure she'll receive the same level of support in the future.

Burke's research has found several barriers to planning for the future: financial constraints, reluctance to have hard conversations, trouble understanding government services. Creating plans for people with disabilities also is a complex process, with many questions for families to answer: What are their relatives' health needs? What activities do they enjoy? What are their wishes? Where will they live?

Burke has firsthand experience answering those questions. Her younger brother has Down syndrome, and she expects to become his primary caregiver in the future – a situation she said is common and spreads the work of caregiving. "This is an impending intergenerational crisis," she said. "It's a crisis for the aging parents, and it's a crisis for their adult offspring with and without disabilities."

Nicole Jorwic, chief of advocacy and campaigns for Caring Across Generations, a national caregiver advocacy organization, said the network of state and federal programs for people with disabilities can be "extremely complicated" and is full of holes. She has witnessed those gaps as she has helped her brother, who has autism, access services. "It's really difficult for families to plan when there isn't a system that they can rely on," she said.

Medicaid pays for people to receive services in home and community settings through programs that vary state to state. But Jorwic said there are long waitlists. Data collected and analyzed by KFF shows that queue is made up of hundreds of thousands of people across the country. Even when people qualify, Jorwic added, hiring someone to help can be difficult because of persistent staff shortages.

Jorwic said more federal money could shorten those waitlists and boost Medicaid reimbursements to health care providers, which could help with workforce recruitment. She blamed chronic underinvestment in Medicaid disability services for the lack of available slots and a dearth of workers to help people with disabilities.

"It's going to be expensive, but this is four decades of funding that should have been done," she said.

PHOTO COURTESY TRISTAN LANE / KHN

Congress recently put about $12.7 billion toward enhancing state Medicaid programs for home- and community-based services for people with disabilities, but that money will be available only through March 2025. The Build Back Better Act, which died in Congress, would have added $150 billion, and funding was left out of the Inflation Reduction Act, which became law this summer, to the disappointment of advocates.

Jeneva Stone's family in Bethesda, Maryland, has been "flummoxed" by the long-term planning process for her 25-year-old son, Rob. He needs complex care because he has dystonia 16, a rare muscle condition that makes moving nearly impossible for him.

NARROW OPTIONS: Rob Stone was born with a condition that restricts much of his movement. His mother, Jeneva, says her family has been "flummoxed" by the process of planning for the future.

"No one will just sit down and tell me what is going to happen to my son," she said. "You know, what are his options, really?"

Stone said her family has done some planning, including setting up a special needs trust to help manage Rob's assets and an ABLE account, a type of savings account for people with disabilities. They're also working to give Rob's brother medical and financial power of attorney and to create a supported decision-making arrangement for Rob to make sure he has the final say in his care.

"We're trying to put that scaffolding in place, primarily to protect Rob's ability to make his own decisions," she said.

Alison Barkoff is acting administrator for the Administration for Community Living, part of the U.S. Department of Health and Human Services. Her agency recently released what she called a "first ever" national plan, with hundreds of actions the public and private sectors can take to support family caregivers.

"If we don't really think and plan, I'm concerned that we could have people ending up in institutions and other types of segregated settings that could and should be able to be supported in the community," said Barkoff, who noted that those outcomes could violate the civil rights of people with disabilities.

She said her agency is working to address the shortages in the direct care workforce and in the supply of affordable, accessible housing for people with disabilities, as well as the lack of disability-focused training among medical professionals.

But ending up in a nursing home or other institution might not be the worst outcome for some people, said Berns, who pointed out that people with disabilities are overrepresented in jails and prisons.

Berns' organization, the Arc of the United States, offers a planning guide and has compiled a directory of local advocates, lawyers, and support organizations to help families. Berns said that making sure people with disabilities have access to services – and the means to pay for them – is only one part of a good plan.

"It's about social connections," Berns said. "It's about employment. It's about where you live. It's about your health care and making decisions in your life."

Philip Woody feels as though he has prepared pretty well for his son's future. Evan, 23, lives with his parents in Dunwoody, Georgia, and needs round-the-clock support after a fall as an infant resulted in a significant brain injury. His parents provide much of his care. Woody said his family has been saving for years to provide for his son's future, and Evan recently got off a Medicaid waitlist and is getting support to attend a day program for adults with disabilities. He also has an older sister in Tennessee who wants to be involved in his care.

But two big questions are plaguing Woody: Where will Evan live when he can no longer live at home? And will that setting be one where he can thrive?

"As a parent, you will take care of your child as well as you can for as long as you can," Woody said. "But then nobody after you pass away will love them or care for them the way that you did."•

ABOUT THE AUTHOR:

Sam Whitehead covers the South for KHN from his base just outside Atlanta. He previously worked as a health care reporter for WABE, where he chronicled the covid-19 pandemic as host of the award-winning podcast "Did You Wash Your Hands?" Before that, he was a general assignment reporter and fill-in radio host at Georgia Public Broadcasting. He co-founded a long-running nightly news program on WRFI Community Radio in Ithaca, New York. He's a graduate of Emory University.

PHOTO COURTESY RAH FOARD / KHN


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WHAT'S NEW GEAR FOR CHEER

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ORGANIZATION SPOTLIGHT

PHOTO PROVIDED BY NATICIA ZOCCA

The Alexander Graham Bell Association for the Deaf and Hard of Hearing (AG Bell) opens up doors for children and their families seeking options.

CHILDREN WHO ARE DEAF OR HARD OF HEARING CAN HEAR AND TALK

BY EMILIO ALONSO-MENDOZA, J.D., CFRE AND LISA A. GOLDSTEIN

In 2009, a few weeks after Marin Zocca was born, her mother Naticia noticed that she wasn't responding to sound or noises. When she laughed or giggled, it sounded nasal and different from other babies.

Naticia and her husband Michael spoke with a pediatrician and a number of doctors, all of whom told them not to worry - it was probably just fluid in her ears that would clear itself out.

Finally, they got an appointment at Children's Healthcare of Atlanta for an Auditory Brainstem Response (ABR) test. There, they were told that Marin had severe to profound hearing loss and that hearing aids would never be sufficient for her to hear spoken language. After taking a few minutes by themselves to cry, the Zoccas asked as many questions as they could, because this was a whole new world.

"American Sign Language (ASL) was an option," Michael Zocca said. "But we didn't know it and were concerned about not being able to communicate with Marin, and her falling behind while we tried to learn it. We opted for cochlear implants, as we were told they would allow Marin to hear and speak.

DISCOVERING AG BELL

At the Atlanta Speech School, where Marin and later, her sister Nala – who was also born with hearing loss – were enrolled, the Zoccas learned about the Alexander Graham Bell Association for the Deaf and Hard of Hearing. AG Bell is an international nonprofit organization that brings families and professionals together to support children with hearing loss. AG Bell's community includes families who have children who are deaf or hard of hearing, adults who are deaf or hard of hearing, and the professionals who work with them. For 132 years, AG Bell has worked to ensure that every child who is deaf or hard of hearing has the opportunity to learn to talk, attend mainstream schools, and thrive in society.

Marin and Nala Zocca are among the more than 34 million children worldwide who are deaf or hard of hearing. More than 30 million of these children are born to parents who can hear. With training and technology, nearly all of them can learn to hear and talk. Early intervention makes all the difference. AG Bell's Cradle to Career concept ensures that families around the world have access to quality resources to help their child learn to listen, speak, and achieve their potential. Membership in AG Bell is free to friends and family. Professionals, who are vital to children's success, pay a fee and receive special benefits like: publications discounts for educational sessions, and networking opportunities to support their excellence.

When Marin was diagnosed, Michael and Naticia were both working parents. The school was 45 minutes away from their house. For the next nine years, Michael drove Marin and then her sister to school, Monday through Friday.

"Going from two incomes to one, adding the expense of school tuition, fuel for all the miles I was driving on a daily basis, wear and tear on the car, etc., was a real financial struggle," Zocca said.

FINANCIAL SUPPORT

One of the ways in which AG Bell supports its families is with financial assistance. The Parent & Infant Financial Aid Program helps families as they take initial steps to provide their child with hearing technology and therapy. There are also financial aid programs for preschool and school age children, and one for arts and science activities. College scholarships are offered as well.

"The financial support from AG Bell allowed us to put both girls on a path to success by giving them, and us as parents, access to early intervention," Zocca said. Through this assistance, they met professionals and educators in the field, who helped them change the girls' lives for the better. They have also built lifelong friendships and connections with others in the community, such as other families like them.

AG BELL COMMUNITY

AG Bell does more than provide financial assistance and general support. There are four goal areas which help the organization carry out its mission: Advocacy and Communications, Community Building, Capacity Building, and Leadership and Management. AG Bell works to promote issues relevant to children and adults with hearing loss, to legislators, regulators, healthcare systems, the media, and educational and legal systems. The organization also participates in a variety of coalitions, like the Joint Committee on Infant Hearing.

NOW HEAR THIS: Gavin Frost *(above)* has recieved multiple scholarships and is an advocate for his community; *(Opposite page)* Nala Zocca, who, like her sister Marin, was treated with bilateral cochlear implants, is at the top of her grade at school.

AG Bell's vibrant community of 17,000 provides information and opportunities for its members like: online resources, parent advocacy training, a digital magazine, an e-newsletter, a Parent Hotline, a network of state chapters, and leadership programs for teens.

The Listen-Learn-Link Parent Hotline began in June 2018 to address the need for parental support. Starting the journey can be overwhelming, so this resource allows parents, caregivers, and guardians for children newly identified with hearing loss, to connect with Julie Swaim, AG Bell's Early Intervention Parent Consultant, who speaks both English and Spanish. Within 24 hours

ABOUT THE ALEXANDER GRAHAM BELL ASSOCIATION FOR THE DEAF AND HARD OF HEARING

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

AG Bell works globally to ensure that people who are deaf and hard of hearing can hear and speak. AG Bell provides support, information, resources and more to help guide you on your journey. AG Bell wants all families to be informed and supported, professionals to be appropriately qualified to teach and help children with hearing loss, public policy leaders to effectively address the needs of people with hearing loss, and communities to be empowered to help their neighbors with hearing loss succeed. Learn more at **www.agbell.org**

PHOTO PROVIDED BY HEATHER KIRBY

of contacting the hotline, Swaim schedules a phone or video call in which she provides a safe space to listen and respond to questions. Swaim has worked in the Early Hearing Detection and Intervention field for the past eight years, and is a parent of an adult who is deaf.

Often at the end of a call, parents tell Swaim that they feel so much better, and have hope that their child can join in with peers with typical hearing, and have a fulfilled life.

Since the start of COVID, AG Bell has hosted Parent Chats on Zoom. At least eight sessions a year, cover topics relevant to parents and caregivers of children with hearing technology. These are also good opportunities for parents to connect with others who share their concerns.

PROFESSIONALS IN THE FIELD OF HEARING LOSS

A key element of the AG Bell community is the professionals in the field of hearing loss. They can obtain their Listening and Spoken Language certification, attend symposiums, and keep up to date on research via a scholarly peer-reviewed journal.

“One of the most important facts about AG Bell is that we work to ensure there are trained and qualified professionals around the world to help children learn to hear and talk,” said Lisa Chutjian, Chief Development Officer. “We dedicate extensive resources to assisting parents, especially in their child’s early years, to understand what is involved in Listening and Spoken Language; but this is only possible when families work closely with audiologists, auditory-verbal specialists, and educators, to provide their child with the best possible outcomes in spoken language and literacy. There are now 1,081 LSL specialists around the world, including 36 working exclusively in Spanish. The added benefit of preparing professionals is that they in turn become mentors to other professionals, creating a multiplier effect globally.”

A volunteer board that represents each part of the community, is helped by AG Bell’s professional staff based at the historic Volta Bureau in Washington, DC, and at AG Bell International in Madrid, Spain.

MEETING OTHER PARENTS

Heather Kirby of Minnesota is another parent who has benefited from AG Bell. When her son Gavin was born deaf, she googled “deaf resources” in Utah, where she lived at the time. The name and number for the president of the Utah Chapter of AG Bell appeared on her screen. When she contacted him, he asked if she wanted to meet a teenager who was deaf. Thus, when Gavin was two weeks old, a 16-year-old visited her house and showed her what was possible.

Gavin is 15 now, and Kirby has met numerous parents, since those early days. “AG Bell has made it much simpler to meet other parents with children who have hearing loss,” she said. Meeting these parents with kids older than Gavin allows her to learn from their experiences and know what to expect. Gavin has also received multiple scholarships. He has been on TV news and in the newspaper, testified before legislative subcommittees, and talked to other parents of children who are deaf.

“AG Bell taught and demonstrated to me that, despite being deaf, my son could learn to listen and communicate in a hearing world,” Kirby said.

Michael Zocca gives back as a parent mentor. His daughters are now 13 and 10, and both are bilaterally implanted. They are at the top of their respective grades in school. Marin has been a ballerina since she was three. She also plays piano, is in choir, and loves going to concerts. Nala is a music lover, too, excels at soccer, loves art, and enjoys cooking. Both girls love to read.

FOLLOWING HER DREAMS: Marin Zocca celebrates her acceptance into a prestigous dance program. She has been a ballerina since the age of three.

“The sky is the limit for them and they can be anything they want to be,” Zocca said. “For us as parents, it has been a long, tough road with many sacrifices along the way. It was absolutely worth it though, and we couldn’t have done it without our village.”•

To learn more, visit www.agbell.org *or contact us at 202-337-5220.*

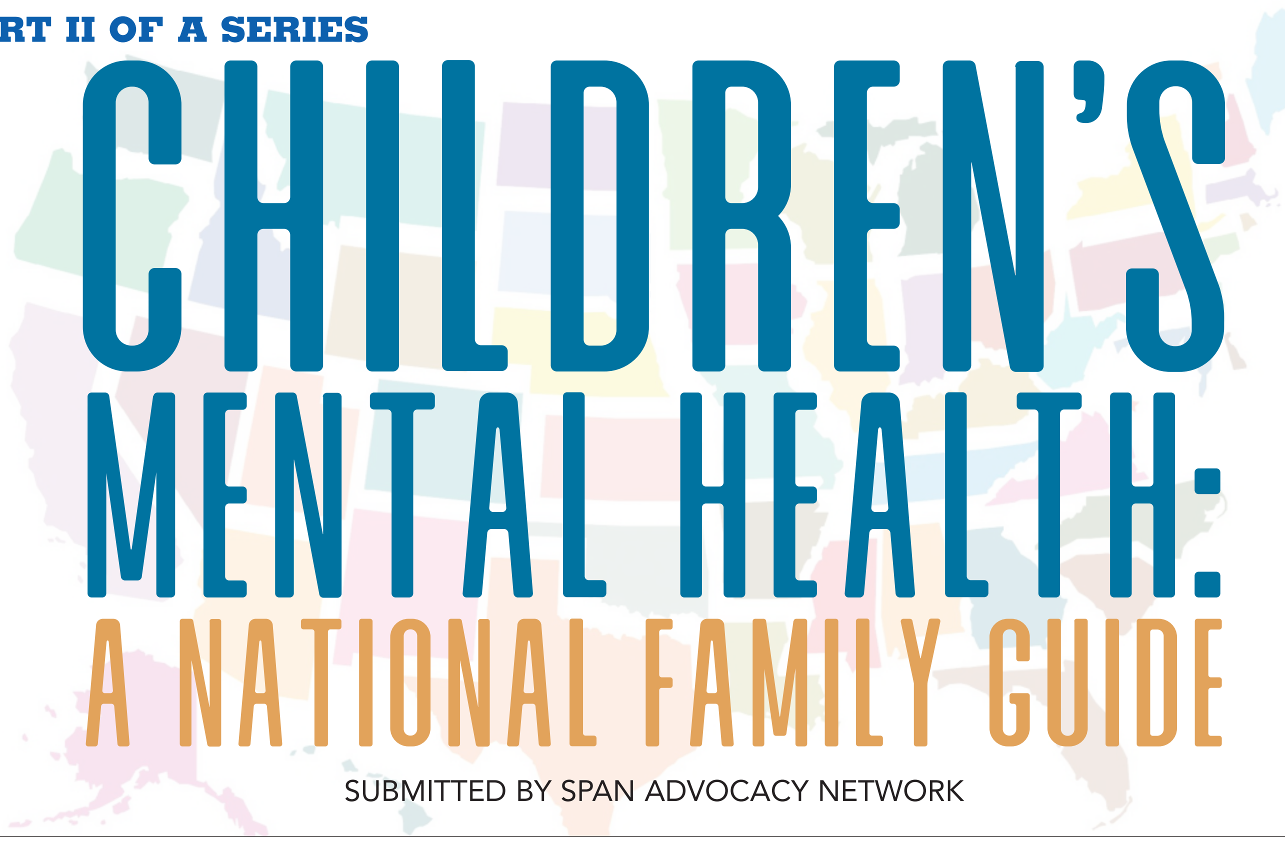
ABOUT THE AUTHORS:

Emilio Alonso-Mendoza, J.D., CFRE has served Chief Executive Officer of the Alexander Graham Bell Association for the Deaf and Hard of Hearing since April 2014, guiding the organization in international growth and innovation. Prior, he served in multiple President and CEO roles for Take Stock in Children; the Catholic Community Foundation; the Children’s Home Society of Florida, and the National Parkinson’s Foundation, where he established 52 centers for research through the US, Europe, South America, and Asia.

Lisa A. Goldstein has been a member of AG Bell since 1982. She was born profoundly deaf, diagnosed at 14 months, learned to lipread and speak, and now listens through a cochlear implant and digital hearing aid. Lisa has a master’s degree in journalism from UC Berkeley and works as a freelance journalist in Pittsburgh, where she lives with her husband and two children.

PHOTO PROVIDED BY NATICIA ZOCCA

PART II OF A SERIES



CHILDREN'S MENTAL HEALTH: A NATIONAL FAMILY GUIDE

SUBMITTED BY SPAN ADVOCACY NETWORK

Editors Note: *The SPAN Parent Advocacy Network has recently updated its* ***National Children's Mental Health Family Guide*** *and have provided it to EP Magazine for publication in a multi-part series. SPAN is here to support you in making the important decisions needed to ensure that your child with mental health challenges receives the services and supports needed for the best life possible. Connect with SPAN at 800-654-7726, online at* www.spanadvocacy.org*, on Facebook at* @parentadvocacynetwork*, and on Twitter at* @SPANadvocacy

WHAT PARENTS AND PROFESSIONALS NEED TO KNOW ABOUT MENTAL HEALTH

Access to care: Mental Health is just as important as physical health. The Affordable Care Act strengthened access to mental health services. One of the ten Essential Health Benefits is coverage for "mental health and substance use disorder services, including behavioral health treatment."

Increased access to behavioral health treatment may also make it easier to get coverage for autism. Although some states like NJ have an "autism and other developmental disabilities" mandate, it only applies to 25% of plans which are subject to state regulations. Federal mental health parity means that mental health treatment must be equal to that for physical health.

Avoiding Stigma: In dealing with mental health, families must try to avoid the stigma associated with mental illness. The National Alliance on Mental Illness (NAMI; www.nami.org) likens it to any other biologically-based illness except the organ affected just happens to be the brain, and the symptoms manifest as behavior. Just as no one would blame someone with diabetes who needed insulin, the same should be true for those who need treatment for mental illness. Although the recent displays of school violence have opened the dialogue on mental illness, research indicates that people with mental health issues are more like to be victims, rather than perpetrators, of violence. NAMI has programs that help parents and schools work together.

WHEN TO GET HELP

Sometimes families can be confused or even unnecessarily embarrassed about getting help. It may be difficult for parents to know what their child is thinking (e.g., sad, angry, lost interest, etc.) Sometimes families just have indications that something is wrong by how the child is acting. Clues can be:

- ✓ Frequent temper tantrums
- ✓ Crying more than usual
- ✓ Not doing things they enjoy
- ✓ Waking up at night
- ✓ Needing a routine or doing the same things over and over
- ✓ Overeating or extreme dieting
- ✓ Not being able to sit still or pay attention
- ✓ Doing poorly in school
- ✓ Drinking, smoking, drugs
- ✓ Not dealing well with loss (such as death in the family)
- ✓ Trauma (natural disaster, abuse, accident etc.)
- ✓ Any behavior that is harmful to themselves or others

If the thoughts, feelings, or behaviors are frequent, intense, long duration, or are having a negative impact on anyone, it's time to seek help.

Families should know that getting help is a sign of strength, not weakness. Parents are brave in recognizing that there is a problem and trying to fix it. Families also need to realize that they are not alone.

WHAT TO EXPECT

What to expect may be different depending on how the child gets involved with the mental health system. Usually, parents are able to find a professional when they have concerns. Some children, however, may have a crisis and end up in the hospital.

When families need to find help they can find mental health professionals using the organizations listed in this guide such as the National Alliance on Mental Illness, Federation of Families for Children's Mental Health, through other parents, or by asking their pediatrician or family practitioner.

Sometimes there is a waiting list to see a specialist. Families can ask to be called if there are any cancellations and can call weekly for updates.

Mental Health America (**www.mentalhealthamerica.net**) may give parents information on faster access.

The mental health provider will do an assessment of the child, including family history. They may use tests to screen for certain conditions. If the assessment shows the possibility of a disorder, the child may need a more detailed evaluation to reach a diagnosis.

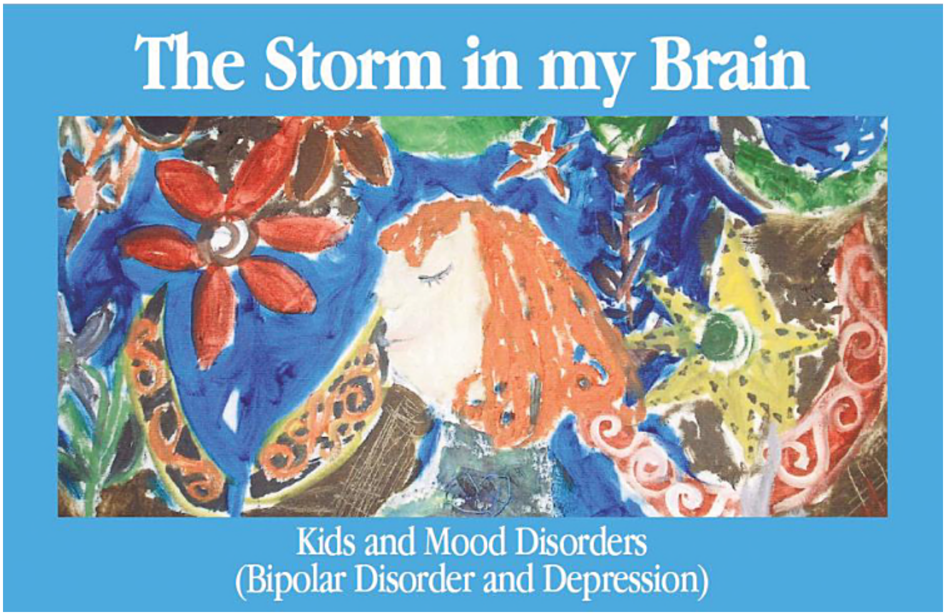
NAMI has a family guide on how to include mental health with care from your child's primary care doctor at **www.nami.org/Advocacy/Policy-Priorities/Improving-Health/Physical-Mental-Health-Integration**

THE DIAGNOSIS

Sometimes the "not knowing" is worse than actually having a name for the condition. Once parents know what's happening, they may not feel so helpless or hopeless.

Parent Center Hub has a helpful section on mental health at **www.parentcenterhub.org/repository/emotionaldisturbance** or Spanish **www.parentcenterhub.org/repository/emocional**. The Maternal/Child Health Knowledge Path for Families has information on both healthy social/emotional development at **www.mchlibrary.org/families/frb_Mental_Healthy.html** as well as mental health conditions at **www.mchlibrary.org/families/frb_Mental_Conditions.html**.

The child may start having questions and ask about his/her condition. Children may ask, "Why I am I different," or "Why is it so much harder for me to do things?" Sometimes children may just want to know what something is called. Other times they may want their parents to explain what it means. Families can start with children's books that explain certain conditions. Children need to understand that they are not "better or worse," simply different. They should also explain that a diagnosis doesn't define their life or their future. Physical or visible disabilities can be easier to explain and to understand for children (and even adults).


The Storm in my Brain

Kids and Mood Disorders
(Bipolar Disorder and Depression)

An excellent publication is "The Storm in My Brain" at **www.dbsalliance.org/pdfs/storm.pdf**. For older children there is a good publication "Accepting My Disability" at **http://www.going-to-college.org/myplace/disability.html** which discusses positive outlook, accommodations, self-advocacy etc. •

TIPS TO HELP YOUR CHILD MANAGE HOLIDAY STRESS

With the holiday season in full swing, you may notice your child exhibiting stress-related behaviors. Changes to routines can be difficult for children with special needs. With schools taking holiday breaks and scheduled days off, the holidays can cause major disruptions to their typical schedule!

BY ANDREA MORRIS, M.ED.

HOLIDAY MODE : PROVIDING STRUCTURE AND MANAGING STRESS

In addition to family gatherings, and unstructured days, some families have guests staying at their home or plan to travel to visit others' homes. If you're worried about how you can help your child manage stress through the holidays, here are a few tips to help you provide structure during this season!

1. PLAN WHAT YOU CAN

If you have a calendar of the activities, gatherings, and holiday travel your family has planned, start early and create simple schedules that you can share with your child.

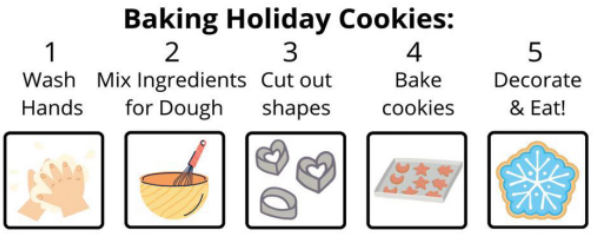
Use visuals or pictures on the schedule to represent different activities and locations. You could also make a countdown tracker and/or calendar for each of the big activities, and encourage your child to check off each day leading up to the event or update the countdown tracker.

Knowing about an event or gathering in advance can help reduce stress caused by surprise visits or activities during the holiday season. There may still be unplanned activities that arise, but preparing in advance as much as possible, can help ease your child's anxiety.

2. PREPARE MINI-SCHEDULES

Break holiday activities into more manageable tasks and routines. As you are preparing for an activity, such as baking holiday cookies, try breaking up the activity into smaller steps.

Use visual representations, pictures, or words (depending upon your child's preferred method of communication) to describe each step in the order in which it should be completed. We've included an example of a mini-schedule for reference!



Breaking down activities and tasks can make them seem more approachable for your child, and can help prevent them from getting overwhelmed. As you complete each step in the mini-schedule, encourage your child to check it off the list or, if you're using visuals with hook-and-loop adhesive, remove each visual as the step is completed.

Giving your child a way to interact directly with the schedule affords them a sense of control as well as providing them a concrete way to mark the passage of time, which can be an abstract concept for some children.

3. USE SOCIAL STORIES

Set expectations for what will happen during a particular holiday event or activity. A social story is a simple explanation of a social situation or activity and includes behavioral expectations and potential outcomes of the situation.

In the story, focus on the social cues your child should pay attention to and the order in which events or social interactions may occur. Read through the story with your child several times before the family gathering or activity, so they are prepared in advance.

The goal is to walk your child through a specific situation, explaining potential interactions they may experience, as well as possible outcomes, in an effort to reduce surprises that may be upsetting or disruptive.

3. PROVIDE STRUCTURED CHOICE OPTIONS

During the hustle and bustle of the holidays, your child may feel like they've lost the autonomy to make decisions within their environment. Giving your child options can help them feel as though they are more in control over their surroundings.

Offering structured choice options means that you, the parent or caregiver, provide your child with a limited number of options to choose from, within a given situation. For example, rather than asking your child, 'would you like a snack?' which could lead to any number of responses, try instead, 'would you like carrots or grapes for a snack?'.

By limiting the options, you can help steer your child towards appropriate behaviors or more positive choices, while giving them the power to choose their course of action.

This strategy can also be used as a way to divert challenging behaviors. During the holidays, many families will sit down to share a meal together. Some children do not enjoy the experience and would much rather play with their toys or watch a movie! Instead of telling your child, 'no, you may not play with your toys, you need to sit down with the family,' try instead to offer them structured choices.

For example, 'after you've finished eating, would you rather play with your toy cars or build a puzzle?'. Continue to offer structured choices throughout the meal ('would you like green beans or corn with your meal?') to keep their attention focused on making decisions, rather than on their desire to play instead of eat dinner.

RESOURCE LINKS

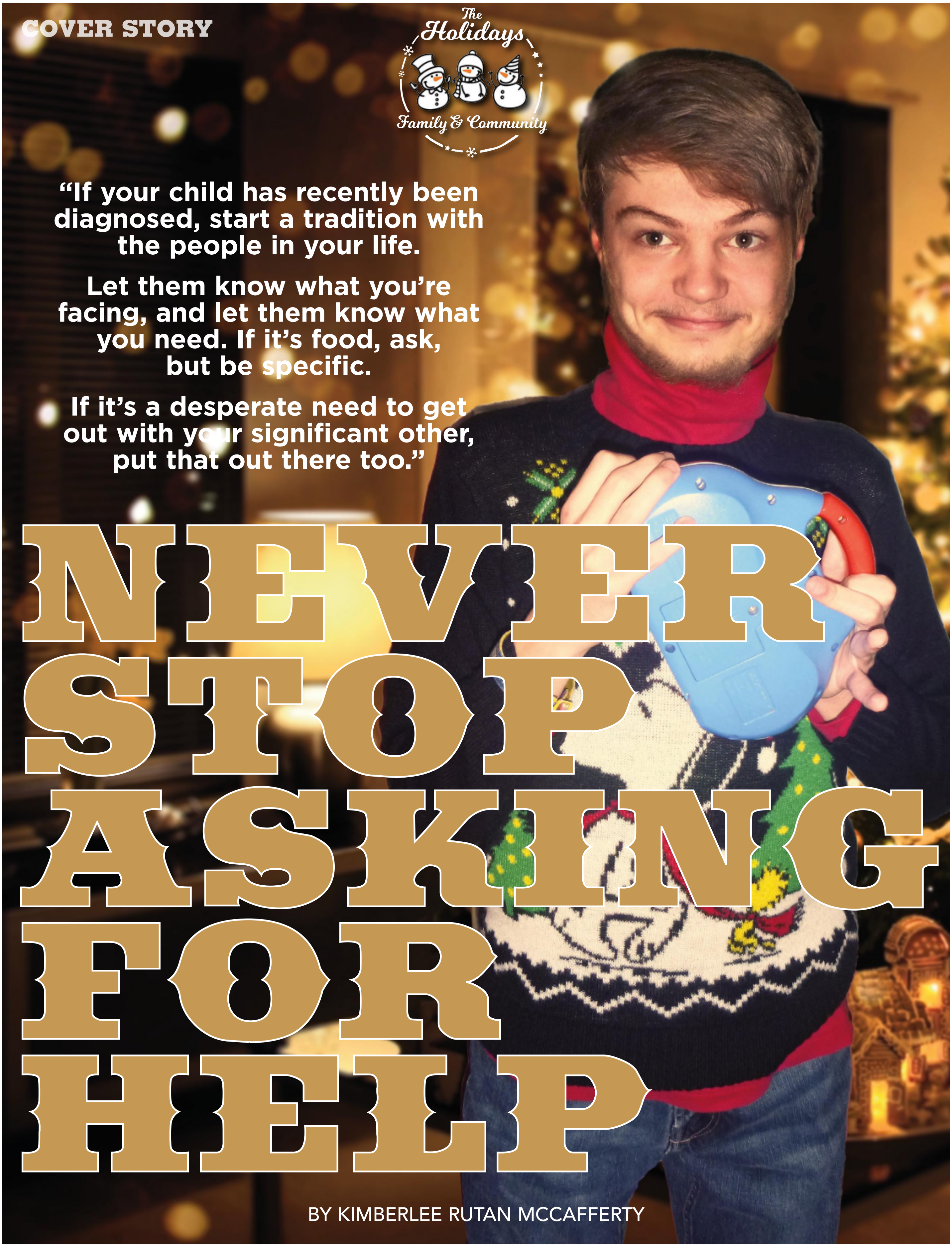
The Watson Institute helps children with special needs achieve their fullest potential in all aspects of their lives.

www.thewatsoninstitute.org/watson-life-resources/situation/strategies-family-gatherings-community-setting/

The holidays can be an overwhelming time for everyone, particularly for parents and caregivers. By taking some time to prepare before the holiday season begins, you can reduce your own stress, as well as that of your child! •

ABOUT THE AUTHOR:

Andrea Morris, M.Ed. has more than 30 years of experience in special education and works as an educational consultant for the Watson Institute. She has a Masters of Education and M/PH Certification to work with students with mental or physical disabilities from the University of Pittsburgh. In her current role, Andrea provides training and consultation to educational teams serving students with disabilities in a variety of educational settings. Her areas of expertise include: autism and related disorders, inclusive practices, positive behavior support, naturalistic and structured teaching strategies. Prior to her work at Watson, Andee was an Early Childhood Consultant for the Early Learning Institute, Developmental Specialist for LEAP Preschool and a Head Teacher for North Area Preschool. She has authored several journal articles and is a skilled presenter.



> "If your child has recently been diagnosed, start a tradition with the people in your life.
>
> Let them know what you're facing, and let them know what you need. If it's food, ask, but be specific.
>
> If it's a desperate need to get out with your significant other, put that out there too."

NEVER STOP ASKING FOR HELP

BY KIMBERLEE RUTAN MCCAFFERTY

**When I wrote this article,
it had been six weeks since my fifteen-year-old son
broke his hip at school in PE class,
and the dust was just beginning to settle.**

**The day before in physical therapy,
we were rewarded by watching his first tentative steps, and I have to
say it was as thrilling as the first time around.**

Looking for the bright side here.

Zach has been absolutely amazing with all the challenges he's had to face: from managing pain to managing a flight of stairs. His freshman year finally concluded, and except for his sophomore year summer work, he was able rest and relax. He earned it. I'm happy to say our family is in a much better place than we were.

We couldn't have done it without the support of his teachers, his guidance counselor, family and friends.

Zach's accident has pretty much thrown me back to the days when both kids were toddlers, in that his father and I were not comfortable leaving him alone until he could walk unassisted, which wasn't for a few months. It's weird negotiating with my husband about when I can run errands, or on a rare occasion get out to see a friend. Although, we can never leave Justin alone, we've been spoiled for years with Zach's independence, and it's jarring to see that taken away. I don't take much for granted in this world, but I appreciate what he had and what he'll got back to, even more than I did months ago.

> “COLLECT A POSSE OF PEOPLE, ALL WHO WILL HAVE DIFFERENT STRENGTHS AND ARE ABLE TO HELP YOU IN DIFFERENT WAYS. START EARLY!”

Spending an enormous amount of time at home has given me the opportunity to think, both about the ramifications of his accident, and the aftermath. We had a huge outpouring of support from multiple places, so much so, that it was hard to keep track of everyone. I took a lot of people up on their offers and they came through – from food and wine (!) and medical equipment, to “babysitting” Zach so Jeff and I could take Justin, our severely autistic nineteen-year-old, to Great Adventure. It was wonderful to weather this crisis with so much support.

And it made me realize, through so many other crises in the past eighteen years since Justin's diagnosis, how I should have asked for similar support.

There have been so many different problems, both large and small since the day Justin's pediatrician shoved a handful of badly printed articles with the word “autism” in the title, into my shaking hands. There have been: periods of sleep deprivation we thought would never end, food refusals, a few attempts at elopement, figuring out how to pay for services without insurance coverage, issues with transportation and schools, aggression, finding friends, Justin's tic disorder coming to call a few short years ago, and the loss of his words and personality.

The list can go on and on, but I don't want to get too dramatic here.

EVERY LITTLE BIT: *(Opposite page)* Justin gets ready for the holidays; “Zach's accident and its aftermath made me realize, through so many other crises in the past eighteen years since Justin's diagnosis, how I should have asked for similar support.”

The truth is, we could have used this level of support throughout all of these incidents, but honestly, we were just trying to make it through the day, and often I didn't have the energy to reach out. It's difficult to explain to people not raising a disabled child, that your fear that what you're dealing with may last forever, is sadly very real.

Still, I should have reached out more.

I've always found the difficult times with our son to be cyclical. I've often felt that autism is like playing Whac-A-Mole – you conquer something and eventually something else crops up. As each problem presents itself, don't be shy about talking about it and asking for what you need. When my youngest broke his hip there was such an outpouring of support, in part, because people could relate to this accident- it could happen to them or someone they love. So many of the things that autism families live through are foreign to neurotypical families.

So, my advice is, if your child has recently been diagnosed, start a tradition with the people in your life. Let them know what you're facing, and let them know what you need. If it's food, ask, but be specific. If it's a desperate need to get out with your significant other, put that out there too. If you need help taking your child to the doctor, find that person. Collect, if you can, a posse of people, all who will have different strengths and are able to help you in different ways. Start early!

People need to know what you're all going through, and they need to know specifically how to help. I have truly found that people want to help, they just might not know how.

Ask.

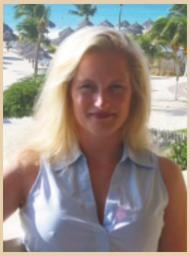
And ask again.

Create assistance traditions. The worst someone can say is no.

Find your people.

And never stop reaching out when you've found them.•

ABOUT THE AUTHOR:



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

The Holidays
Family & Community

TIPS FOR SHOPPING FOR KIDS WITH SPECIAL NEEDS

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

When it comes to holiday shopping, friends and family members of children with developmental disabilities have a lot more to consider besides whether a given toy or activity is trending on TikTok.As with typical children, thoughtfully-selected activities can be a great way to facilitate social engagement with children who have special needs, and also enhance a variety of cognitive and motor skills.

> **“IN MY EXPERIENCE, NO ONE KNOWS A CHILD BETTER THAN HIS OR HER PARENTS AND OFTEN TEACHERS AND THERAPISTS, SO DON’T HESITATE TO ASK THEM WHAT’S APPROPRIATE AND WHAT THE CHILD MIGHT TRULY ENJOY.”**

GOOD SENSE: In general, it’s good to look for toys that engage a child’s senses, such as touch, sound and sight. The child’s parents are the best source for identifying sensitivities and sensory preferences that can affect your gift selections.

HERE ARE SOME QUICK TIPS TO HELP YOU SELECT A TOY OR ACTIVITY FOR EACH CHILD ON YOUR HOLIDAY SHOPPING LIST.

CONSIDER DEVELOPMENTAL AGE, NOT CHRONOLOGICAL AGE

Many children with special needs have a cognitive disability, so the age range listed on a particular toy may not be suitable for them. A parent or other caregiver will know the child’s developmental age. However, remember that while some toddler-age toys may be developmentally-appropriate, they could present a barrier to social interaction for older children. For example, a typical teen may be less inclined to engage with a teen who has special needs, if they’re playing with what they’d consider a toddler-age toy.

CONSIDER SENSORY PREFERENCES

In general, it’s good to look for toys that engage a child’s senses, such as touch, sound and sight. But remember that loud sounds and bright or flashing lights that delight one child, can be distressing for another. Similarly, certain textures and scents can be comforting to some children, but unpleasant to others. The child’s parents are the best source for identifying sensitivities and sensory preferences that can affect your gift selections.

TAKE INTO ACCOUNT PHYSICAL CHALLENGES

Like typical children, those with special needs can benefit from toys that encourage them to use their fingers and hands in ways that build fine motor control, while encouraging creativity and imagination. This can include building blocks, such as wooden blocks and snap-together sets, as well as arts and crafts. Even simple musical instruments like kazoos, drums or xylophones can be both fun and enriching, while toys such as rocking bowls can help a child develop better balance. For a child who uses a wheelchair, consider whether the toy will be accessible from the chair or if it will require assistance.

LOOK FOR DURABILITY

Like typical children, those with developmental disabilities, require repetition to master new skills which, in turn, encourages them to try new and different things. So, look for well-made, quality items that will last and can handle heavy use, since children with special needs may keep and enjoy playing with a given toy much longer than their typical peers.

BUILD SOCIAL SKILLS

While independent play is important, many children with developmental disabilities, especially autism, struggle to develop social relationships. Activities that promote social interaction, such as board and card games, can help children engage with others and practice communication skills, sharing, problem solving and understanding others’ feelings. Of course, remember to verify that the game does not have any very small parts that could pose a choking or other safety hazard.

CONSULT THE CHILD’S THERAPIST

Many toys and games can foster important physical, cognitive, social and behavioral/emotional development. The therapists working with the child can be a great resource for toys and gift ideas that use play to nurture developmental progress and reinforce lessons and skills learned in therapy sessions.

SAFETY FIRST

Children with developmental disabilities can be at greater risk for injury, so standard advice about toy safety – such as avoiding high-powered magnets, tiny batteries and other small parts -- may not be sufficient. When in doubt, opt for the safer choice.

Of course, these tips and suggestions are just a start. Since no two children are exactly alike, the key is to individualize your gift choices. In my experience, no one knows a child better than his or her parents and often teachers and therapists, so don’t hesitate to ask them what’s appropriate and what the child might truly enjoy. Not only will most parents welcome questions about prospective gifts, they’ll appreciate your thoughtfulness in wanting to select activities that will support their child’s development and bring happiness and enjoyment.•

ABOUT THE AUTHOR:

A clinical psychologist, Bonnie Ivers, M.A., Psy.D., is Clinical Director for Regional Center of Orange County, the private, nonprofit organization contracted by the State of California to coordinate lifelong services and supports for more than 23,000 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**

PHOTO PROVIDED BY HILLARY SUSSMAN

PHYSICAL THERAPY SAFETY TIP SERIES • PART ONE

SAFETY FOR THE ELDERLY POPULATION DURING THE HOLIDAYS AND THROUGHOUT THE YEAR

BY HILLARY SUSSMAN, MSPT

If you are planning on having your parents or grandparents for the upcoming holidays, it would be helpful to review some of these tips to create a safe environment for their visit.

This article will share a few simple, yet important home safety tips, which can help with fall prevention and overall safety for an elderly person living alone, or with family or visiting family. As many of us get older, and our parents age as well, we are suddenly faced with caring for an elderly grandparent, or parent, and our roles seem reversed. For many people, this new responsibility can feel extremely overwhelming and scary to navigate.

The articles will be providing simple, clear, and helpful tips that can be applied to anyone who is a caregiver or beginning the process of caring for an elderly family member. To start from the beginning, this article focuses on general home safety. This article will allow you to see things from a different perspective, and hopefully encourage you to take a step back; and gain a new perspective, in order to improve the overall safety of your family member's surroundings, utilizing some new and helpful tips. •

YOUNG AT HEART: *(Opposite page)* The author working with with senior patient Geneva Young; "Geneva was a beautiful soul – she was a dancing queen, and had a spirit unlike anyone I have ever treated. She is truly missed by all those who were lucky enough to know her."

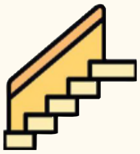
SAFE AT HOME : SIMPLE TIPS FOR GENERAL HOME SAFETY

Simple, yet important, home safety concepts can help with fall prevention and overall safety for an elderly person living alone or with family, or an elderly person visiting family.

ENTERING THE HOUSE

☐ Are there steps?
☐ Are they even, uneven?
☐ Is there a railing to hold for support when entering the home?
☐ Is the railing intact?
☐ Are there any obvious safety concerns entering the home?
☐ Is there a ramp?

Take notes as you enter and write down any safety concerns. Entering and exiting home is a big issue for going to doctor appointments, visiting family and overall emergency preparedness.



INSIDE STEPS

Upon entering the home, one of the first things to do is see if there are steps.

☐ If there are steps, is there a railing?
☐ Is there clutter on the steps?
☐ Are the steps all even?
☐ Is there carpet on the steps?

All of these make a difference in home safety, and it is important to understand how the client navigates steps to avoid falls.

BATHROOM

Next, it is important to see all of the bathrooms and understand how they are utilized by the client.

☐ Is there a powder room on the first floor?
☐ Is the toilet too low?
☐ Are there grab bars?
☐ Are there rugs that move around which could increase slipping and falling?
☐ Where does the family member spend most of his/her day?
☐ Are they struggling with using the bathroom?

Bathroom safety is extremely important, and a very common area for falls. There are many simple, affordable, yet effective ways to improve the safety of your bathrooms; thus reducing fall risk.

EQUIPMENT

☐ Does the family member use a cane, walker?
☐ Do they need a cane or walker?
☐ Is there a shower chair? Or stool?
☐ Do they need a commode either bedside or over the toilet?
☐ Is a stair glide something that could be helpful?
☐ Think about recliner options, if family member has difficulty getting in and out of chairs

Ordering equipment can often feel overwhelming, with so many options out there. In subsequent articles, there will be more information on durable medical equipment and simple, affordable, yet effective ways to improve the safety of your home.

CHAIRS

It is important to look at all of the chairs in the home, especially the ones utilized by your loved one.

☐ Where does your loved one spend his her time?
☐ Do they spend a significant amount of time In a recliner? Is it electric?
☐ Are there arm rests on the chairs where he/she eats?

Aside from providing a comfortable place to rest, chairs with armrests are KEY for safe transfers and important for improving safety and reducing falls.

SAFE AT HOME : SIMPLE TIPS FOR GENERAL HOME SAFETY cont.

ROUTINE

What is your loved one's routine? This is always an important discussion with family.

- ☐ Do they stay upstairs all day?
- ☐ Do they sleep on the first floor in a recliner?
- ☐ Do they struggle with getting dressed and bathed?
- ☐ What do meals look like?
- ☐ How often are they left alone?

Establishing a safe and consistent routine is key for improving safety and making sure your loved one has the help and support he/she needs.

GENERAL HOME SAFETY

Lastly, this article will touch upon a few basic things to observe when entering a home for the first time. Future articles will elaborate on many of these topics, but these are important things to evealuate in order to ensure a safe environment.

- ☐ **Cords:** Are there any exposed cords that could pose a fall risk? Tape them down or move them out of sight.
- ☐ **Lighting:** Does your loved one have proper lighting, especially in the bathroom, if they get up in the middle of the night to use the bathroom
- ☐ **Footwear:** Wearing non-slip, supportive footwear can play a big role in reducing falls; wearing slippers and slip ons can often increase fall risk.
- ☐ **Phone Numbers:** Does your loved one have all of the important phone numbers? Emergency contacts should be written in large, clear print and placed in an easily accessible area.
- ☐ **Rugs:** One of the MOST common safety hazards are throw rugs and bathmats. If the rugs in the home are not adequately held down, then they can pose a serious fall risk.
- ☐ **Vision:** Visual impairment can create a fall risk with the elderly population. It is important to visit this topic in regard to medication management, lighting, and creating a clear pathway for movement in the home. •

ABOUT THE AUTHOR:

Hillary Sussman has been a physical therapist for 24 years, working closely with her clients and their families as they navigated life with physical and cognitive challenges. She is the author of the *Adventures of Roxy* Book Series. Her physical therapy background has primarily been in the home care setting; working with the geriatric population. She works part time in an assisted living facility, where she enjoys working with her clients, their families, and staff, to improve her clients' mobility and quality of life. When her dog Roxy underwent her fourth surgery and faced losing a leg, she was inspired to write a book series about a three-legged dog to help kids who are different, live life with confidence, and not allow any limitations to hold them back. She hopes that the *Adventures of Roxy* book series can help all kids learn important life lessons about inclusion, kindness, empathy, acceptance, and the impact that words have on others. Hillary is a mother of three and lives in Pennsylvania. Learn more at **www.adventuresofroxy.com**

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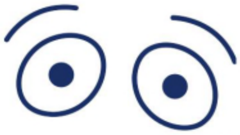

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The Holidays
Family & Community

TEACHER COMMUNICATION WITH PARENTS DURING VACATIONS AND THROUGHOUT THE YEAR

BY JENN ADAMS

Most educators believe that communication with families is important. I think it's safe to say that most parents also appreciate the communication between school and home.

Communication between home and school is especially important when students are struggling academically, socially, behaviorally or emotionally. Communication with families is very important when it comes to special needs learners. Parents need to understand what's happening at school so that they can continue with the learning at home, but many times our students cannot share about their day through typical means of communication, so we must find another way.

However, sometimes it feels like the lines of communication are jammed. Teachers use lingo that parents don't understand. Parents are busy and don't have time to read all the notices. So how can we increase communication with families between home and school? I've been contemplating this question for a while, so here are some of my thoughts.

DO YOU READ ME? : IMPROVING COMMUNICATION WITH FAMILIES BETWEEN HOME AND SCHOOL

Communication between home and school is especially important when students are struggling academically, socially, behaviorally or emotionally. Parents need to understand what's happening at school so that they can continue with the learning at home, so how can we impove the lines of communication with families between home and school? Here are my thoughts.

REACH OUT FIRST

I'm a big believer that it's the teacher's responsibility to initiate a relationship. So, at the beginning of the school year, take time to call each parent and introduce yourself as their child's teacher. The conversation doesn't have to be long, but it's a way to show the parents that you truly care about their child. It's also a great way for parents to tell you anything important about their child that you should know in the first days of school, such as carpool information, allergies, or learning needs. Teachers can even prepare a script for the conversation to help lessen anxiety about calling.

Additionally, when you reach out, you can ask what types of communication in the future work for them, such as phone calls or emails. You can also check with them on what times of the day and what days of the week work best . This then gives you the opportunity to try and make contact when the families are most available.

KEEP COMMUNICATION WITH FAMILIES POSITIVE

Over the first few weeks of school, try to keep an eye out for positive behaviors you see in the classroom. When you notice a child doing something positive, affirm the child, but also send home a note to let the parents know about the positive thing their child did. You don't have to have some fancy form, you can simply write it on a sticky note or in an email. So often communication ends up being about the inappropriate choices students make. How amazing would it be if the first feedback parents received was positive? Then continue that throughout the year to show both students and families that you notice the positive things their child is doing too.

KEEP COMMUNICATION WITH FAMILIES SIMPLE

It's easy to fall into the trap that more words are better. But sometimes, less is more. It's also easy to add in teacher jargon that won't make sense to parents. So, when you're writing your notes, newsletters, and emails, try to put them in user-friendly language. Each teacher has a different communication style. Here are some of the ways I've seen teachers communicate with families:

- Class Dojo: a website that allows teachers and parents to communicate and share, not just notes, but photos and videos about a student's day. www.classdojo.com
- Blogs: Teachers can create a private blog that is only available to the families in their class, and that shares updates and information about what is happening in school. Also, providing students with a shout-out in the blog is a great positive motivator!
- Emails: Send an email to families on a regular basis. Many email providers also have a feature that you can schedule your emails ahead, using a template that takes less time but still allows for some personalized information about each student.
- Monthly Newsletters: Although in paper form to send home with students, just like the blogs, this provides information to parents about what is going on in the classroom.
- Daily Behavior Logs: These are individualized for students that specifically may need more support with behavior. There are many types of logs you can use, some with pictures, rating scales, and checklists. Often these are specific plans to be done with teachers and families, when a student has behaviors of concern, and more information needs to be shared on a regular basis. www.teacherspayteachers.com/Product/School-Home-Communication-Logs--8229193

You should pick the communication style that works for you. Some educators love using online portfolios and other teachers prefer giving out paper newsletters. Some prefer to email, others prefer to have a blog. I think everyone has opinions about which is better, but at the end of the day, you have to pick what works for you and the families. Pick something you'll be able to stick with.

GIVE CLEAR EXPLANATIONS TO PARENTS

Whichever method of communication you pick, make sure you communicate clearly with parents. If you tell parents you're going to be communicating monthly, then you need to follow through on this. If you tell parents, you're going to post something on their child's portfolio weekly, then make sure this is what you are doing. Parents deserve to have consistency from their child's teachers. Of course, there are extenuating circumstances, but to the best of our abilities, we need to be consistent.

Along with this, we need to give clear expectations of what we need from parents. If you want parents to verbally chat with you, let them know. If you want parents to email their questions, let them know. I like to give a "Welcome to School" newsletter at the beginning of the year. In this newsletter, I include the ways that parents can communicate with me. This helps to lay it out clearly for everyone.

COMMUNICATE SUPPORTS FOR BREAKS DURING THE YEAR

During times of the year when there are breaks in school, like during winter break and summer break, communication before those breaks start, can be vital. Students' routines are thrown off by special events like holidays, events and parties, and parents may look to us for ideas and support. I find that giving families a cheat sheet of what has worked well for us in the classroom can be very helpful during these extended breaks from school. I do this by typing up a quick and short list of strategies that we use in the classroom, that can be applied when they are at home.

One thing I often encourage families to do during our extended breaks is create a schedule for students so they know what to expect. This can be a visual schedule or a written checklist, showing things that will be happening and especially noting changes. I also give families a list of items that the student seems to enjoy using in the classroom. I have had families use these as items for presents during holidays or birthdays. They are often things like: sensory toys, fidgets, or items students like to earn, by completing tasks. Lastly, I like to share with families some phrases that we use in the classroom when giving instructions to students, so they are consistent in the home, as well. Statements like, "First clean up, then have a snack."

GRACE, UPON GRACE, UPON GRACE

No one is perfect. Teachers aren't perfect. Parents aren't perfect. Along the way, someone is going to mess up. Make sure to give yourself grace when miscommunication happens. Apologize, clarify and move on. We so often put pressure on ourselves to be perfect teachers. We forget that we're human and humans make mistakes from time to time. So, grace needs to become a part of our everyday communication style.

Increasing communication between school and home is going to take effort and time. But the effort will be well worth it in the end, when you have open lines with a family and can work together to help that student be successful! •

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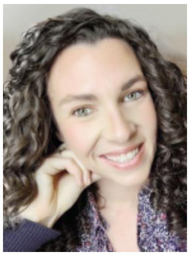

Jenn Adams is a special education and elementary teacher living and work in Pennsylvania. She has taught in multiple classrooms, grade levels and settings including regular education, special education, and alternative education. She has taught grades Pre-K, 1st, and 5th-12.Currently, Jenn works for a public cyber charter school teaching students in grades 5th through 8th in an autistic support virtual classroom. Jenn obtained her Bachelor's degree in elementary and early childhood education in 2007 from Millersville University. She also obtained her Master's degree in 2014 in special education from Saint Joseph's University. Jenn also added the credentials of becoming a registered behavior technician (RBt) working closely with students with autism and intellectual disabilities working with principles of Applied Behavior Analysis. Lastly, Jenn is currently pursuing her principal's certificate from California University of PA. In her 14 years in education she truly has found that building relationships is what needs to come first and loves learning new ways to reach her students. During her time not spent in the classroom Jenn conducts parent training with colleagues in the special education field and provides information through her blog, website, and social media channels all called Teach Love Autism. Jenn also works hard every day to find a work and life balance and believes that is the key to happiness in doing what you love.

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USING A CHILD'S SELF-STATEMENT TO SUPPORT INCLUSION

BY JEAN BUDD, LPC, NCC, IMH E® AND CORINNE G. CATALANO, PH.D., IMH E®

In 2002 and again in March 2022, *Exceptional Parent Magazine* published the article, *A Child's Self-statement: Who Am I?* (https://reader.mediawiremobile.com/epmagazine/issues/207743/viewer?page=24) In the article, the authors explained how they wrote a profile from a child's perspective, to communicate information regarding that child, and promote a deeper understanding of that child by other people in that child's life. A template was provided to guide parents/caregivers, educators, and therapists to work together as a team to write the child's profile. In this article, we use a case example of how the process of writing a child's self-statement profile was used by a team as part of a system of support, to foster a positive emotional connection between a preschooler and his early childhood teacher. The goal was to invite the parent to become part of the team and to build the teacher's sense of competence in working with this child so that the child could remain included in the general education classroom.

CREATING A SYSTEM OF SUPPORT

Early Relational Health is the state of emotional well-being that grows from the positive emotional connection between young children and their parents/caregivers when they experience strong, positive, and nurturing relationships with each other. This emotional well-being is foundational, not only to children's healthy growth and development, but also to their parents'/caregivers' sense of competence, connection, and overall well-being (Center for the Study of Social Policy, 2022). For some children and their families, achieving a state of emotional well-being is very difficult due to stress from both within and outside their bodies and homes.

One way to help children and families is for consultation to be provided by professionals with formal preparation in children's mental health and experience specifically working with young children and their families. This type of consultation, known as Infant and Early Childhood Mental Health Consultation (IECMHC), builds capacity for systems, as well as individuals, to understand the powerful influence of parents', caregivers' and educators' relationships and interactions on young children's development (Center of Excellence for IECMHC, 2020). The Montclair State University Center for Autism and Early Childhood Mental Health provides this type of consultation for childcare centers throughout New Jersey. One tool used by these consultants, is a profile written about a child by the people in the child's life who know the child best. This involves creating a collaborative team that includes the child's parent(s) or caregivers, the child's teacher in the childcare classroom, and in some cases, any therapists who might be working with a child who is receiving these services. The IECMH consultant facilitates the process with the goal of helping everyone to have a shared understanding of the child's strengths, challenges, and needs.

WRITING A CHILD'S PROFILE TO PREVENT EXPULSION

Directors and owners of childcare facilities request IECMH consultation support for their teaching staff when there is a child who is exhibiting behaviors that are challenging to the adults. These behaviors typically make it difficult for the child to participate in the daily routines of the class. For example, one consultant received this request for support:

> *The director at a private childcare center requests support for a 4 and a half-year-old child who consistently flees large group activities and aggressively harms any child who approaches him during his free play. The child is protective of his play designs, such as Lego structures, and artwork. He growls at peers who approach him, and if they do not retreat, he physically pushes them from his space. The teacher does not know how to help this child, and the director is considering letting the parents know that they can no longer care for this child in their center.*

Unfortunately, this scenario is all too common as is the stress parents experience when they cannot find childcare for their child so that they can work. While the term "expelled" is not often used, telling a family that a child needs to be removed from a childcare center is early childhood expulsion. Preschool expulsions and suspensions cause young children to lose their early educational placement or time in care, directly undermining their access to educational opportunities (Gilliam, 2005; Gilliam et al., 2016).

With the goal of emotional well-being for the child, his teacher, and his parents in mind, the IECMH consultant assigned to this case, chose to begin her relationship with the adults in this child's life by using what has come to be known as a **Hello My Name Is** profile. She knew that sharing a list of questions about the child with the team, and writing this profile from the child's viewpoint, using the child's voice, was an effective strategy to promote parents'/caregivers' and teachers' sense of competence, connection, and overall well-being.

WRITING A PROFILE : SAMPLE OF QUESTIONS TO ASK UNDER EACH DEVELOPMENTAL DOMAIN

Close interactions and observations are key in writing the self-statement or profile. Here is a sample of important questions to ask under each developmental domain in order to write a helpful profile.

EXPRESSIVE AND RECEPTIVE COMMUNICATION

1. Do I communicate with others and how? (i.e., gestures, words, phrases, augmentative systems)
2. Is it difficult for me to understand things people tell me to do or questions they ask me?
3. What helps me to understand? (i.e., visual cues, fewer words, time to process what they said)
4. How do I feel when I can't communicate my needs and ideas? (i.e., angry, frustrated)
5. What do I do when I can't communicate? (i.e., scream, hit, withdraw)

COGNITION

1. Can I look for something I was playing with after it goes out of sight?
2. Can I represent my feelings and ideas with my words and gestures or through my play?
3. Can I use past experiences to solve my problem, (i.e., drag a chair over to reach something out of reach)

SENSORY INTEGRATION AND MOTOR PLANNING

1. How does my body feel most of the time? (i.e., floppy and tired, overexcited and uncomfortable)
2. What helps my body calm down or wake up so I can tune into the world and other people? (i.e., burying myself in pillows or beanbags, jumping, marching, swinging, running)
3. Do I know where my body is in space? If not, what kinds of things do I do to help me understand where my body is? (i.e., lay on the floor so that I can feel each part of my body, sit in a chair with arms so I can feel where I am)
4. Can I organize and feel the stimuli that come at me through my different senses? Do I get overwhelmed because I can't shut out unimportant stimuli? Do I close my eyes or cover my ears so that I only have to pay attention to one type of stimulus? (i.e., auditory or visual)
5. Do I have ideas about what I want to do? (i.e., build with blocks, climb the ladder, play with toy cars) Do I know how to start? Do I know what steps come next?

RELATIONSHIPS

1. Do I recognize and/or smile when I see certain favorite people?
2. Do I have ideas and memories about fun things I did with certain people? (i.e., when I see Daddy, do I put myself near him and say "up" so we can play the same game we played last night?)
3. Can I calm myself down when I get upset or do I need help from someone else? (i.e., someone talking slowly and softly or rocking me)

GROSS AND FINE MOTOR SKILLS

1. Can I independently move around my environment to explore things?
2. Do I have the upper body strength to support myself in a seated position?
3. Can I use two hands to explore materials and play with toys?

SURFACE BEHAVIORS

1. What do I do when I am left alone? (i.e., run back and forth, watch familiar videos, play with toys)
2. What do I do with other people? (i.e., move away so they won't interfere with my play, hand them familiar objects)
3. What do I do if someone gives me something new and different? (i.e., throw it, explore it with my mouth and hands, bang it)

TAKING TIME TO LISTEN

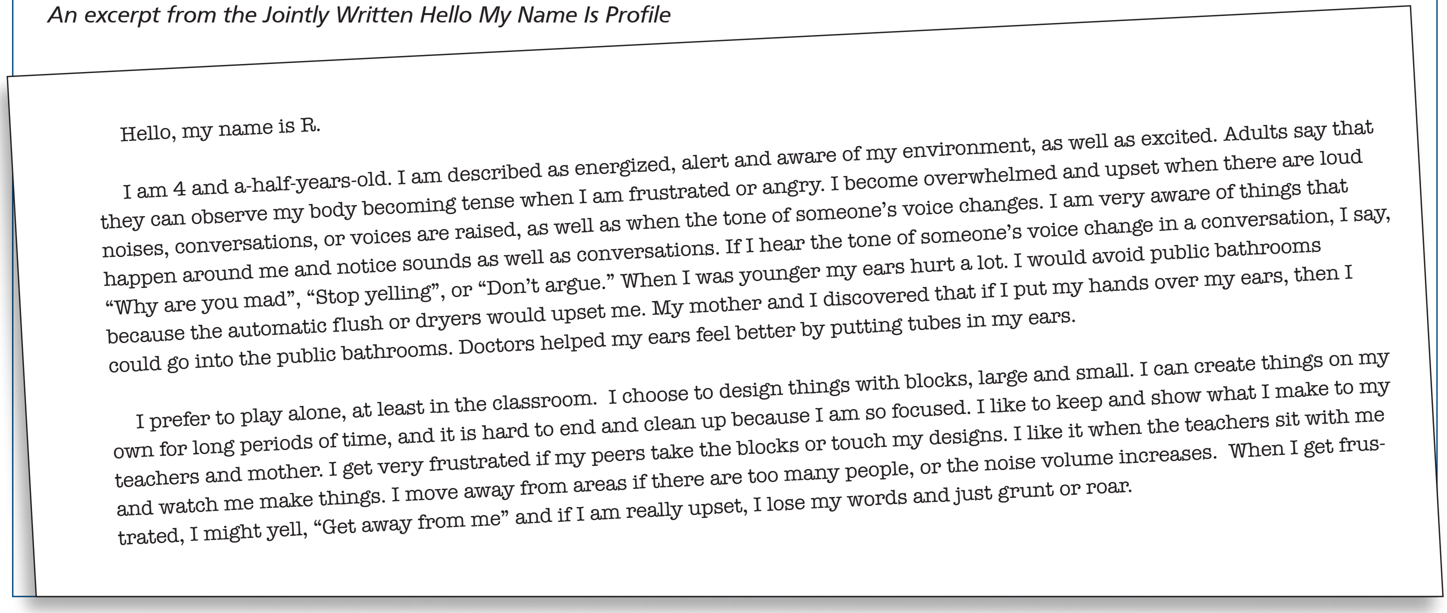
The IECMH consultant met with the director and the child's teacher to listen and learn more about the challenges they were facing with this child in the classroom. The teacher explained that the child's flight from large group activities typically occurred when there was movement in the close carpet space and when the voices of all the other children were loud. The consultant then asked to meet separately with the child's mother.

The consultant invited the mother to tell her about the child, guided by the questions in the template. The mother shared that her son has always been sensitive to loud noises, especially loud voices. He had many ear infections and ended up getting tubes put in his ears. Early in the child's life, and actually even before he was born, the mother was in a combative relationship with her son's father. Arguments were loud and frightening. The mother was aware that at home, her son did not like the loud sounds of appliances or loud music. She learned that in order to make her son more comfortable, it helped to cover his ears and to keep their home environment extremely quiet. She also shared that he liked long periods of uninterrupted time to create structures and artwork.

With the mother's permission, the consultant helped her to share her child's medical history, as well as the family story with the director and teacher. This led to intense moments of awareness as well as empathy. The consultant, mother, director, and teacher worked together to continue to write a profile from the child's perspective.

HELLO MY NAME IS R : A UNIQUE PROFILE FROM THE CHILD'S PERSPECTIVE

An excerpt from the Jointly Written Hello My Name Is Profile



Hello, my name is R.

I am 4 and a-half-years-old. I am described as energized, alert and aware of my environment, as well as excited. Adults say that they can observe my body becoming tense when I am frustrated or angry. I become overwhelmed and upset when there are loud noises, conversations, or voices are raised, as well as when the tone of someone's voice changes. I am very aware of things that happen around me and notice sounds as well as conversations. If I hear the tone of someone's voice change in a conversation, I say, "Why are you mad", "Stop yelling", or "Don't argue." When I was younger my ears hurt a lot. I would avoid public bathrooms because the automatic flush or dryers would upset me. My mother and I discovered that if I put my hands over my ears, then I could go into the public bathrooms. Doctors helped my ears feel better by putting tubes in my ears.

I prefer to play alone, at least in the classroom. I choose to design things with blocks, large and small. I can create things on my own for long periods of time, and it is hard to end and clean up because I am so focused. I like to keep and show what I make to my teachers and mother. I get very frustrated if my peers take the blocks or touch my designs. I like it when the teachers sit with me and watch me make things. I move away from areas if there are too many people, or the noise volume increases. When I get frustrated, I might yell, "Get away from me" and if I am really upset, I lose my words and just grunt or roar.

IDENTIFYING SUPPORTS AND SERVICES THAT WORK BEST

As a result of this collaboration, the teacher worked with the consultant to create protected space for the child in the classroom and modeled ways that the child could invite a peer to play with him. The teacher also learned from spending time with the mother, how to loan her calmness to the child or co-regulate him when he began to get upset. Over the next few months, the number of times the child fled group activities or became aggressive became less and less.

The director reversed her request to have the child leave the center, and worked with the mother to follow the necessary steps to get her son support, when it was time for him to transition to the public school.

In this example, as in many others where teams worked together to develop a **Hello My Name Is** profile, the caring adults in a child's life transform *their* behaviors of labelling a child as challenging and demanding expulsion to empathizing with a child and family, jointly problem solving and forming partnerships between families and educators. IECMH consultants know that change does not occur by just focusing on what is wrong with a child but by creating a shared vision of how best to support the child and all of the important adults in that child's life.•

References

Catalano, C.G., Hernandez, P. & Wolters, P. (2022). A Child's Self-Statement: Who Am I? Exceptional Parent Magazine, 32 (4), 60-65. (Reprint of 2002 article -Invited)

Center for the Study of Social Policy (2022). How to Communicate Effectively About Early Relational Health: What It Is and Why It Matters A Messaging Guide. Retrieved from https://cssp.org/

Center of Excellence for Infant and Early Childhood Mental Health Consultation (2020). Status of the evidence for infant and early childhood mental health consultation (IECMHC). http://www.iecmhc.org/documents/CoEEvidence-Synthesis.pdf

Gilliam, W.S. (2005). Prekindergarteners left behind: Expulsion rates in state prekindergarten systems. New Haven, CT: Yale University Child Study Center. Retrieved from http://www. ziglercenter.yale.edu/publications/National%20Prek%20Study_expulsion_tcm350-34774_

Gilliam, W.S., Maupin, A.N., Reyes, C.R., Accavitti, M., & Shic, F. (2016). Research Study Brief: Do early educators' implicit bias regarding sex and race relate to behavior expectations and recommendations of preschool expulsions and suspensions? New Haven, CT: Yale Child Study Center.

ABOUT THE AUTHORS:

For eighteen years, Jean Budd LPC, NCC, IMH E® Clinical has supported infants, toddlers, pre-schoolers and their families with a relationship-based approach to social emotional development. Her current role is Assistant Director for Infant and Early Childhood Mental Health Consultation, Socio-Emotional Formation Initiative (SEFI) at the Center for Autism and Early Childhood Mental Health, Montclair State University. Jean supports the quality improvement mission for Grow New Jersey Kids TAC – and county-based QIS efforts through collaboration with Technical Assistance Specialists and QIS managers in developing and implementing professional formation goals and plans for private childcare center professionals. She directs the team of IECMHC professionals, clinicians, and early childhood master- level educators. In addition to developing and directing the NJ state's IEMCHC team, her responsibilities include Pyramid Model and Keeping Babies and Children in Mind training, specialized training in early childhood topics, classroom and staff support in partnership to promote healthy relational and emotional development for all children and mental health consultation for individual children and their families. Jean has developed training programs based on Routines to the Third Power, Relationship based care for student parents at Project Teach high schools and Reflective Supervision/Consultation Certification workshops. She is the New Jersey Association for Infant Mental Health Endorsement Coordinator, past president and is currently an active leader for the Alliance for the Advancement of Infant Mental Health. Previously, in her role as a clinician, she promoted development of social and emotional skills for at risk families and their children in a Head Start, Early Head Start, Family Childcare Providers and Home Visiting program.

Corinne G. Catalano, Ph.D., IMH E® worked as a school psychologist at the Montclair State University (MSU) Demonstration Program from 1995 until 2005 as a member of an interdisciplinary team using a developmental, relationship-based approach to work with 3-5 year old children diagnosed with developmental delays. During that time, she developed a template to support families and professionals to write a first-person narrative about a child with the goals of deepening their understanding of individual children and supporting transitions. She wrote about this with a parent and colleague for Exceptional Parent Magazine in 2002. Corinne then went on to coordinate the Demonstration Program, a state-approved special education school program for preschool age children with pervasive developmental delays and autism spectrum disorders embedded in the MSU Ben Samuels Children's Center. The "Hello My Name Is" template became an instrumental part of parent workshops and the transition of children from the inclusive preschool classrooms at the Center to general education classrooms in their home school districts. Currently, Corinne is the Assistant Director for Consultation Services at the MSU Center for Autism and Early Childhood Mental Health. She is the project manager for the NJ Inclusive Education Technical Assistance (NJIETA) project funded by the NJ Department of Education and executed in partnership with the NJ Coalition for Inclusive Education. Corinne teaches graduate courses in MSU's Teaching and Learning Department and is a faculty member for the Infant and Early Childhood Development Ph.D. program at Fielding Graduate University. She is a member of the NJ State Interagency Coordinating Council (SICC) for Early Intervention and serves as Chair of the SICC Personnel Preparation Committee. Corinne has published her research on early childhood teacher beliefs, autism and inclusive education in the Journal of Early Childhood Teacher Education and has several book chapters.

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LJS Fac/X, a twenty-two year old company, has undergone its own evolution since the 1990s. Larry Smith began as an individual electrical contractor, founding the company as LJS Electric as his commercial clients grew his business. Larry saw the need to expand his capabilities, and, over the next two decades, he brought talented professionals together to complement each other's unique skill set. Together the staff of LJS Fac/X offers practical, hands-on experience in a broad array of specialties.

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COMPETENT ■ PROFESSIONAL ■ COMPASSIONATE

How a Montclair State University program is preparing educators to create a better learning experience for students with disabilities

IMPROVING VIRTUAL LEARNING

ARTICLE COURTESY OF MONTCLAIR STATE UNIVERSITY

In response to the shift in teachers' professional development, from ***how to use*** *technology to* ***how to teach*** *with technology, Montclair State University launched a Virtual Learning for Students with Disabilities certificate program in 2020, to better equip educators with these critical skills.*

Teachers in the program discover new technologies, as they redesign curricula and instruction for a more accessible, high-quality virtual learning environment. The immediately applicable skills they acquire through the program, will allow them to better guide students through virtual learning and prevent them from falling behind.

Classes are taught by practicing special educators who are also technology leaders in their schools, and experienced adjunct faculty in the Department of Teaching and Learning.

"As educators, we were all challenged by the abrupt shift to online instruction brought on by the pandemic," says Montclair Associate Professor Jennifer Goeke. "This program is not just about learning new apps and programs; it's about understanding how to use technology to create an interesting, inviting and engaging virtual classroom for all students."

THE PROGRAM

The Virtual Learning for Students with Disabilities online graduate certificate is a two-course, six-credit program offered fully online.

The courses are geared toward teachers seeking to understand how to use technology as a seamless part of their teaching practice in order to maximize the learning experiences of students, including those with disabilities, across a range of education settings.

Those who complete the certificate program will also understand the legislative and policy mandates for utilization of technology for students with disabilities, and be able to implement various hardware and software tools to increase student learning, including disability-specific assistive technology applications.

MEETING THE MOMENT

Educators who have completed our graduate certificate program have learned strategies and resources that are useful far beyond a remote or virtual setting.

One student of the program, Melissa Becker, said, "When I first decided to take this course, I was under the assumption that the materials taught in this class would assist me in the remote learning setting. But after taking this course, I have learned about different strategies and resources that I can use inside and outside of my classroom, to help my students learn to the best of their abilities. Technology continues to grow and I have learned just how beneficial it can be to use in the classroom." •

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Creating a Special Needs Estate Plan that Works

SECOND OF A THREE-PART SERIES

BY JOSHUA FISHKIND, J.D., MBA

You've decided to create an estate plan to protect your family – well done! Peace of mind is around the corner. You've got a few decisions to make and guess what…you will be hiring! There are a number of roles that need to be filled in order for your plan to work as intended, and it's critical that you choose the right legal infrastructure for your plan and place the right team members into the right roles.

For all the information below, please note: everyone's estate plan, and special needs plan is unique and needs to reflect their financial and family situation. Additionally, terminology varies state by state. The information below is reflective of the most commonly used definitions. Even with variations, these concepts largely hold true, even when a different name is used in your state of residence. "A rose by any other name would smell as sweet." Still, it is always recommended to speak with an attorney licensed to practice in your state, that has special needs expertise. Looking for lawyers who belong to the Special Needs Alliance, Academy of Special Needs Planners, Life Care Planning Law Firms Association, or hold the CELA designation is a great place to start.

STEP 1 : CHOOSE THE RIGHT TRUST TYPE

1st party (Special Needs Trust) v. 3rd party (Supplemental Needs Trust)

If your loved one has a settlement, or acquired their disability later in life, they will likely need a 1st party trust to protect their assets and ensure that they still qualify for government benefits, such as Medicaid. Frequently, these trusts are created with court supervision, so you likely know if you have a 1st party trust, or if one is needed.

In some cases, an individual with a disability builds up assets in their name, and the need for a 1st party trust arises outside of the settlement context. An individual with (in most cases) more than $2,000 of assets in their name is ineligible for Medicaid, but moving those assets into a 1st party SNT (Special Needs Trust) can restore program eligibility, after a lookback period.

Key Takeaway

Even if you have a 1st party SNT, you may still need a 3rd party SNT. These two trusts address different problems, and many beneficiaries have both types of trusts.

A 3rd party Supplemental Needs Trust (SNT) holds money that was never in the disabled individual's name. Often, this is money that was inherited from parents or grandparents. If your loved one will inherit more than $2,000, you probably need a Supplemental Needs Trust.

The biggest difference between 1st and 3rd party SNTs is how the trusts work with Medicaid.

Medicaid payback: 1st party trusts are subject to a Medicaid payback lien. This means that upon the demise of the beneficiary (the disabled individual), before any money is distributed to remainder persons, often siblings or the children of the beneficiary, any money that Medicaid has paid out gets repaid first, with interest. Often the payback amount is greater than the trust assets, eliminating any further distribution. Don't worry though, the excess Medicaid lien does not pass as debt to anyone else – it just bills against the trust balance to whatever extent funds are available.

3rd party trusts are not subject to a Medicaid lien, so excess assets can be distributed to the persons or organizations that you designate as remainder persons.

Another note on Medicaid liens: Since Medicaid is waiting to be paid back for their expenditures out of the funds in the SNT, Medicaid will monitor expenditures from a 1st party trust closely to ensure funds are being preserved for their eventual payback. Accountings, oversight, and strict adherence to the Social Security Administration POMS (Program Operations Manual System) is required.

The Medicaid payback and oversight of 1st party trusts are the primary reasons that families strategize to place as much money into a 3rd party trust as possible, while spending down the 1st party trust, if one exists.

Absent proper planning, such as the creation of a 3rd party SNT, courts may create a 1st party SNT to protect a disabled individual's benefits that would be lost. For instance, in the case of an accident or medical malpractice, where there is a settlement or money inherited from parents who didn't have an estate plan, money would go into the disabled person's name, barring them from qualifying for benefits (or would kick them off existing benefits). Courts often step in and create 1st party SNTs to protect this from happening – if/when they are alerted. Sometimes, no one lets them know, then it's a very arduous clean up process that doesn't always work out well.

While creating the 1st party SNT provides protection for the beneficiary, so that they don't lose benefits, the lack of planning unnecessarily gives Medicaid oversight of trust expenditures, and results in a payback lien – not to mention the substantial legal fees involved in creating a trust via judicial intervention. Creating an SNT now avoids these legal fees and can eliminate the complexities that come with a 1st party trust.

Key Takeaway

You almost always need a 3rd party SNT if your loved one is receiving or will receive benefits, or would benefit from the financial guidance and protections of a supplemental needs trust. You only need a 1st party SNT if your loved one receives or intends to receive government benefits and has assets of their own. These two types of trusts can work together, and one does not replace the other.

DECISION TIME: When selecting trustees, the first question families face is whether they want a family member or a professional in the role.

STEP 2 : CHOOSE THE RIGHT TRUST FORM

Standalone v. Testamentary/Sub-Trusts (3rd Party)

Some lawyers choose to create a supplemental needs trust within a will (testamentary) or another seperate trust document (sub-trust). This can save clients money when drafting documents, and in some situations may be a cost-efficient solution for creating a supplemental needs trust. Often, however, this can lead to complications when it comes to administration, or inheritances and gifts from other family members. Here are a few such challenges:

1

When an SNT is created in a will, or as part of another trust, that trust doesn't exist until it is triggered, e.g., when someone dies and the trust is created as a part of the will. While this may cover the primary need of the trust, it raises a few issues that families frequently encounter. The first is the unplanned gift or inheritance from another family member. As an example, grandma passes away and leaves each of her grandchildren $25,000. This money cannot go into a trust in mom and dad's wills, because while they are alive, that trust doesn't exist.

2

When a trust is used to pay for certain expenses, or applications are made for various government services, often the trust needs to be produced, in its entirety. This means that in a trust created under a will, the will must be shared, or the terms of a living trust in the case of a sub-trust. Many families feel this is an unnecessary violation of their privacy.

3

Trusts created under wills/sub-trusts need time upon the grantor's (parent's) demise to be set up, accounts need to be opened, tax ID numbers need to be established, and more. In some cases, trustees find out for the first time, that they have been appointed and need to get up to speed before they can begin to fulfill their obligations. If there are probate issues, additional delays can arise. During this set-up time, which can be lengthy, beneficiaries are left waiting.

4

Sometimes the need arises to fund the trust before a grantor's (parent's) demise. This could be to "try out" the trustee, or for the convenience of an aging parent, who wants to offload some responsibility, or where relations between beneficiary and parents are tenuous, or, most commonly, because a parent is losing capacity themselves and need to create a mechanism to support their loved one. A trust setup under a will does not exist until the death of the parent, so it cannot be used in any of these situations.

5

Lastly, and this is a more practical than legal concern, SNTs within other trusts or wills are usually short, for the sake of efficiency and readability. Sometimes this is sufficient, but frequently parents want a robust trust that accounts for the myriad of challenges and situations that may arise. Additional protections for the beneficiary, guidance for the trustee, powers of the trustee, and successors, the various trust roles are all incorporated into larger trusts. SNTs that address these concerns can be 20 - 40 pages, or more. A document of that length is a nightmare to try to integrate into other documents, but **short documents often lack critical details and protections.**

The solution: A stand-alone supplemental needs trust. This option may cost a few dollars more when creating your plan but solves every one of the above issues, and can save money in the long term. **A common misconception is that by drafting a standalone trust, it needs to be funded now – this is not the case.** Some attorneys like to staple $20 to the back of the trust to show that it has been established, but that is the extent of the funding requirement. You do not need to start filing tax returns, or any of the other administrative tasks that come with trust administration. **Other than paying a small amount more of money on upfront legal expenses, the standalone trust option has no drawbacks, and the downsides of the testamentary trusts can be meaningful.**

STEP 3 : IDENTIFY THE RIGHT TRUSTEES

Trustees, Co-Trustees & Successor Trustees

For both 1st and 3rd party SNTs, the first role to consider is who will serve as trustee. **Trustees are responsible for all decisions made relating to the trust.** They can manage the trust assets (the money) themselves or hire an investment manager. They also make all distribution decisions, such as what type of housing, food, services, support, and equipment will be paid for by the trust, **since special needs trusts are required to place all discretion with the trustee.** The Trustee files taxes for the trust, does annual accountings, reports to the court where needed, and may need to interact with the Medicaid office to ensure compliance.

Co-trustees are additional trustees serving at the same time and have all the above responsibilities. Mom and Dad can be co-trustees, or two siblings, and occasionally a professional trustee and a family member. **Critically, co-trustees are liable for each other's actions, since they have both taken on a fiduciary role, which includes reviewing each other's actions.** Assume two siblings are co-trustees: If sibling 1 makes a mistake or acts improperly, sibling 2 can also be found liable, as it was their duty to monitor and prevent such activity. For this reason, most professional trustees will not serve as co-trustee with a family member.

Successor Trustees are future trustees. They are on deck, waiting to serve, until such time as the currently serving trustee is no longer able or willing to serve, generally due to death or incapacity. Frequently you will see Mom and Dad as trustee, and upon their death, incapacity or resignation, a bank, trust company, or child appointed as successor. Also note, you can have multiple levels of successor trustees. This is particularly helpful when there are age disparities between the beneficiary and the trustee. For a younger beneficiary, for example, they may not have a peer who is currently able to serve, so you could select an uncle or aunt as first level successor, then the child's sibling as second level successor trustee.

Key Takeaway

Practically speaking, unless there are tax planning considerations, or a unique family dynamic, the most common scenario with a 3rd party trust is to see Mom and Dad as initial co-trustees, then, upon their resignation or demise, a successor trustee. The successor trustee can be a professional, like a trust company, or an individual, like a sibling.

INDIVIDUAL V. PROFESSIONAL TRUSTEES

When selecting trustees, the first question families face is whether they want a family member or a professional in the role. Most of the time, a family's first instinct is to appoint a sibling, but after further consideration, many select a professional trustee. **If you are considering appointing a friend or family member as trustee (or successor trustee), consider if the person you have in mind meets ALL the below requirements:**

- *Is a contemporary of your child (age wise) and will be available to serve throughout your child's lifetime;*
- *Understands government benefits;*
- *Understands investment management;*
- *Can make appropriate distributions proportionate to the trust's assets, beneficiary's expected changes in cost of care, and the beneficiary's life expectancy;*
- *Will be responsive to your child's needs;*
- *Is willing and able to interact with Medicaid and government offices;*
- *Will file accountings, tax returns, and perform other administrative tasks;*
- *Knows how to protect government benefits and what distributions are permissible;*
- *Can maximize the impact of the money you've set aside to improve your child's life;*
- *Is willing to serve and is open to a lifelong commitment;*
- *Will assume the risk of being a fiduciary;*
- *Do you trust this person now and in the future to put your child's interests ahead of their own (be a fiduciary)?*

If you have someone who meets all the above criteria,

congratulations, you've found good candidate to serve as trustee! If not, consider a professional trustee.

Even if all the above criteria are fulfilled there are a few additional considerations:

- Families often find that a professional trustee, as a neutral party, makes planning easier. Rather than trying to decide if mom's sister or dad's brother should be trustee, a professional causes no conflict. Similarly for divorced families, selecting a corporate trustee can make collaboration on trust planning possible.
- One of the most important reasons families opt for a professional trustee is to protect their family dynamic. Placing one sibling, or family member, in charge of another can cause a lot of conflict. Sibling 1 telling Sibling 2 that they cannot buy something they want, or spend money as they choose, even if they are correct and being prudent, can be very disruptive to family relations. Since most trustees assume the job after mom and dad have passed, these conflicts arise during a grieving and adjustment period, when tensions are high, and when the beneficiary is most in need of support. Now, their sibling or family member, who they need emotional support from, also feels like a case manager or accountant. This rarely works out well.
- What happens when a mistake is made by that family member that triggers a loss in benefits? Professionals rarely make such mistakes, but when they do, they get sued, funds are often recovered, and the beneficiary (the trust) is made whole. What happens when Sibling or Uncle are trustee? Do we want to put the beneficiary in the position of suing family members to recover trust funds? Non-professional trustees (individuals) frequently run afoul of government benefits regulations, so this is a topic that should be thoroughly considered when thinking about the right type of trustee.

STEP 3 : IDENTIFY THE RIGHT TRUSTEES cont.

The two most frequent objections that arise to professional trustees are: “Professionals are going to be expensive,” and “Professionals won’t know/understand/love my child.”

First, as to cost: Assume a trust is set up for $250,000, funded upon your demise. If you appoint a family member, unless they have financial expertise, the first thing an individual would do as a prudent trustee, is hire an investment manager. Most of the time, fees for investment managers are 0.80% to 1.00% ($2,000-2,500/year). So, when looking at the cost of a professional, consider that in most cases, investment management fees are a given either way. Professional trustees, like Hope Trust, can charge as little as 1.10% on a $250,000 trust – and even less for larger trusts. In this example, the cost difference could be as little as $250/year. For just 63 cents per day, no family member or friend is being put out or assuming a fiduciary liability (yes, that’s a Sally Struthers reference).

The second objection: “But how will a professional understand my loved one, and will they be there for them like family would?” *Firstly, a good professional trustee will immediately get a care plan in place for your loved one so they know everything about their medical, legal, social, and financial needs. Even better, if parents create and maintain a care plan during their lifetimes, they can ensure a seamless transition to the professional.* Interview professionals and find one you like and feel comfortable with. Ask about how they handle care management, do they have social workers, nurses, psychologists on staff to help support your loved one. If the answer is yes, your child will have a level of support that family would be hard pressed to provide. Moreover, unlike family, professionals don’t have other obligations like work, family, illness, or death, that will prevent them from serving your loved one’s needs. The professional trustees, like Hope Trust, are under a fiduciary obligation to be there and be responsive throughout the lifetime of the trust.

Don’t worry, a professional trustee doesn’t cut your family out of the mix. There is still plenty for willing family members to do, and, if you choose, your family can still have oversight of the trust, without any of the daily work or risk. Where appropriate, consider roles like *trust protectors* for family members (to be discussed in detail in another article). Also consider family members for roles like healthcare proxy, power of attorney, guardian, conservator, or as executor of your will.

The role of trustee requires a deep understanding of financial, legal, and regulatory requirements, as well as a comprehensive understanding of the beneficiaries needs. The best trustee will ensure all available supports and resources are provided to your child, will check-in and make sure that they are thriving, and that the trust is being used wisely. Frequently, trustees interact and collaborate with siblings or family members, when they serve in the role of trust protector, guardian, or conservator. This is how the “love” is delivered, collaboratively, with the right people and professionals in the right roles.

GETTING TO KNOW YOU: A good professional trustee will immediately get a care plan in place for your loved one so they know everything about their medical, legal, social,and financial needs.

STEP 3 : IDENTIFY THE RIGHT TRUSTEES cont.

Ultimately, you, the creator of the trust (grantor), will decide the right type of trust, form of trust, and the appropriate trustees. The below check list may help in that analysis, and of course, reaching out to a professional to aid you in your planning is always a good idea!

TRUST TYPE: 1ST, 3RD, OR BOTH	CONSIDER:
My loved one has, or will have, assets of their own (in their name) in excess of $2,000:	1st Party Trust
My loved one will be inheriting money from me or others:	3rd Party Trust
Both of the above are true:	Both trust types

STANDALONE V. TESTAMENTARY	CONSIDER:
My loved one may inherit money before I/we pass away (e.g., from grandparents) or	Standalone Trust
I/we do not want to disclose additional information to government agencies, financial institutions, or care providers, or	
I/we would like to be able to fund the trust before my/our demise, or	
I/we would like a more comprehensive trust with terms that are tailored to our family's situation:	
None of the above apply to my family:	Testamentary Trust

Key Takeaway

*It is always recommended to speak with an attorney licensed to practice in your state, that has special needs expertise. A great place to start is with the Academy of Special Needs Planners (*https://specialneedsanswers.com*), Special Needs Alliance (*www.specialneedsalliance.org*) attorneys with the CELA designation, or Hope Trust (*www.hopetrust.com*).*

INITIAL TRUSTEE SELECTION	CONSIDER:
My assets are below the federal estate tax limits (currently ~12MM for an individual or ~24MM for a couple, though this is changing), and	All of 4 of these are true: Parents as initial Trustee
My assets are below the state estate tax limits (varies by state), and	
I do not live in a state with an inheritance tax, or my intended beneficiary would not trigger the inheritance tax (e.g., beneficiary is your child), and	
There is nothing in my family dynamic that would cause conflict with parents serving as trustee:	
Any one of the above is false:	Professional Trustee

SUCCESSOR TRUSTEE SELECTION	CONSIDER:
There is an individual who has all the identified skills, is willing to serve, understands the workload and risks, and is an age-appropriate trustee for my loved one:	Individual Trustee
Our family dynamic would be negatively impacted by putting one sibling, or family member, in charge of another, or	Professional Trustee
I do not have someone who meets all the criteria, do not want to burden that person, or ask them to assume fiduciary risks or obligations:	

The best time to start planning for your loved one is now. A holistic team of professionals, including lawyers, financial advisors, benefits experts, and care/support coordinators will ensure that your loved one is supported throughout your lifetime and beyond. •

ABOUT THE AUTHOR:

Joshua Fishkind, J.D., MBA is the CEO and a co-founder of Hope Trust, a full-service care planning company dedicated to helping families plan for their loved one with special needs, provide daily care management and support, and administer special needs trusts.

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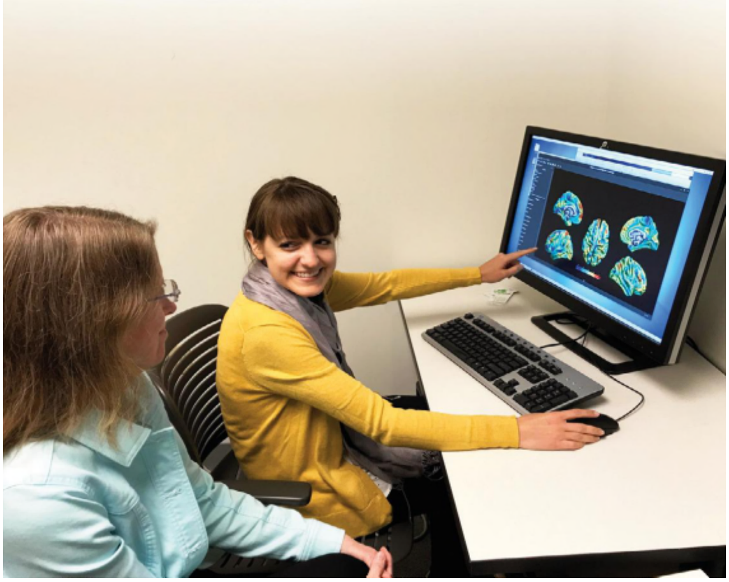

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54 SKILLS

TO INCLUDE WHEN WRITING INDIVIDUALIZED, FUNCTIONAL IEP GOALS

BY STEPHANIE DELUSSEY

IEP goals are written to help a student achieve and master new skills. But IEP goals do not and should not be only academic in nature. This goes for any student of any age – we don't have to wait until a child is at transition age (depending on your state, this is age 12-16) to begin working on these skills.

There are so many ways to make an academic goal more functional, by writing IEP goals that align with independence. This can be done at any age, not just for students that are of transition age.

Here is a list of 54 skills to get you started with helping students achieve independence at any age. You won't be able to help your student work on all of these skills at once, so it is important to prioritize your child's needs. Start with 3 or 4 skills to work on at first, and then build on that list as your child masters the new skills. The parent, teacher (and child) are the child's best advocates!

54 SKILLS : WRITING FUNCTIONAL IEPs

This list of skills can also be directly aligned with your state's academic standards:

PERSONAL INFORMATION AND PERSONAL SAFETY

1. Provide personal information (name, address, phone number, birthday)
2. Identify personal information in written format
3. Fill out applications with personal information
4. Use technology to store personal and family information (example: phone numbers and addresses)
5. Address an envelope to someone
6. Carry identification on your person (i.e., with you in a wallet or purse)
7. Share personal information with appropriate people (safety)
8. Identify family members and friends
9. Label important objects or places in your community (school, house, grocery store, library, etc.)
10. Know personal health information
11. Know family healthy information
12. Know and communicate likes, dislikes, wants, needs, etc.
13. Know what size clothes and shoes you wear

ENGLISH AND LANGUAGE ARTS

1. Write and send a card in the mail
2. Read for fun
3. Read road signs and signs in the community
4. Answer comprehension questions about the community
5. Sign or print your name
6. Use technology to send an email
7. Use a phone to send a text message
8. Communicate and have conversations with others
9. Tell someone about yourself
10. Retell a joke or facts from a prior conversation
11. Read directions on medicine bottles
12. Read a recipe
13. Fill out a check or pay a bill online
14. Complete an application for a job
15. Research and learn about unknown places, people, etc.

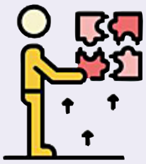
54 SKILLS : WRITING FUNCTIONAL IEPs cont.

MATHEMATICS

1. Make appointments using a calendar (dentist, personal care doctor, eye doctor, etc.)
2. Attend appointments on time using a clock
3. Write the date in various formats
4. Identify when a store is open and closed using a clock
5. Money budgeting and planning
6. Money saving for items and for emergencies
7. Balance your bank account
8. Pay for a service
9. Pay a bill in full and on time by the due date
10. Match items to stock shelves
11. Check store receipts to make sure it is correct
12. Calculate an expected paycheck based on hours worked
13. Identify shapes, colors, and numbers in the real world

SCIENCE AND SOCIAL STUDIES

1. Follow a schedule
2. Locate a specific place or room within a public building or area
3. Use a map or GPS to find a location
4. Use a map or GPS to get from one place to another
5. Schedule transportation or use public transportation to attend appointments
6. Identify holidays
7. Identify the season and how to dress for the weather



SELF-CARE AND LIFE SKILLS

1. Personal hygiene (taking a bath/shower, using bathroom, washing hands, using deodorant, brushing teeth, clipping nails, female personal hygiene)
2. Cooking, eating, and preparing food (use microwave, oven, stove, refrigerator, and other kitchen appliances and supplies, kitchen safety, eating healthy foods and the Food Pyramid)
3. Care for pets
4. Dress appropriately for weather
5. Housekeeping (vacuum, sweep or mop, take out trash, wash dishes, clean, use washer and dryer, put clothes away, dust, etc.)
6. Safety (fire, water and pool, severe weather, etc.)

This list of skills is a starting point, but also this should be a discussion for the entire IEP Team, the parent and child included. To start the conversation with the child's IEP team, the parent should reach out to the child's caseload manager. Feel free to share this list with the child's IEP team too!

Remember: you won't be able to help your student/child work on all of these skills at once, so it is important to prioritize your student/child's needs. Start with three or four skills to work on at first, and then build on that list as your student/child masters the new skills. The parent, teacher (and child) are the child's best advocate! •

ABOUT THE AUTHOR:

Stephanie is a dual-certified special education teacher, Master IEP Coach®, children's book author, and teacher mentor. She has a passion for creating engaging, adapted resources for teachers and students with disabilities, and is self-proclaimed #datanerd. She understands that not everyone will love IEPs as much as she does, but it is her hope that with the appropriate training and resources, teachers will not only advocate harder for student services and supports, but also bridge the gap between teachers and families to foster a true IEP Team. She also provides professional development for teachers. You can connect with her at **www.mrsdscorner.com** and **www.theintentionaliep.com**. Stephanie is also a huge mental health advocate, sharing her experiences and struggles to let others know that you can survive the dark seasons and thrive in life and teaching with a mental illness.

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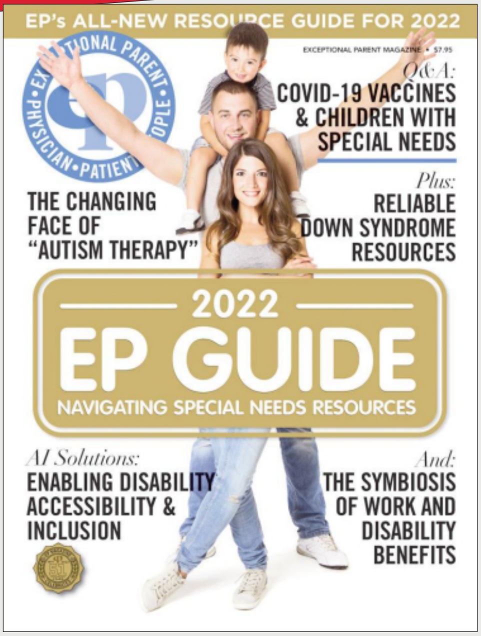

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I AM A VETERAN
AND THIS
IS MY VICTORY.

FROM OUR FAMILIES... TO YOUR FAMILIES

MILITARY

SECTION

MILITARY LIFE

BIDEN ADMINISTRATION ANNOUNCES FREE ADMISSION TO NATIONAL PARKS FOR VETERANS, GOLD STAR FAMILIES AND MILITARY MEMBERS

On November 8th, the Biden-Harris administration announced that starting on Veterans Day (Nov. 11), veterans of the U.S. Armed Services and Gold Star Families can obtain a free lifetime pass to more than 2,000 federal recreation sites spread out across more than 400 million acres of public lands, including national parks, wildlife refuges, and forests.

"We have a sacred obligation to America's veterans. This new lifetime pass is a small demonstration of our nation's gratitude and support for those who have selflessly served in the U.S. Armed Forces," said Secretary of the Interior Deb Haaland, whose father served during the Vietnam War. "I'm proud the Department of the Interior can provide veterans and Gold Star Families opportunities for recreation, education and enjoyment from our country's treasured lands."

"Our national forests and grasslands represent so much of the beauty of the nation our brave service members have sacrificed so much for," said Agriculture Secretary Tom Vilsack. "Though they can never be fully repaid, by connecting the families of the fallen and those who served with these iconic places, we can, in a small way, say thank you."

"The U.S. Army Corps of Engineers and our federal teammates are proud to honor our veterans with free lifetime access to more than 2,000 federal recreation areas across the nation," said Lieutenant General (LTG) Scott Spellmon, Chief of Engineers, U.S. Army Corps of Engineers. "This is a small token of appreciation for veterans who have bravely dedicated their lives to defending our freedom."

Each lifetime pass covers entrance fees for a driver and all passengers in a personal vehicle (or passholder and up to three adults at sites that charge per person) at national parks and national wildlife refuges, as well as standard amenity fees at national forests and grasslands, and at lands managed by the Bureau of Land Management, Bureau of Reclamation and U.S. Army Corps of Engineers.

SACRED OBLIGATION: All U.S. veterans and Gold Star family members will be able to get a free lifetime entrance pass for federal parks and recreation sites nationwide starting Nov. 11.

Veterans can present one of the four forms of acceptable ID (Department of Defense ID Card, Veteran Health ID (VHIC), Veteran ID Card, or veteran's designation on a state-issued US driver's license or ID card) at participating federal recreation areas that normally charge an entrance fee. Gold Star Families obtain information, self-certify they qualify and download a voucher by visiting the U.S. Geological Survey's website.

The Alexander Lofgren Veterans in Parks Act, passed in December 2021, authorized free lifetime access to federal lands to veterans and Gold Star Families. The new lifetime pass for veterans and Gold Star Families is in addition to the free annual Military Pass, which has been available to active duty servicemembers and their families since Armed Forces Day, May 19, 2012.

Federal recreational land management agencies offer additional lifetime passes, including a Senior Pass for US citizens or permanent residents over age 62 and an Access Pass for US citizens or permanent residents with a permanent disability. More information is available on NPS.gov.

The Interior Department and other federal land agencies also offer fee-free entrance days for everyone throughout the year to mark days of celebration and commemoration, including the birthday of Martin Luther King, Jr., National Public Lands Day, and Veterans Day.

Passes can be obtained on the United States Geological Survey website at **https://store.usgs.gov/MilitaryPass** *Before being issued a pass, users are required to select how they are eligible for one.*

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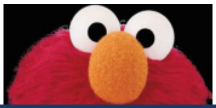
is available to help with your concerns regarding military life.



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

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U.S. MILITARY ★ BOOK EXCERPTS 1ST OF A SERIES

THE RESILIENT WARRIOR

BATTLE-TESTED LIFE HACKS FOR MILITARY MEN & WOMEN

BY NICK BENAS AND BUZZ BRYAN

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 first in a series of five that EP Magazine will feature over the coming months.*

INTRODUCTION

The two of us are frequently reminded of signage we once saw splayed on a blast wall back in Iraq: COMPLACENCY KILLS.

That graffiti was our reminder to keep moving, questioning, examining, re-examining, and attacking. It remains our decision to this day to keep moving, by adapting and overcoming, skipping the ailments, and the reactionary. Yet many of our fellow warriors are torn and in tatters, empty shells of their former physically and mentally fit selves. Both veterans and those actively serving are stuck, suffering, and often suicidal. Some wage a war within, as high-stakes as the war without, and still lose the battle. We are burdened by this truth.

The following pages are our personal exploration of what lies beyond the "traditional methods" of care. We have enlisted the help of our close friends and friends of friends; veterans, divorcees, single mothers of military families, military sexual assault victims, drug and alcohol users, former and active U.S. Marines, Navy, Army, Rangers, Berets, a former member of The British Royals, an auxiliary Coast Guard Member and Master Barber, providers, and caretakers who are practitioners in their respective niche(s). They are doing the daily rinse and repeat. They are getting themselves unstuck, seeking and practicing with positive, healthy alternatives, all in the name of chipping away and coping with setbacks and struggles. The WARRIORS featured in this book are relentless. They take care of business.

The two of us have made a career out of working and supporting veterans post-military, and we avow that the warrior contributors featured, are appropriate for this project. They have expressed comfort in their sharing. They have fostered an aesthetic of smoothness and speed in their operational environments. They continue to shock the enemy, even while others dwindle away their time with the manufactured suffering.

Throughout this book you will hear many voices, each with their own tips and tricks to gaining the upper hand against the powerful enemies of the modern day-to-day. The gains they have won are immeasurable, and now they are offered to you freely.

This book is a field manual for feeling well.

THE WAY OF THE WARRIOR: Nick Benas conducts training exercises in Iraq in 2004; "Know that regaining and managing your physical, mental, and emotional health, is possible, with some effort and a desire to change. All warriors deserve to be at peace and free of chaos outside the theatre of war."

FOR THE WARRIORS

For those with military backgrounds, we know you have been trained to execute effectively during the toughest of times. You were mentally fit, physically ripped. Know that regaining and managing your physical, mental, and emotional health, is possible, with some effort and a desire to change. All warriors deserve to be at peace and free of chaos outside the theatre of war. You need a field manual that works. To lift the fog, you must be motivated. Passivity prevents you from moving forward. Waiting for others to aid and assist, will always keep you waiting. You can endure, if you want better for yourself and others. Don't get left behind in the reception area of your medical office or the isolation of your home. You alone control your course of action.

And with that, we welcome you WARRIORS. We are honored that you are joining the Resilient Warrior community. We thank you for following our writing and exploration. The support we have received after writing *The Warrior's Book of Virtues* has been incredible. The many readers we touched were unexpected, and they inspired us in return. This writing process has motivated us to continue on the path leading to discovery and life-long learning.

We thank you for your commitment to grow and improve, for leveling up and ending suffering. Our hope is that you will lead others on your path to ascension and victory. Your resolve is inspiring.

The Resilient Warrior will…

- *Challenge the belief that traditional healthcare has your immediate solution*
- *Prevent you from becoming a "cog" in a medical treatment plan or healthcare system*
- *Challenge the belief that medication is the only way out*
- *Teach you what other WARRIORS are doing for remedy and happiness*
- *Chip away at the anxiety, depression, and suffering*
- *Help you regain your confidence and eradicate fears*

HOW TO READ THIS BOOK

The Resilient Warrior is a collection of easy strategies, practical tips, and self-care ideas for military men and women, and everyday people. Our book is not a solution, but an embarkation. You will find hacks that pry the warrior out of isolation.

Hacks are annotated in the table of contents and a list of the Warrior Resources can be found at the back of the book.

We are not doctors, and the following is not a prescription. Do not be stupid, and do not hold us, the contributors featured within, or the publisher accountable. Make sure you proceed with caution. Let the following content be an introduction to novelty, a return to our days of play. This book is an attempt to create more awareness, positive action(s) and a focus on what matters, making you and all of us more balanced Warriors. We

PHOTO COURTESY NICK BENAS

WALKING THE LINE: Buzz Bryan *(left)* interacts with Iraqi civilians while on patrol in 2004; "Take the stuff you enjoy from this book, do more of it, and do it consistently. Be good to yourself. Make this manual a part of your battle kit and refer to it often. You will have the ability to maximize your healthy habits, while adding new life hacks."

are all in this together, Coalition Forces, Army, Air Force, Coast Guard, National Guard, Reserves, Navy, Marine Corps, friends, and family. Everything you need to help you attack the day is right here. Collaborating on this book has helped us grow in so many ways. We had no idea of the immediate impact this project would have. A big thank you for the warriors that fill the following pages… we are grateful for this newly found friendship and your contributions to help our fellow WARRIORS.

> **"THE REASON THE UNIVERSE IS ETERNAL IS THAT IT DOES NOT LIVE FOR ITSELF; IT GIVES LIFE TO OTHERS AS IT TRANSFORMS."**
> **— LAO TZU**

Take the stuff you enjoy from here, do more of it, and do it consistently. Be good to yourself. Make this manual a part of your battle kit and refer to it often. You will have the ability to maximize your healthy habits, while adding new life hacks. Taoist philosophy believes that life is always flowing and transforming, and things that are static become dead. Be fluid. WARRIORS keep moving and stun their opponents with great fury. •

The next excerpt in this series will appear in the January 2023 issue of EP Magazine.

ABOUT THE AUTHORS

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

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

PHOTO COURTESY OF BUZZ BRYAN

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When Help Arrives

Our mornings and evenings were filled with trivial rituals. I don't think I realized how eccentric we were until I started sharing our daily schedule with my parents.

John Lithgow once said "Time sneaks up on you like a windshield on a bug." It's uncanny how time can slip by, while you're diligently planning so time will not slip by. Mark's parents live in Montana, and we realized that as we were getting older in South Carolina, Mark's parents were getting older in Montana. Time has a tendency to do that. A few years ago, Mark flew to Montana and I stayed with the boys, but this time was different, "Shelly, I need you to come with me this time." Unfortunately, we do not have access to a respite service to stay with Broden for a few days, so Mark and I could see his parents.

The only option I could think of was to ask my parents for help, "Mom? Dad? Do you think you could fly to South Carolina for about 10 days, learn how to take care of Broden and drive him to therapy everyday, so we can visit Mark's parents?" I was prepared to hear a click and then a dial tone, but my mom chimed in and said that they would make it happen. We coordinated our flights so that my parents could have a few days to learn the ropes, and when we returned, they would have a few days to rest before their flight home. I don't think I realized how eccentric we were until I started sharing our daily schedule with my parents.

My parents decided that the "divide and conquer" approach would be the most effective. My mom said she would make all of his meals and pack his lunch, and my dad would learn how to shower Broden and shuttle him back and forth to clinic. Together, they would plan his schedule, and post it in his room so he knew what he would be doing for his weekend outing.

The first morning my parents were with us for "Broden Training," my dad watched me make Broden's breakfast. As I was placing the food on his plate, I told him that we always use the same plate. The four pieces of bacon need to be stacked on top of each other. The bread has to be toasted twice in the toaster, because Broden likes firm toast. He watched me as I cut the toast in half and stacked it perfectly on the other side of the plate so it didn't touch the bacon. Then I put about four blueberries on the other side of the plate. My dad asked, "This is how his breakfast plate looks every morning?" At first, I was confused with the question because it forced me to step out of our routine and look at it from someone who was seeing this breakfast ritual for the first time. "I guess this is sort of a unique ritual, isn't it? Yes, no food can touch and stack the bacon and toast

REPORTING FOR DUTY: "My parents decided that the 'divide and conquer' approach would be the most effective. My mom said she would make all of Broden's meals and pack his lunch, and my dad would learn how to shower him and shuttle him back and forth to clinic."

PHOTO COURTESY SHELLY HUHTANEN

vertically." My dad grabbed his phone and took a picture of the plate, "Yep, I'm going to send this picture to your mom so she knows exactly how he likes it." My mom took a look at the picture and nodded, "Got it. I can do this in the morning."

My dad followed me into Broden's room when it was time to start getting him up in the morning. "Sometimes he doesn't want to get up right away, so you have to rub his back and pull his blankets off of him. If that doesn't work, turn on the hall light." My dad nodded while he observed as Broden slowly rolled out of bed. After I grabbed Broden's robe to head with Broden into his bathroom to give him a shower, I threw on some shorts and a t-shirt, "Dad, stick your head in the shower and watch how I do this. His shower is also a ritual. He likes the showerhead to be at a certain setting and he uses a certain type of shampoo and facewash." As I talked through each step of the shower process, I could see my dad watching very intently to make sure he did each step the way Broden wanted to be showered.

> My parents smiled and said, "This is what we do. We're here when you need us and we're going to be just fine."

Once Broden was dressed and had eaten his breakfast, I showed my parents how I pack his backpack for the day. We jumped into the car to head downtown to the Unumb Center. The traffic was hairy, "Dad, you can't leave after 8:10 am or you'll be late. Call them if you think you're running behind so they can look for our car from the door." My dad took note of it on his notepad, and continued to watch intently so he knew the route that I always take in the morning, "Shelly, why did you take a right? Don't you go straight to Bull Street?" I realized that months ago I started taking a right on Harden Street to avoid the intersection on Bull Street. "Sorry Dad, you're right. This route is a little faster and not as stressful, so once you see Allen University, turn right." My dad nodded and took note of the difference.

After dropping Broden off and heading home, I continued to answer any questions my parents had about Broden's routine. I realized that our mornings and evenings were filled with trivial rituals, "For dessert, Broden likes a bowl with a few gummies, and he wants a popsicle cut off from the wooden stick. The popsicle pieces need to lay in the bowl next to his gummies, but he doesn't get upset if they touch." I actually started rolling my eyes after listening to what was coming out of my mouth. Mark and I conduct these rituals each day and don't even give it a second thought.

I sat back and pulled my legs on the couch to get comfortable, as my parents sat on the other couch in front of me, "Thank you so much for doing this. I'm realizing how much detail you need to care for Broden, now that I talk through the schedule with you." They smiled and said, "This is what we do. We're here when you need us and we're going to be just fine." These are the moments when you can't seem to find a way to show your parents how much you appreciate them. All you can do is continue to show your children the same unconditional love that your parents have shown you. •

PUZZLES & CAMO

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

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IT CAN BE HARD TO GET HIS ATTENTION.

While you’re dropping off your child, discuss a plan to help him avoid alcohol and other drugs.

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