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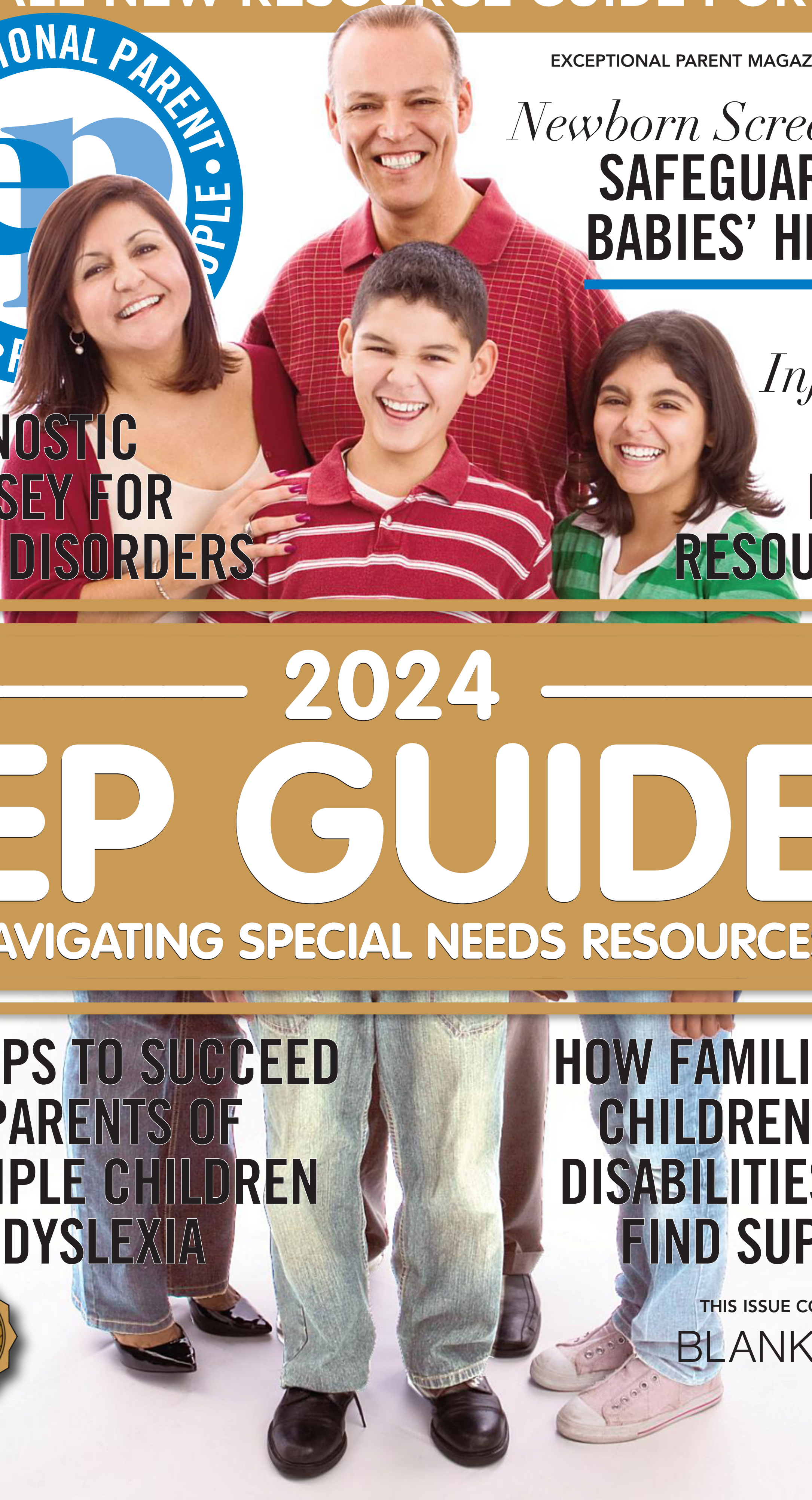

Newborn Screening:
SAFEGUARDING BABIES' HEALTH

Birth Injuries:
TOP EIGHT RESOURCES

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2024
EP GUIDE
NAVIGATING SPECIAL NEEDS RESOURCES

SIX TIPS TO SUCCEED FOR PARENTS OF MULTIPLE CHILDREN WITH DYSLEXIA

HOW FAMILIES OF CHILDREN WITH DISABILITIES CAN FIND SUPPORT

THIS ISSUE COURTESY OF
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EP Magazine's Annual EP Guide is a giant-sized issue packed with inspirational stories, valuable resources and expert insight on a wide range of topics. Sincere thanks to Blank Rome LLP for sponsoring this special issue.

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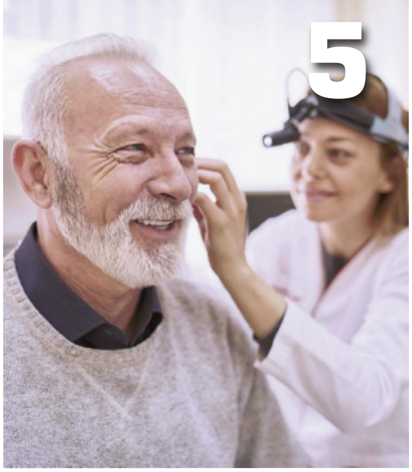

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Spreading the Word

I am honored to have been interviewed by the SFN Dad To Dad Podcast and the Oscar Mike Radio Podcast.

I wish all of you good health, strength, peace and happiness in this New Year. What a great way for me to begin 2024. I am honored to have been interviewed by David Hirsch of the Special Fathers Network's Dad To Dad Podcast #286 aired December 29th, 2023 (**https://podcasts.apple.com/us/podcast/sfn-dad-to-dad-286**) and Travis Partington of Oscar Mike Radio Podcast #377 aired January 4th, 2024 (**https://fb.watch/poOn6gEvME**). I am extremely appreciative of both Travis and David and how enthusiastically they have supported and shared the magazine and EP for Free with their audiences – thank you David and Travis! I am also flattered and encouraged by the positive feedback I have received from those of you who have had a chance to listen to one or both of these interesting podcasts.

> "Our annual EP Guide features articles about newborn screening, resources for parents whose child was born with a birth injury, and much more."

Our annual EP Guide: Navigating Special Needs Resources features articles about newborn screening, dental health, resources for parents whose child was born with a birth injury, and much more. Several articles focus on reading difficulties, including "For Parents Of Multiple Children With Dyslexia: Six Tips To Succeed" by Georgie Normand and "Supporting Your Child's Reading Journey" by Dr. Prarthana Franklin-Luther, Ph.D. To help with creating future care plans for your child, Kelly Coleman contributes "Set Your Child Up for Success with a Vision Statement," and Ernst VanBergeijk, Ph.D., M.S.W and Alexandra LaVoie, M.S.O.T. offer "Helping Youth with Low Vision and Blindness Transition into the World of Work."

Like every issue of EP Magazine, our digital version can be read using a wide variety of universal access features for those with visual or hearing impairments. Download whole articles, view them with larger high-contrast type, or share them on social media. Many other accessibility solutions and services are available on our reader platform.

I would like to remind those that are signed up for EP for Free that they will receive the new issue announcement email and the monthly newsletter from **news@epmagazine.com** (Please do not reply to this email; it is used for distribution only).

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

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Faye Simon
Editor In Chief

THE EDITOR IN CHIEF'S DESK

Faye Simon is a certified pre-K–8 teacher with a wide range of educational experience. She has worked in deaf/blind and infant stimulation programs, taught K–2 in public schools, and was a Head Teacher and Parent Coordinator for Head Start. She is Founder and President of the volunteer-run IES Brain Research Foundation. As EP's Editor In Chief, Faye sources and edits articles, creates partnerships with businesses and not-for-profit organizations, and develops relationships with EP's writers, corporate partners, readers and staff.

Information and Support for the Special Needs Community

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WHAT'S HAPPENING

DOJ ISSUES GUIDANCE ON THE ADA AND EMPLOYMENT SERVICES FOR PEOPLE WITH DISABILITIES

The Justice Department recently announced that it has issued guidance to explain how the Americans with Disabilities Act (ADA)'s "integration mandate" applies to public employment and day services. The integration mandate requires state and local governments to provide services to people with disabilities in the most integrated setting appropriate.

WORKER'S BENEFITS: "People with disabilities are entitled to work alongside their friends, peers and neighbors without disabilities. Employment is fundamental to contributing to and being fully included in society."

Integrated employment services can help people with disabilities work in typical jobs where they can interact with non-disabled coworkers, customers and peers. Integrated day services allow people with disabilities to engage in community activities of their choosing – like social, educational, recreational or cultural activities – when they are not working. As the guidance describes, the ADA requires state and local governments to make their employment and day services available in the most integrated setting appropriate to each person's needs.

Nationally, however, many people with disabilities spend most of their time receiving public services in segregated settings like sheltered workshops and facility-based day programs. Sheltered workshops are segregated facilities that primarily or exclusively employ people with disabilities. In facility-based day programs, people with disabilities participate in non-work activities with other people with disabilities. These settings separate individuals from the community and provide little or no opportunity to spend time with people without disabilities, other than paid staff.

> ***"The guidance helps people with disabilities understand their rights under the federal law and provides an overview of the ADA, the integration mandate and the types of employment and day services that are often offered to people with disabilities."***

"Simply put, people with disabilities are entitled to work alongside their friends, peers and neighbors without disabilities," said Assistant Attorney General Kristen Clarke of the Justice Department's Civil Rights Division. "Employment is fundamental to contributing to and being fully included in society. This guidance makes clear that the ADA requires that people with disabilities have access to the integrated services they need to contribute, grow and advance in typical workplaces throughout the country."

The Civil Rights Division has published this guidance to help state and local governments understand their nondiscrimination obligations and people with disabilities understand their rights under the federal law in this area. The guidance provides an overview of the ADA, the integration mandate and the types of employment and day services that are often offered to people with disabilities. It then answers nine questions about how the ADA applies to those service systems. For example, the guidance explains:

- *The ADA's integration mandate applies to public employment and day services.*
- *The most integrated employment setting under the ADA is the one that lets people with disabilities spend time with non-disabled people as much as possible.*
- *People with disabilities who receive services in segregated employment or day services settings should receive accurate information about integrated employment options.*

The guidance may be found at **www.ada.gov/resources/olmstead-employment-qa**. A Federal Register notice discussing the guidance will be forthcoming. To learn more about the ADA, call the toll-free ADA Information Line at 1-800-514-0301 or 1-833-610-1264 (TDD), or access the Justice Department's ADA website at **ada.gov.**

WHAT'S HAPPENING

PEOPLE WITH DISABILITIES HOPE AUTONOMOUS VEHICLES DELIVER INDEPENDENCE

BY TONY LEYS

Myrna Peterson predicts self-driving vehicles will be a ticket out of isolation and loneliness for people like her, who live outside big cities and have disabilities that prevent them from driving.

THE ROAD AHEAD: One of the five self-driving vans now serving the northern Minnesota community of Grand Rapids. The vans are part of a program called "goMARTI," which stands for Minnesota's Autonomous Rural Transit Initiative.

Peterson, who has quadriplegia, is an enthusiastic participant in an unusual test of autonomous vehicles in this corner of northern Minnesota. She helped attract government funding to bring five self-driving vans to Grand Rapids, a city of 11,000 people in a region of pine and birch forests along the Mississippi River.

The project's self-driving vans always have a human operator in the driver's seat, poised to take over in complicated situations. But the computers are in control about 90% of the time, and they've given 5,000 rides since 2022 without any accidents, organizers say.

"It's been fun. I'm really sold on it," said Peterson, who used to rely on her power wheelchair to travel around town, even in winter.

Autonomous vehicles, which can drive themselves at least part of the time, are making news in urban areas, such as San Francisco, where extensive tests of the technology are underway.

Rural experiments have been set up in a few other states, including Iowa and Ohio. Peterson hopes the pilot projects help bring a day when fully autonomous cars and vans assist the estimated 25 million Americans whose travel is limited by disabilities.

Fully independent vehicles remain far from everyday options, as tech companies and automakers struggle to perfect the technology. Recently, for example, General Motors recalled all its self-driving cars after one struck and dragged a pedestrian who had been hit by another vehicle.

But Waymo, a corporate relative of Google, is forging ahead with fully autonomous taxi rides in multiple cities.

Peterson is among those who believe autonomous vehicles someday will become safer than human-driven models. "Look at how many times the lightbulb failed before it worked," she said.

Unlike many smaller towns, Grand Rapids has public buses and a taxi service. But Peterson said those options don't always work well, especially for people with disabilities. The autonomous vehicle program, known as goMARTI, which stands for Minnesota's Autonomous Rural Transit Initiative, offers a flexible alternative, she said. She hopes it eventually will ease a national shortage of drivers, which tends to be especially acute in rural regions.

The project is funded through the spring of 2027 with more than $13 million from federal, state, and local sources, much of it coming from the 2021 federal infrastructure bill.

The project's distinctive Toyota minivans are outfitted by a Michigan company, May Mobility, which is backed by the Japanese auto giant and other investors. Slogans painted on the side invite the public to "Experience Self Driving in Minnesota's Nature." The vans bristle with technology, including cameras, radar, GPS, and laser sensors. Their computer systems constantly monitor surroundings and learn from situations they encounter, said Jon Dege, who helps manage the project for May Mobility.

Users arrange free rides via a smartphone app or the 211 social service telephone line.

On a recent chilly afternoon, a goMARTI van pulled up near Peterson's house. She soon emerged, bundled in a bright purple parka honoring her beloved Minnesota Vikings football team. She rolled her electric wheelchair to the van, up a ramp, and into the back. Van operator Mark Haase helped strap the wheelchair in, then climbed into the driver's seat for a demonstration.

As the van pulled onto the street, the steering wheel seemed to shudder, reflecting tiny adjustments the computer made. Haase kept his foot poised near the brake pedal and his hands cupped around the steering wheel, ready to take over if a complication came up. After moments when he needed to take control of the vehicle, he pressed a button telling the computer system to resume command. "It was weird at first, but it didn't take long to get used to it and trust the system," Haase said.

PHOTOS COURTESY TONY LEYS/KFF HEALTH NEWS

The Minnesota Department of Transportation helped direct federal money toward the Grand Rapids project, which followed a similar effort in the southern Minnesota city of Rochester. Tara Olds, the department's director of connected and automated vehicles, said her agency sought smaller communities that wanted to give autonomous vehicles a shot.

Neither kind of driver will ever be perfect, Olds said. "You know, humans make mistakes, and computers make mistakes," she said. But the public would understandably react differently if a fatal crash were caused by an autonomous vehicle instead of a human, she said.

Frank Douma, a research scholar at the University of Minnesota's Center for Transportation Studies, has analyzed the Grand Rapids project and other autonomous vehicle programs. He said running such projects in smaller towns isn't necessarily harder than doing so in urban areas. "It's just different."

TICKET TO COMMUNITY: Myrna Peterson rolls her wheelchair into a goMARTI van as operator Mark Haase watches.

For the foreseeable future, such services probably will need to run on predetermined routes, with regular stops, he said. It would be more complicated to have autonomous vehicles travel on demand to unfamiliar addresses out in the countryside.

Developers will need to overcome significant challenges before autonomous vehicles can become a regular part of rural life, he said. "But it's no longer something that can be dismissed as impossible."

A 2022 report from the National Disability Institute predicted that autonomous vehicles could help many people with disabilities get out of their homes and obtain jobs.

Tom Foley, the group's executive director, said a lack of transportation often causes isolation, which can lead to mental health problems. "There's an epidemic of loneliness, particularly for older people and particularly for people with disabilities," he said.

Foley, who is blind, has tried fully autonomous vehicles in San Francisco. He believes someday they will become a safe and practical alternative to human drivers, including in rural areas. "They don't text. They don't drink. They don't get distracted," he said.

For now, most riders who use wheelchairs need attendants to secure them inside a van before it starts moving. But researchers are looking into ways to automate that task so people who use wheelchairs can take advantage of fully autonomous vehicles.

The Grand Rapids project covers 35 miles of road, with 71 stops. The routes initially avoided parking lots, where human drivers often make unexpected decisions, Dege said. But organizers recognized the street-side stops could be challenging for many people, especially if they're among the 10% of goMARTI riders who use wheelchairs. The autonomous vans now drive into some parking lots to pick riders up at the door.

The autonomous vans have gone out in nearly all kinds of weather, which can be a challenge in northern Minnesota. Grand Rapids received more than 7 feet of snow last winter.

The robot drivers can get stymied as well by roundabouts, also known as traffic circles. The setups are touted as safer than four-way stops, but they can befuddle human drivers too.

Haase took control each time the van approached a roundabout. He also took the wheel as the van came up on a man riding a bicycle along the right side of the road. "Better safe than sorry," Haase said. Once the van was a few yards past the bicycle, he pressed a button that told the robot to resume control.

Peterson takes the vans to stores, restaurants, community meetings, hockey games — "and church, of course, every Sunday and Wednesday," she said.

She said the project has brought Grand Rapids residents together to imagine a more inclusive future. "It's not just a fancy car," she said.

ABOUT THE AUTHOR:

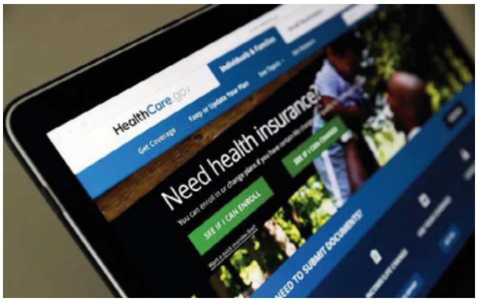
Tony Leys, Rural Editor/Correspondent, is based in Des Moines, where he worked 33 years as a reporter and editor for The Des Moines Register. Tony was the Register's lead health care reporter for more than 20 years and served four terms as a board member for the Association of Health Care Journalists. He is an alum of the University of Wisconsin-Madison and the Knight Science Journalism program at MIT.

WHAT'S HAPPENING

HEALTHCARE.GOV ENROLLMENT EXCEEDS 15 MILLION, SURPASSING PREVIOUS YEARS' MILESTONES

The Biden-Harris Administration encourages everyone who needs affordable, quality health insurance to visit HealthCare.gov and sign up for coverage by the January 16 final deadline.

The Biden-Harris Administration announced today that the Affordable Care Act (ACA) Marketplace enrollment continues at a record-breaking pace. As of December 15, 2023, for HealthCare.gov states and December 9, 2023, for State-based Marketplaces, preliminary data projects that over 19 million consumers will enroll in 2024 coverage through the ACA Marketplaces – over 7 million more than when President Biden took office. This includes 15.3 million individuals who have selected a health plan using the HealthCare.gov platform. On December 15 alone, the deadline for coverage starting January 1, 2024, more than 745,000 people selected a Marketplace plan through HealthCare.gov — the largest single day in history.



CLOCK'S TICKING: Consumers will have until midnight on January 16 to enroll in coverage.

"Millions of Americans signing up for health care coverage under the Affordable Care Act is good news. It means more Americans have the peace of mind of knowing that going to the doctor won't empty their bank account," said Secretary Xavier Becerra. "The Biden-Harris Administration will continue working to expand health care coverage and lower prescription drug costs, so taking care of your health is not a luxury."

"More than 15.3 million people have signed up for Health Insurance Marketplace plans in states that use HealthCare.gov, an impressive 33% increase compared to this time last year," Administrator Chiquita Brooks-LaSure said. "The Marketplace clearly meets an important need in Americans' lives, making access to health care possible for adults and their children. The Affordable Care Act connects more people to preventive and life-saving care, helping more people and their families live the American dream. We look forward to continuing to get people enrolled ahead of the January 16 deadline."

The Biden-Harris Administration encourages all families to visit HealthCare.gov and check out the health care coverage options and savings available to them. CMS expects nine out of 10 customers to be eligible for savings. People with current coverage through HealthCare.gov are encouraged to return and shop to see if another plan better meets their needs at a lower cost.

Many people are eligible for Medicaid and the Children's Health Insurance Program (CHIP). However, those who are no longer eligible for Medicaid or CHIP should visit HealthCare.gov to see if they are eligible to enroll in a low-cost, quality health plan today.

The Marketplace Open Enrollment Period on HealthCare.gov generally runs from November 1 to January 15. In 2024, January 15 is a federal holiday; accordingly, consumers will have until midnight Tuesday, January 16 (5 a.m. EST on January 17) to enroll in coverage. Consumers who enroll before the January 16 deadline will have coverage that starts February 1, 2024.

As enrollment grows, ACA Marketplace coverage continues to evolve. In addition to important changes for 2024 coverage – including more choices, improved shopping tools, more providers, and improved health equity – CMS recently shared proposed measures to further expand access to more robust, affordable health coverage options for 2025 coverage. For example, if finalized, these measures would, among other things, allow states to add routine adult dental services as an essential health benefit (EHB) by updating their EHB benchmark plans. Comments on the proposed policies are due on January 8, 2024.

IDAHO POLICE DEPARTMENT PULLS THE PLUG ON DIVISIVE AUTISM AWARENESS PATROL CAR

The Caldwell, Idaho Police Department abandoned an idea to unveil a new autism awareness patrol car just four days after announcing it.

"We want to respect the autism community and the symbols used to represent them," said Char Jackson, spokesperson for the city of Caldwell, in a news release. "Our role is to always remain neutral and unite the community, and the car was causing too much division."

Jackson said the car featured puzzle pieces, which were a popular symbol for autism but have fallen out of favor over the years. She said the department recognized the symbol was a tipping point for some people, with some thinking it was not proper representation. "We just came to realize the car was causing a division in the autism community," Jackson told the Idaho Statesman by phone. "That's the last thing we want to do."

Tiffany Klauba, executive director of the Autism Society of Idaho, called it a difficult subject and said there are camps on both sides of the puzzle-piece symbolism.

The Autism Society of Idaho, which is based in Coeur D'Alene, provides statewide support for those in the community, including help with referrals, estate planning, education, training for businesses and first responders, and assistance with legal issues. Klauba told the Statesman that the organization is trying start more support groups in Southwest Idaho after the Treasure Valley Autism Society dissolved earlier this year.

PIECE OF MIND: "One criticism of the puzzle piece is its implication that autistic people are a problem requiring a solution."

Klauba said some members of the autism community find the puzzle piece symbol to be "extremely offensive," and believe it represents that something is missing and they need to be fixed. Others, however, see it as a way to show their uniqueness and how they fit in like a puzzle piece. "It's very hard to have conversations with individuals about this," Klauba said by phone.

According to a study published in *Autism,* a research journal associated with the United Kingdom's National Autistic Society, the puzzle piece symbol can evoke negative associations. In a study of 400 participants, the researchers found participants associated puzzle pieces with incompleteness, imperfection and oddity.

"One criticism of the puzzle piece is its implication that autistic people are a problem requiring a solution," according to an editorial published in the journal following the study. "A related point is that the puzzle piece implies that autistic people are somehow incomplete and need to be made whole."

Other symbols, such as a rainbow infinity symbol, have become more popular representations for the community, Klauba said. But people often get hung up on the symbol.

"That's not what this is about. This is about autism," she said. "The symbol is such a minor detail in the grand scheme of things."

After police had the car finished, Jackson said she spoke with Klauba and other groups and said the department's decision came after these discussions.

"It was an educated decision that we came to," Jackson said. "We will continue to work with groups like that."

Klauba said the Caldwell Police Department received a heavy amount of backlash after driving the car around town and admitted that police had not done a lot of research on the symbol beforehand. "They did have the best intentions," Klauba said. "They really were trying to bring attention to autism."

WHAT'S HAPPENING

BIPARTISAN LEGISLATION ALLOWS DIRECT ACCESS TO MEDICARE COVERAGE FOR AUDIOLOGICAL SERVICES

American Academy of Audiology has strongly endorsed legislation currently before the House and the Senate to improve outcomes for seniors by allowing direct access to audiological services and streamlining Medicare coverage policies so that audiologists can provide the full range of Medicare-covered diagnostic and treatment services.

Representatives Gus Bilirakis (R-Fla) and Matt Cartwright (D-Penn) introduced the Medicare Audiology Access Improvement Act (H.R. 6445) in the House. Identical legislation (S.2377) was also introduced by Senators Elizabeth Warren (D-Mass) and Chuck Grassley (R-Iowa) and Rand Paul (R-Ky.) in the Senate.

SOUND POLICY: “Allowing audiologists to fully participate in Medicare will provide seniors with improved access to hearing health and balance care.”

This legislation would remove the physician order requirement, reclassify audiologists as practitioners, and allow audiologists to provide Medicare-covered treatment services within their scope of practice. Further expanding access to audio-vestibular care, this legislation would also add audiologists as practitioners to Federally Qualified Health Centers and Rural Health Clinics. The legislation has been endorsed by the National Association of Rural Health Clinics.

“Medicare reimbursement policies should be patient-centered and maximize patient choice whenever possible,” said Congressman Bilirakis. “Updating these policies to allow licensed audiologists to fully participate in Medicare will bring greater parity and provide seniors with improved access to hearing health and balance care.”

According to the National Institute of Health’s National Library of Medicine, the U.S. will have more than 70 million seniors by the year 2030. Seniors are the largest population of Americans with hearing loss. Hearing loss impacts communication and functional ability and is strongly associated with decreased quality of life, cognitive decline and depression.

In addition, there are other studies that demonstrate the link between hearing and dementia and falls in seniors. A study published by the Lancet Commission on Dementia Prevention, Intervention and Care cited 11 risk factors for dementia including hearing impairment in mid-life. The report also stated that dementia typically starts many years before it is recognized. Untreated hearing loss can impact the brain and cognitive health.

There is also a link between untreated hearing loss and falls. According to a study conducted by Johns Hopkins University School of Medicine, an increase in hearing loss in an individual, for instance going from normal hearing to an untreated mild hearing loss, is associated with a three-fold increase in fall risk.

“Age related hearing loss is one of the most common conditions affecting older adults. Left untreated, it can lead to other health risks including dementia and falls,” said Congressman Cartwright. “Outdated Medicare rules make it difficult for seniors with hearing loss to get the care they need. That’s why I’m glad to be working with my colleagues across the aisle to ensure seniors can access a full range of hearing and balance health care services provided by licensed audiologists.”

“Advancing this legislation is necessary to remove outdated barriers that prevent older Americans from receiving the hearing health and balance care coverage that they need and deserve,” said American Academy of Audiology President Bopanna Ballachanda, Ph.D. “Treating hearing loss and balance disorders improves individual’s ability to communicate and connect with loved ones, decreases risk for falls and results in greater overall quality of life. Passage of this cost-effective legislation will give patients timely access to these services and strengthen support for seniors’ mental health and mental acuity in the process.”

In addition to endorsement of this landmark legislation by the American Academy of Audiology, other endorsers include the Academy of Doctors of Audiology, American Speech-Language Association and the Hearing Loss Association of America.

For more information, visit www.audiology.org •

ABOUT THE AMERICAN ACADEMY OF AUDIOLOGY:

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AUDIOLOGY

The American Academy of Audiology serves as the collective voice of audiology. It is committed to advancing the science, practice, and accessibility of hearing and balance health care for thier patients. Representing the interests of audiologists and future audiologists nationwide, the Academy is dedicated to fulfilling its mission: providing quality hearing-care services through professional development, education, research, and increased public awareness of hearing and balance disorders. The American Academy of Audiology is the world's largest professional organization of, by and for audiologists. For more information, visit **www.audiology.org**

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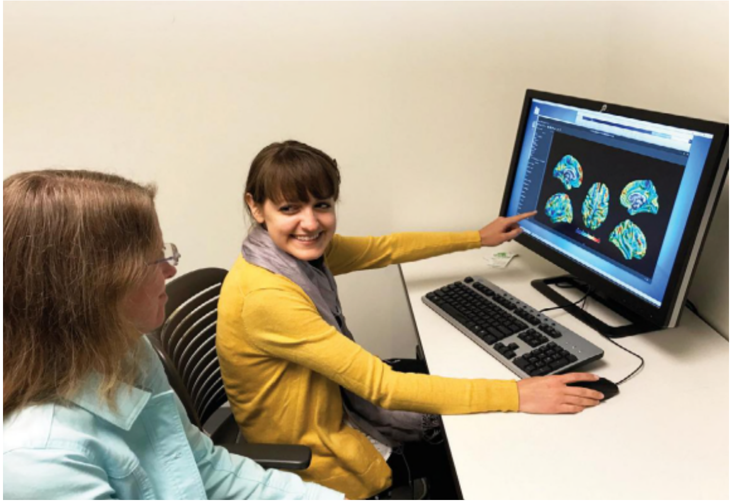
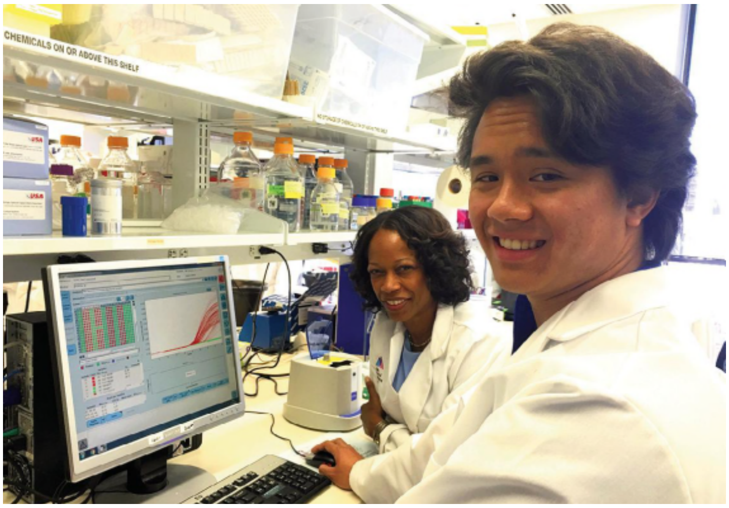
2024 is also the 20th anniversary of Irene and Eric Simon Brain Research Foundation being announced.





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WHAT'S NEW

HAPPY NEW GEAR

ROLLZ MOTION

The Rollz Motion combines a rollator walker and wheelchair in one. As a result, you don't need to worry about your energy when going out as you will have both options with you. This walking innovation keeps you moving. You can walk as long as you want, sit down in the comfortable seat and be pushed to regain some strength, and then walk again if you feel like it. From now on you can always be part of the fun and not miss holidays with your family or days out with your friends. It can easily be transformed from a rollator walker into a wheelchair (and vice versa) on the go whenever it suits you.

ROLLZ MOBILITY US
www.rollz.com

EXPRESS YOUR FEELINGS SENSORY BOTTLES

Provide children with quiet, self-directed, tangible ways to identify how they're feeling, release the energy those feelings create, and calm down. Each bottle features a unique emotion, color, and interactive element that ties to 1 of 4 emotions-happy, angry, scared, and sad. Each bottle mimics a unique emotion, color, and interactive element, and is filled with liquid and material to create a flowing action that represents the emotion. Four easy-to-grip, securely sealed shapes help children learn to use facial and body clues to identify their emotions. Happy includes gold glitter, sad has a slow-motion lava lamp-like effect, angry is red, and scared is green. Move the bottles around and watch the mesmerising motion of the liquid and colour inside. Activity Guide is designed to encourage discussion about responding to emotions in positive, proactive ways.

HAND2MIND
www.hand2mind.com

TOOBALOO

The Toobaloo is an educational tool designed to provide auditory feedback which helps children learn to read and increase fluency and comprehension. By speaking into the Toobaloo, children hear themselves and can make adjustments to fluency, pronunciation and even increase comprehension. Children with special needs such as autism, auditory procession disorder, and dyslexia see remarkable benefits from the auditory feedback process of listening to themselves read aloud.

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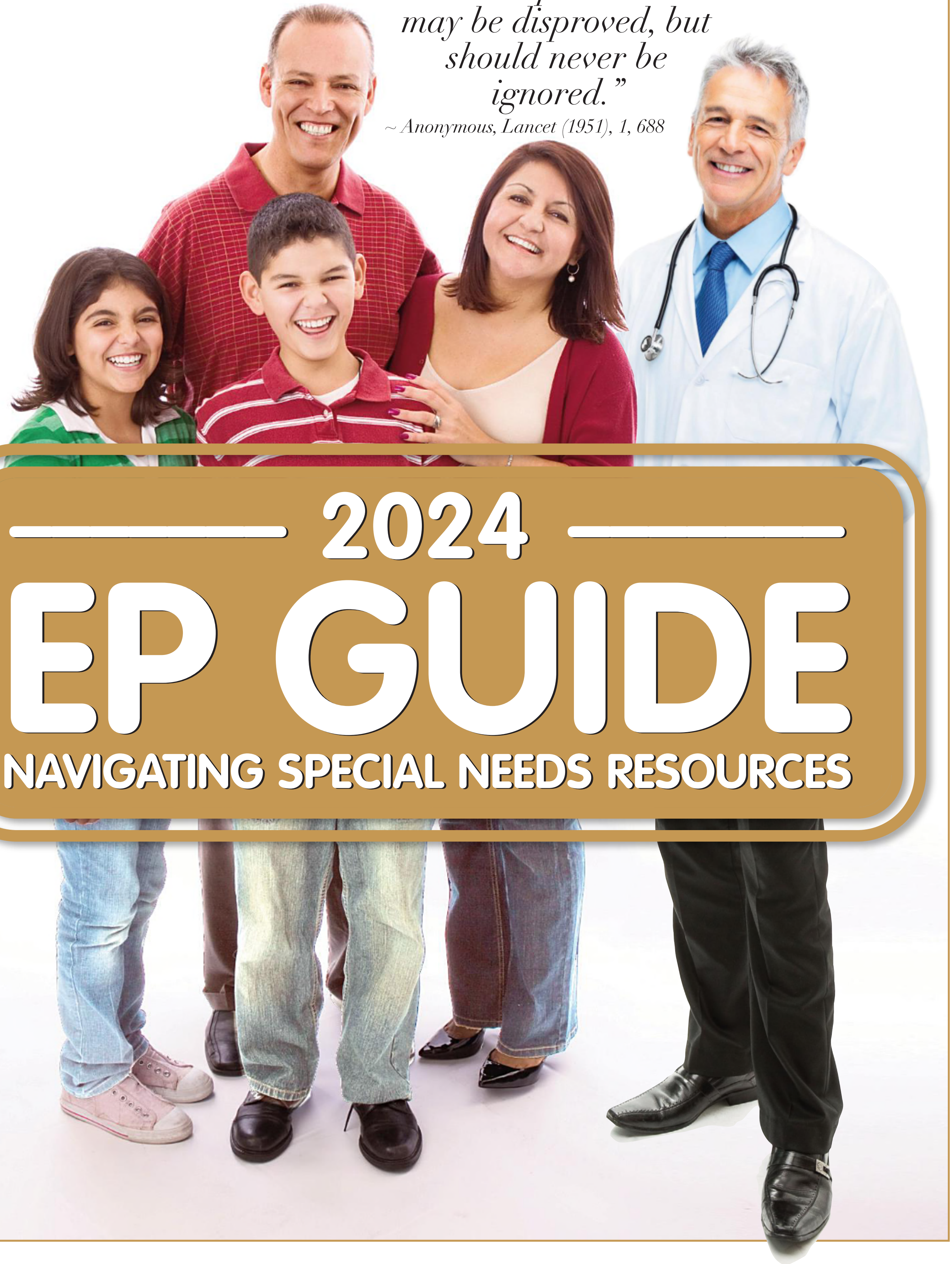
should never be
ignored."
~ Anonymous, Lancet (1951), 1, 688



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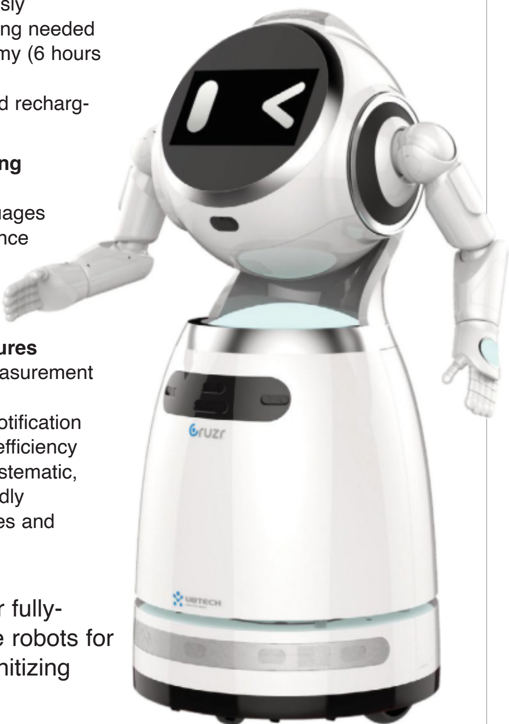

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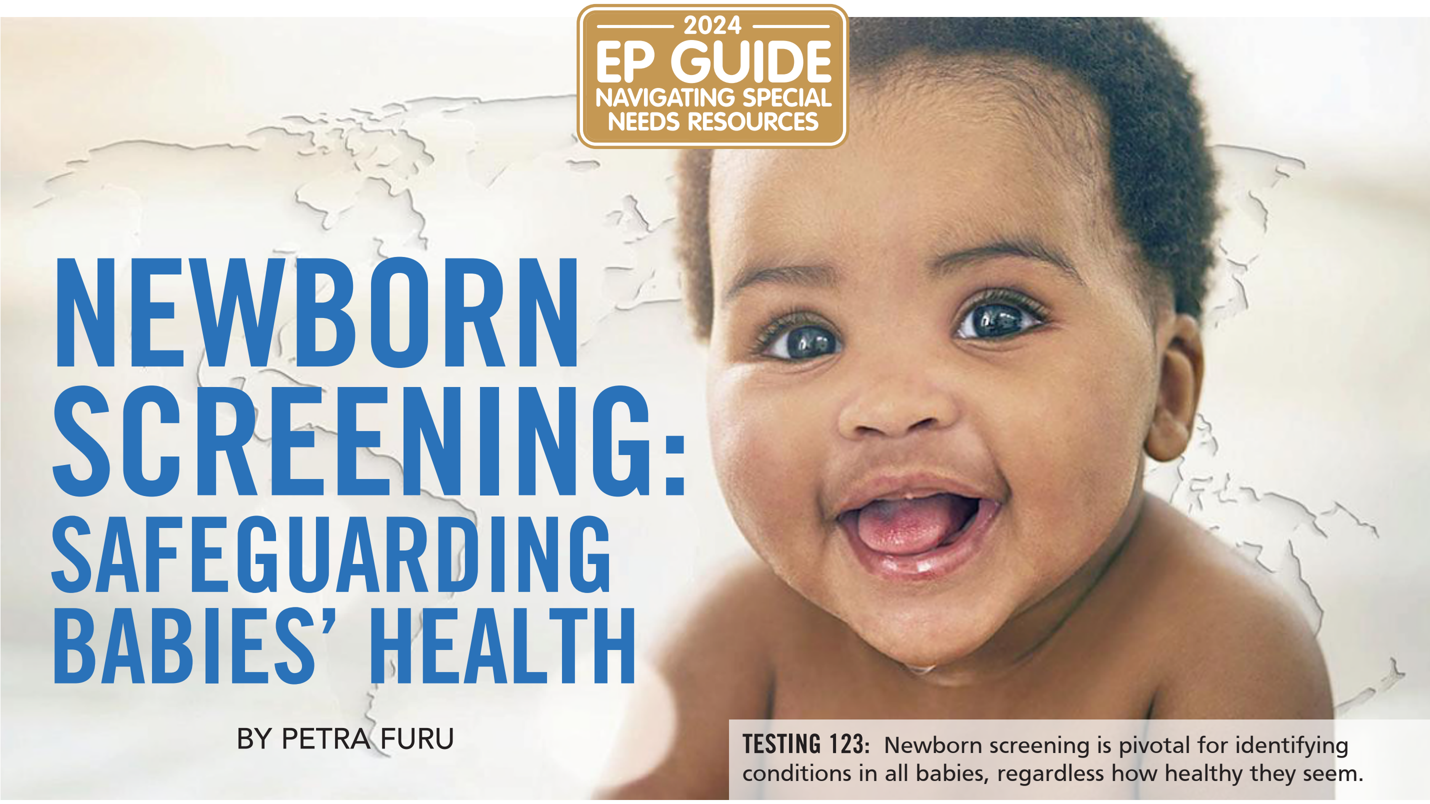
NEWBORN SCREENING: SAFEGUARDING BABIES' HEALTH

BY PETRA FURU



TESTING 123: Newborn screening is pivotal for identifying conditions in all babies, regardless how healthy they seem.

Newborn screening can prevent hundreds of thousands of instances of physical and mental disabilities and even deaths.

WHAT IS NEWBORN SCREENING (NBS)?

When a baby is born, a healthcare professional will administer a simple heel prick to collect a blood spot sample, which typically occurs 24 to 48 hours after birth. The dried blood spot (DBS) card is then shipped to a lab where it can be punched into smaller specimen samples to undergo various sample prep processes, then ultimately be processed by different technologies at a specialized NBS lab. Depending on the country/region of the birth and the family's option, the scope of the screened conditions may vary. However, a couple of the most common diseases that are universally screened for include:

- **Congenital hypothyroidism (CH)** is defined as thyroid hormone deficiency, which can lead to irreversible neurological deficits. as well as poor appetite and breathing problems.[1] The overall incidence of CH ranges from 1 in 3,000 to 1 in 4,000 live births, with variation worldwide among different ethnicities.
- **Phenylketonuria (PKU)** is caused by a change in the phenylalanine hydroxylase (PAH) gene that can quickly cause infants to exhibit irritability, posturing, increased deep tendon reflexes, a peculiar "mousy" odor and vomiting.[2] Approximately 1 in 12,000 Caucasians are born with PKU.

Beyond the disorders above that are more commonly screened for globally, there is momentum to expand screening for other rare diseases, at the time of birth. In some instances, states and countries are just beginning to build these disorders into their newborn screening programs:

- **Spinal Muscular Atrophy (SMA)** is a genetic disorder that affects approximately 1 out of every 10,000 people.[3] Most cases of SMA occur when a segment of a gene called SMN1 is missing. This gene is primary responsible for making survival motor neuron protein, which is required for maintaining normal, motor neuron function. SMA can affect a baby's ability to swallow, breathe, sit, and walk. However, without early detection and treatment, SMA can cause premature death.
- **Duchenne Muscular Dystrophy (DMD)** is a genetic disorder characterized by progressive muscle degeneration and weakness due to the alterations of a protein called dystrophin that helps keep muscle cells intact.[4] In Europe and North America, the prevalence of DMD is approximately 6 per 100,000 individuals. The disease primarily affects boys, but in rare cases it can affect girls. Muscle weakness is the principal symptom of DMD.
- **Mucopolysaccharidosis type II (MPS II)** is a rare inherited lysosomal storage disease, mostly found in boys (also recognized as Hunter syndrome), in which the enzyme is missing or the body does not have enough of an enzyme needed to break down long chains of sugar molecules, called glycosaminoglycans (GAGs).[5] As a result, the molecules build up in different parts of the body and cause damage that leads to various symptoms, between the ages of 18 months and four years, including coarsened facial features, such as: full lips, rounded cheeks, and a broad nose, an enlarged tongue and vocal cords. Many other organs and tissues can become enlarged with MPS II, including the head, liver and spleen, while growth for children with MPS II usually slows by the age of 5.

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1. www.ncbi.nlm.nih.gov/books/NBK558913
2. www.mayoclinic.org/diseases-conditions/phenylketonuria/symptoms-causes/syc-20376302
3. www.cdc.gov/nceh/dls/nsmbb_sma.html
4. www.mda.org/disease/duchenne-muscular-dystrophy
5. www.mountsinai.org/health-library/diseases-conditions/hunter-syndrome

PHOTOS PROVIDED BY PETRA FURU

WHY DOES NBS MATTER?

According to the CDC, each year, more than 13,000 newborn babies are identified with abovementioned conditions, and more. NBS has been proved to be a relatively easy and cost-effective way of improving the overall health of a population. A simple heel prick of a newborn, in the first week of life, is all that is needed to screen for up to 50 inherited conditions.

Many disorders screened today show no signs in the first few weeks of life, which means a seemingly healthy baby could have a condition that may affect mental and physical development or cause early death. Through screening, potentially life-threatening conditions in the first stages of life are identified for timely treatment and therapies to be introduced. The treatment for conditions can also be straightforward and inexpensive, such as dietary changes or the introduction of a supplement. Some therapies also require knowledge of an individual's precise genetic code, which makes genetic testing crucial, not only for diagnosis, but also future treatments.

SCREEN TIME: When a baby is born, a healthcare professional will administer a simple heel prick to collect a blood spot sample.

WHAT ARE THE CURRENT PROGRAMS THAT HELP PROMOTE NBS NATIONALLY AND INTERNATIONALLY?

NBS programs are required by law in all 50 U.S. states, the District of Columbia and Puerto Rico. The Recommended Universal Screening Panel (RUSP)[6] – a list of primary and secondary disorders that all newborns should be screened for, was established in 2002 by the Department of Health and Human Services (HHS) to guide each of these individually led programs.

Today, the RUSP includes CH, PKU, SMA, severe combined immunodeficiency (SCID), and cystic fibrosis, to name a few. As science evolves and innovation in the detection and treatment of congenital diseases continues, groups of researchers, physicians and patient advocacy organizations petition to add new disorders to the RUSP.

In 2022, Parent Project Muscular Dystrophy submitted its newest nomination package[7] to add DMD to the list. A core component of this submission was the completion of a large pilot study in October 2021 to help demonstrate the efficacy of testing newborns for DMD. Exciting news has also come out in October 2023, when Governor Hochul of New York State[8] signed bill S6814/A5042, making Duchenne NBS mandatory for all babies born in the state.

There have also been efforts making NBS more accessible for populations around the world. For example, the Noguchi Memorial Institute for Medical Research (NMIMR)[9] has trained seven countries in sub-Saharan Africa, including: Ghana, Nigeria, Liberia, Uganda, Tanzania, Kenya and Zambia, to efficiently screen newborns for sickle cell disease (SCD).

NBS is pivotal for identifying conditions in all babies, regardless how healthy they seem. With the collaboration between test providers, labs and governments, more and more newborns around the world are getting the medical treatments they need, in a timely fashion. As the understanding of the potential life-altering impacts of NBS rises, we hope to advance the technology thorough various tools we currently have, and make it more convenient and affordable for all populations, to truly democratize NBS for millions of families.•

ABOUT THE AUTHOR:

Petra Furu is the general manager of reproductive health at Revvity. She is solution driven and forward looking, leading by example. She is passionate about driving the right decisions to help provide solutions enabling a healthy start in life. Petra has a PhD in biochemistry and eMBA in strategic business and organizational management. She has worked in science, product management and strategic business planning, as well as research and development. Petra has strong knowledge about both IVD and medical device industry regulations.

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6. www.hrsa.gov/advisory-committees/heritable-disorders/rusp
7. www.parentprojectmd.org/ppmd-submits-rusp-nomination-package-for-duchenne-muscular-dystrophy/
8. www.parentprojectmd.org/duchenne-added-to-new-york-states-newborn-screening-panel/
9. https://gna.org.gh/2023/09/noguchi-revvity-train-seven-consa-countries-to-enhance-newborn-sickle-cell-screening/

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THERE ARE MANY EMOTIONAL AND FINANCIAL RESOURCES AVAILABLE TO HELP YOU CARE FOR YOUR CHILD WITH A BIRTH INJURY

TOP 8 RESOURCES FOR PARENTS WHO HAVE A CHILD WITH A BIRTH INJURY

Did you know that 30,000 infants are born each year with a birth injury? [1]

BY MARK MCKENNA

Parenting is a challenging journey in itself, but when a child faces a birth injury, the path can become even more daunting. Coping with the emotional, physical, financial, and logistical challenges can be overwhelming and even scary. However, you aren't alone in this journey. There are numerous resources available to help you navigate the complexities of caring for a child with a birth injury. Below, we explore some of the top resources that can empower and support you as you raise your child.

WHAT IS A BIRTH INJURY?

A birth injury refers to any physical harm or damage that occurs to an infant during the process of childbirth or shortly after. These injuries can result from various factors, including medical complications during labor and delivery, the use of medical interventions such as forceps or vacuum extraction, or the baby's position during birth.

Birth injuries can range in severity from mild to severe, and they can have both short-term and long-term consequences for the child's health and development. In cases where medical negligence or improper medical care is a contributing factor, you can pursue legal action to seek compensation for your child's injuries and associated medical expenses.

Several common types of birth injuries include:

- **Cerebral palsy:** *Cerebral palsy is a group of neurological disorders that affect movement and muscle coordination. It can result from brain damage or abnormalities that occur before, during, or shortly after birth.*
- **Preeclampsia:** *This complication is characterized by high blood pressure during pregnancy and, if not treated immediately or correctly, can result in brain damage or cerebral palsy.*
- **Hypoxic-Ischemic Encephalopathy (HIE):** *HIE is a condition caused by reduced oxygen and blood flow to the baby's brain during labor and delivery. It can lead to brain damage and neurological deficits.*
- **Fractures:** *In some cases, infants may experience bone fractures during delivery, typically involving the collarbone or clavicle. These fractures usually heal with proper medical care.*
- **Intracranial hemorrhage:** *This refers to bleeding within the baby's brain, which can occur due to trauma during delivery or other medical complications.*
- **Facial nerve injury:** *This injury involves damage to the facial nerve, which can lead to facial paralysis in newborns, often from pressure or trauma during delivery.*
- **Infections:** *Infections acquired during birth, such as Group B Streptococcus or neonatal sepsis, can lead to a range of health issues for the newborn.*
- **Brachial plexus injury:** *This type of injury involves damage to the network of nerves controlling the arm and hand muscles. It can occur when excessive force is applied during delivery, leading to conditions like Erb's palsy or Klumpke's palsy.*

Birth injuries can be devastating for you, your family, and your child. Healthcare providers, including obstetricians, nurses, and midwives, are trained to minimize the risk of birth injuries, and provide appropriate care during labor and delivery. In cases where a birth injury is suspected to be the result of medical negligence or improper care, you can take legal action to seek justice and compensation to cover your child's medical expenses and long-term care needs.

It's crucial to consult with legal experts and medical professionals to determine the specific circumstances surrounding a birth injury, and the options for addressing it.

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[1] www.cerebralpalsyguide.com/birth-injury/statistics

BUILDING A SUPPORT NETWORK : TOP EIGHT RESOURCES FOR PARENTS WHO HAVE A CHILD WITH A BIRTH INJURY

EMOTIONAL SUPPORT RESOURCES FOR FAMILIES WITH BIRTH INJURIES

Coping with a birth injury can be emotionally challenging. Fortunately, there are numerous resources to help you get the emotional support you need, as you navigate these life changes.

1. MEDICAL PROFESSIONALS AND SPECIALISTS

It's critical to establish a network of medical professionals who specialize in the specific condition or injury. This may include pediatricians, neonatologists, pediatric neurologists, orthopedic specialists, and therapists (physical, occupational, or speech). These experts will play a crucial role in diagnosing and managing the injury, and developing a treatment plan tailored to your child's needs, as well as answering any questions you may have.

2. SUPPORT GROUPS

Connecting with other parents who have experienced similar challenges can provide invaluable emotional support and a sense of community. Various support groups and organizations focus on specific birth injuries or disabilities. For example, organizations like the United Brachial Plexus Network (**ubpn.org**) offer resources and a network of support for families dealing with brachial plexus injuries. The March of Dimes (**marchofdimes.org**) provides support for families dealing with premature birth-related complications. Momique (**momique.org**) also offers niche support groups, including the Birth Trauma Support Group. Joining these groups can help you navigate your unique journey and gain insights into managing your child's condition.

3. MOMMY AND ME GROUPS

Parents can connect with their children and other like-minded parents by joining Mommy and Me Groups. Mommy and Me groups often consist of parents who are facing similar challenges and experiences. In these groups, parents can connect with others who understand the unique struggles, emotions, and triumphs associated with raising a child with a birth injury.

4. MOBILE APPLICATIONS

Mobile apps like Peanut (**peanut-app.io**) offer an opportunity for women to connect with other women who are navigating their children's brain injuries. Peanut connects women who plan to become pregnant, are pregnant, and are mothers. According to the app, it's a "safe space to ask questions, find support, and connect with other women."

FINANCIAL SUPPORT RESOURCES FOR FAMILIES WITH BIRTH INJURIES

Navigating the legal and financial aspects of caring for a child with a birth injury can also be overwhelming. Parents should seek out legal assistance and financial planning services that specialize in disability and healthcare law. Understanding your rights and available financial resources, such as Medicaid or disability benefits, is essential for ensuring that your child receives the care they need.

5. CHARITY ORGANIZATIONS

There are several charitable organizations and foundations that provide financial assistance and support to families that have a child with a birth injury. For example, Variety – The Children's Charity (usvariety.org) provides financial assistance to families with children who have disabilities or special needs. This can include covering the cost of medical equipment, therapy, or other essential services.

6. HEALTH INSURANCE

When choosing a licensed and accredited health insurance company, make sure that your child's chosen providers are included in that network.

7. GOVERNMENT PROGRAMS

Government programs can also help support families navigating a birth injury. Supplemental Security Income (**ssa.gov/ssi**) provides monthly payments to people with disabilities, while Medicaid provides healthcare coverage to eligible low-income individuals and families, including children with disabilities. Alternatively, the Children's Health Insurance Program provides low-cost or no-cost health insurance coverage for children in families who earn too much to qualify for Medicaid, but cannot afford private insurance.

8. COMMUNITY-BASED ORGANIZATIONS

Community-based organizations or hospitals are also helpful financial resources. For example, Easter Seals (**easterseals.com**) offers a wide range of services, including: medical rehabilitation, therapy, and support for children with disabilities, including birth injuries. This organization has local chapters across the U.S. Additionally, Shriners Hospitals for Children (**shrinerschildrens.org**) has locations throughout the U.S. and provides specialized pediatric care, at no cost to families.

NAVIGATING YOUR CHILD'S BIRTH INJURY

Parenting a child with a birth injury may present unique challenges, but it also opens doors to a vast array of resources and support systems. These resources, ranging from medical professionals to legal assistance, to advocacy groups, are essential in helping parents provide the best possible care for their children. By tapping into these resources and building a strong support network, parents can navigate the complexities of caring for a child with a birth injury with unwavering resilience and strength. •

ABOUT THE AUTHOR:

Mark McKenna, a partner at Hurley McKenna & Mertz (**mmckenna@hurley-law.com**), has been a trial lawyer since 1994. He has extensive trial experience in the Illinois state courts, and state and federal courts throughout the U.S., including Wisconsin, Indiana, Michigan, Nevada, Florida, Ohio, and Maryland. He has successfully won more than $75 million for families with children who have birth injuries.

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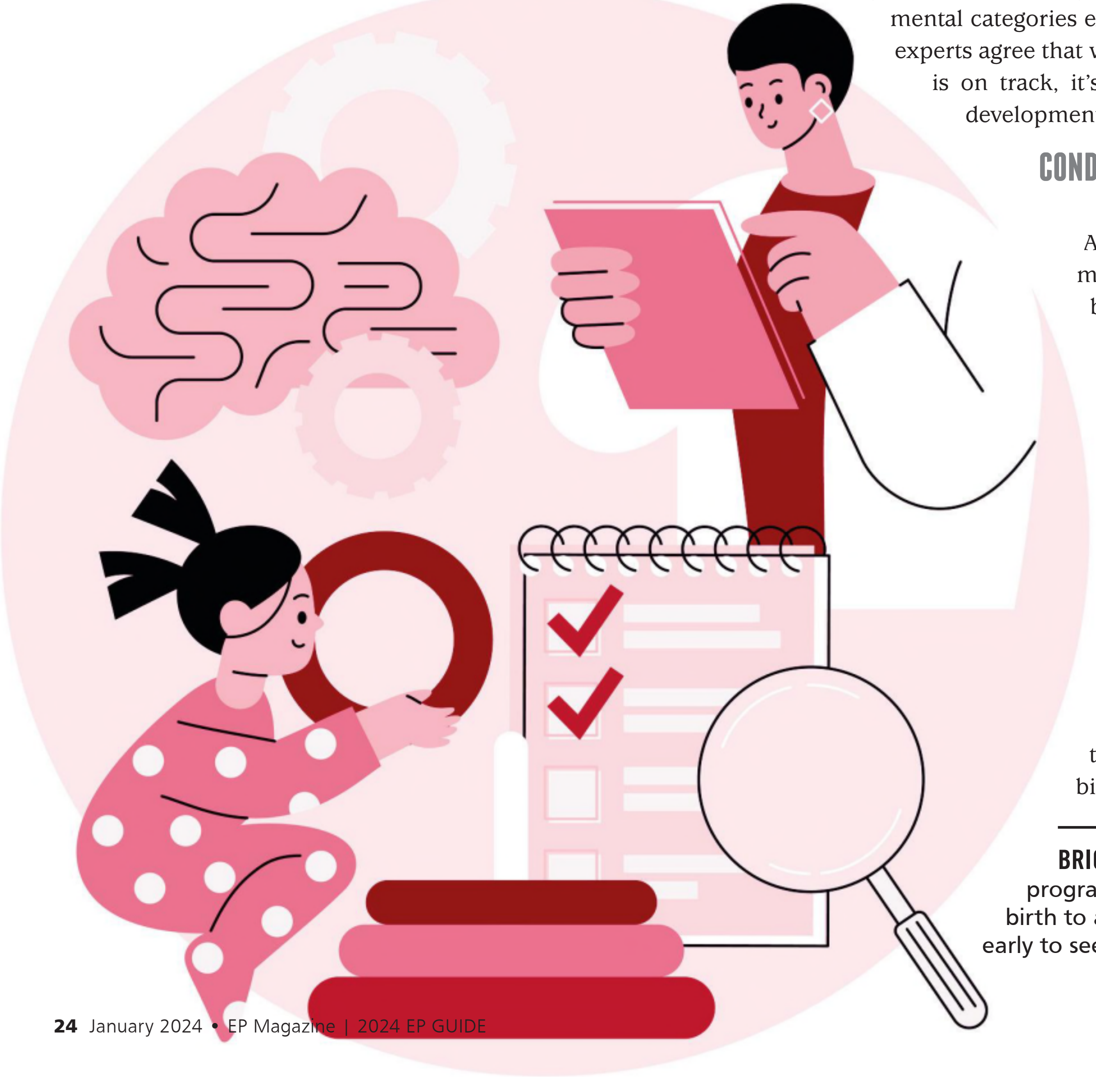
EARLY SCREENING
FOR DEVELOPMENTAL DELAY AND DISABILITY

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

All babies are individuals, learning and growing at their own rate. Some will reach certain developmental milestones before others. Sometimes, pediatricians attempting to allay an anxious parent's concerns will tell parents not to worry too much about the pace of a child's development.



While that makes sense in many cases, sometimes it can result in a child with a developmental delay, needlessly falling further behind. So, how can a parent know how early to seek a developmental screening?

EARLIER IS BETTER THAN LATER

Among the reasons early intervention is so effective in helping a child narrow and often close developmental gaps is that a child's brain is most adaptable in the first three years of life. That's why early intervention programs in the U.S. are generally offered to those birth to age three. Because so much development takes place in this brief period of time, and various developmental categories exert influence on one another, most experts agree that when a parent isn't sure if their child is on track, it's almost never too early to seek a developmental screening.

CONDITIONS THAT PUT A CHILD AT RISK FOR DEVELOPMENTAL DELAY

Any child can experience developmental delays, which are thought to be the result of a complex mix of factors. In fact, the Centers for Disease Control (CDC) reports an estimated one in six, or about 17 percent of children aged 3 through 17, has one or more developmental disabilities. Some conditions that are known to increase a child's risk, include fetal alcohol syndrome, as well as genetic conditions such as: Down syndrome, Fragile X syndrome, and Prader-Willi syndrome, among others.

In addition, it's been established that numerous other factors in combination, can put a child at greater

BRIGHT AND EARLY: Early intervention programs are generally offered to those birth to age three, but it's almost never too early to seek a developmental screening.

risk. Your pediatrician will likely be on the look-out for these, and recommend early intervention services right away. Just a few examples include: premature birth of less than 32 weeks gestation and/or low birth weight of less than 1,500 grams (3.3 pounds); assisted ventilation for 48 hours or longer during the first 28 days of life; neonatal seizures or non-fever-related seizures during the first three years of life; insufficient oxygen before, during or directly after birth with a five-minute Apgar score of 0-5; and one or both parents with a developmental disability.

WHAT TO EXPECT AT A DEVELOPMENTAL SCREENING

A well-structured developmental screening will involve expert professionals who assess the child's functioning in key developmental areas. This will include cognitive development, involving memory and imitative behavior, as well as physical development, which refers to gross motor and fine motor skills, along with vision and hearing. It will also cover communication, including both receptive language (understanding others) and expressive language (age-appropriate talking and other expression), social/emotional development which covers things like infant-caregiver attachment, and adaptive skills such as feeding.

At the conclusion of the screening, the parent is provided with a "score" indicating how their child is doing in each category. In California, the child will be eligible for early intervention services if the screening uncovers a delay of 25 percent or more in any of these categories.

STEPS TO TAKE AFTER SCREENING

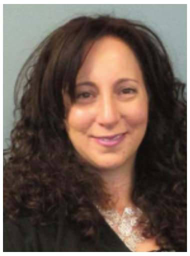
If your child's developmental screening was performed at a community screening event, such as those that Regional Center of Orange County hosts regularly, it's likely the organizer will be prepared to provide referrals to appropriate local resources to get help. In California, families access early intervention services (through the Early Start program) through local regional centers like RCOC. However, these services and supports are funded by the federal government and are available in every U.S. state and territory, and are provided free or at reduced cost.

Here is a link to the Centers for Disease Control website page, where you can locate the early intervention contact in your state or territory: **www.cdc.gov/ncbddd/actearly/parents/states.html#textlinks**.

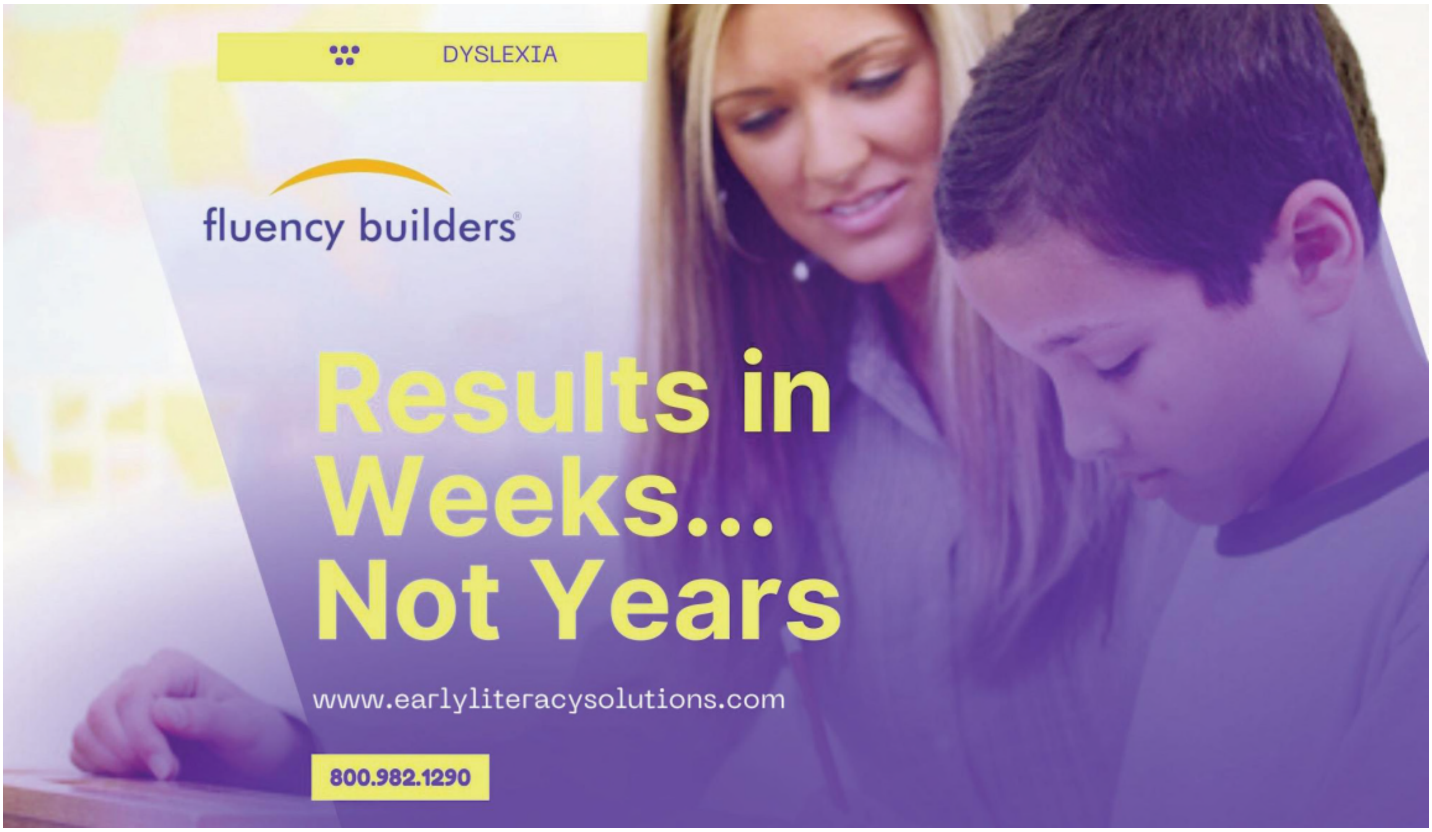
If you are unable to connect with an early intervention contact, another great place to start would be a local Family Resource Center (FRC). Throughout the United States and in many other countries, FRCs are typically funded by state or national governments, and help to connect families to local social services, public benefits and other support services they may be eligible to receive.

Remember, if it's determined your child has any delay, it's important to get help, as soon as possible. Early intervention is known to be phenomenally successful in helping children narrow and sometimes even close the developmental gap, which can have a huge and positive impact on the child's ability to learn and succeed in school and in life. •

ABOUT THE AUTHOR:



A clinical psychologist, Bonnie Ivers, M.A., Psy.D., is Clinical Director for Regional Center of Orange County, (**www.rcocdd.com**) the private, nonprofit organization contracted by the State of California to coordinate lifelong services and supports for more than 25,000 Orange County residents with developmental disabilities and their families. The Regional Center is the first stop for those seeking to obtain local services and supports to help them live safely and with dignity in the community. Developmental disabilities include intellectual disabilities, autism, epilepsy and cerebral palsy.



FOR PARENTS OF MULTIPLE CHILDREN WITH DYSLEXIA

6 TIPS TO SUCCEED

BY GEORGIE NORMAND, M.A.

It's both possible and even likely that if you already have one child with dyslexia, one or more of their siblings may also struggle with the process of learning to read. This is especially true if either parent experienced problems learning to read, write, or spell.

Dyslexia, the most common learning disability, affects 15-20% of the population and can occur in up to half of those children who have a parent or sibling with dyslexia. The risk and severity are greater when both parents have dyslexia.

Managing the academic success of just one child with dyslexia can be challenging. Since dyslexia is not a one-size-fits-all reading disability, working towards successful outcomes for multiple children with dyslexia can feel a lot like juggling balls. If that's how you feel, the following tips can help you navigate the process with less stress and more success.

DOUBLE DUTY: Help each child discover and focus on their strengths. Giving them time to develop their gifts individually will create resilience, build confidence, and improve self-esteem as they tackle and conquer reading, writing, and spelling skills.

TIP #1: AVOID PARENTAL GUILT SYNDROME

Whether you are their primary tutor, you've hired a private tutor, or the intervention takes place in the school (or some combination of these options), you will seldom feel that you are doing enough for each child. Replace this guilt with action in the form of knowledge, advocacy, and determination.

Expect periods of frustration and discouragement as each child works through the hurdles involved in becoming a proficient reader. The journey will be different for each of them, depending on their specific dyslexia profile, personality, and emotional resilience. Keep your expectations high for all of them and make sure they know you are always there to support them, even when they experience occasional plateaus in their progress. The nagging feeling of not doing enough may tempt you to skip much needed holiday and summer breaks from tutoring. Although breaks in the intervention can certainly cause learning loss, there are ways to minimize the loss and maintain the momentum of reading gains. (See our article, "Fun Ways to Prevent the Summer Reading Slide in Dyslexia" featured in the June 2023 issue of *Exceptional Parent Magazine* at **www.epmagazine.com/archive** to learn more about how to manage breaks from tutoring.)

TIP #2: BUILD AND MAINTAIN THEIR SELF-ESTEEM

Since each of your children can be anywhere on the spectrum from mild to severe, depression might accompany the child with the most severe profile. Children who tend to be more competitive or self-aware, may be highly sensitive to where they stand in reading levels at school compared to their classmates. It's especially important to help this child focus on academic areas of strength, along with extracurricular activities that provide opportunities to excel. When they share their emotions and thoughts about not feeling as smart as their classmates because of their reading struggles, explain to them that dyslexia has nothing to do with intelligence. Introduce them to the many successful individuals with dyslexia from all walks of life. Well known examples include celebrities like: Cher, Tom Cruise, CNN journalist Anderson Cooper, Hollywood director Steven Spielberg, Daymond John from Shark Tank, and super athletes like Muhammad Ali. There are also professors, scientists, and others who did not let dyslexia keep them from their dreams. The genius Albert Einstein was able to achieve more in the field of theoretical physics than many of his fellow scientists who did not have dyslexia.

In fact, some companies are beginning to actively recruit dyslexic individuals, because there is greater awareness of the value of "dyslexic thinking." We know from neuroimaging studies that although dyslexic children approach reading itself in a less efficient way than their non-dyslexic peers, they often recruit other brain regions to help them with reading tasks. This compensatory approach might explain their success in tasks related to problem solving and creativity. Einstein explained that he tended to think in images, and as a visual thinker he was able to produce his greatest work. He also quipped that if you judge a fish by its ability to climb trees, it will live its whole life thinking that it is stupid. As you help each of your children develop their reading proficiency, give them plenty of time to explore and build on their natural talents and abilities.

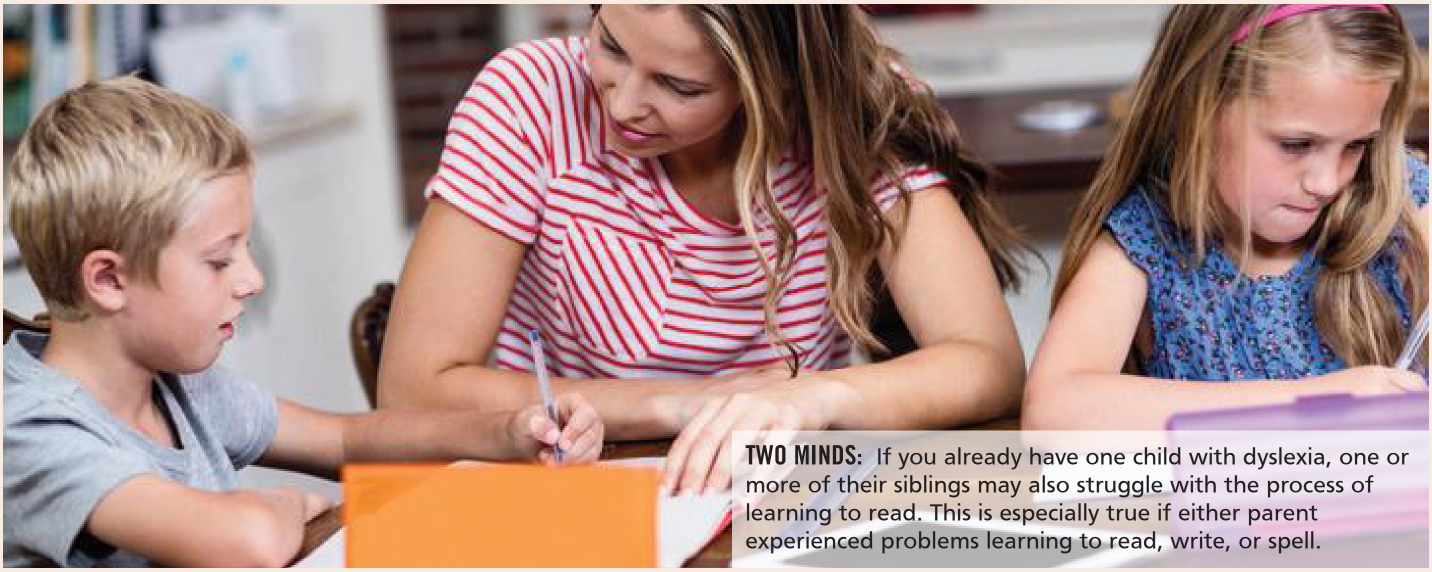
Considering that each child with dyslexia has their own distinct reading profile, it's important that you find out more about each child's dyslexia, to ensure that their profile is being addressed in their individual interventions. This can be done through comprehensive screening that looks at the many components of dyslexia. Don't expect to see the same profile for each of your children, but if they are similar enough, they may be able to be tutored together, either by you or an outside tutor. This is not as unusual as you might think. Dyslexia intervention in schools is mostly taking place in a small group setting of two or three students, where they are grouped according to various measures. But the most logical way of ensuring success is to group your children by level of severity. If you have two children who are severely affected, they could be tutored together and receive the same level of pacing and intensity. If one has severe dyslexia and the other does not, then individual tutoring would be best.

TIP #3: CATCH IT EARLY IN YOUNGER SIBLINGS

The first child in the family to be identified as dyslexic may have endured years of missed opportunities for early reading intervention, with parents frequently being told to wait for testing because the child is not far enough behind. Many children have had to wait until third or fourth grade to be screened for dyslexia, even though they remained at a kindergarten or first grade reading level.

These children lost so much ground academically, not to mention the terrible toll on their self-esteem. This scenario, although still common, is in the process of being turned around because of state legislation requiring early dyslexia screening.

If there is already a family history of dyslexia or reading problems, be on the lookout for any early signs of dyslexia in each child. One of the very first risk factors to show up in a child's life is early language delay, a strong predictor of dyslexia. Not every dyslexic child will experience this, and not every child with early language delay will have reading problems, but parents should certainly ask the school to screen this child for dyslexia, and initiate an early dyslexia-specific intervention, in PreK if possible. Early identification and intervention can prevent reading failure. It's important to know that it is possible to identify young children at



TWO MINDS: If you already have one child with dyslexia, one or more of their siblings may also struggle with the process of learning to read. This is especially true if either parent experienced problems learning to read, write, or spell.

risk of dyslexia by simply screening for early language delay and family history of reading problems in PreK.

There are other assessments that can also be used in early and late PreK. In addition to early language delay and a family history of reading problems, dyslexic children may perform poorly in an assessment called RAN when given in PreK, kindergarten, and even older grades. RAN (rapid automatized naming) tasks measure a child's processing speed in tasks that are very similar to the skills required in reading. Since it is a test of processing speed, the results of this assessment can determine whether the child will have difficulty becoming a fluent reader. Research on the fluency problem in dyslexia found that there are ways to successfully address it during the intervention. Without an intensive intervention that focuses on fluency, a poor performance on this assessment means that the child may eventually read accurately, but never progress to the grade level fluency needed to succeed in reading assignments, school tests, and homework.

Over 60% of dyslexic students score poorly on the RAN assessment because reading itself and the tasks on this assessment rely heavily on executive function, which tends to be weak in dyslexic children. Executive function in reading refers to how well the reading related regions of the brain synchronize with each other. Reading interventions that do not address the executive function issue in dyslexia, often take years and generally fail to bring the child to grade level fluency norms. Intensive fluency training (discussed in more depth in Tip #5 below) is a research-proven intervention strategy to improve executive function in dyslexia. But it is often neglected in favor of phonics instruction. Both should be prioritized.

Most dyslexic students also perform poorly in another skill needed for reading, called phonological awareness or PA. PA relates to a child's awareness of units of sound such as individual words in a sentence, syllables within a word, and the ability to distinguish between words that rhyme and those that don't. Blending the individual sounds in a word and segmenting the individual sounds in a word (so important to spelling) depends on a subskill of phonological awareness called phonemic awareness.

A parent will want to have younger siblings tested for these skills, as early as possible, if there is already one child in the family with dyslexia. Fortunately, early dyslexia screening is being mandated in most states, but a yes/no screener is not very helpful. Each younger sibling should be screened in PreK or kindergarten with a comprehensive screener that includes other indicators of risk for dyslexia, such as poor verbal working memory. Once the child has been able to benefit from formal instruction in letter name and letter sound knowledge and basic phonics instruction, these skills should also be included in the screening. By mid-first grade, their oral reading of simple passages can be assessed for fluency and comprehension.

TIP #4: WHAT ELSE TO LOOK FOR IN YOUNGER SIBLINGS

A younger sibling may not display the same signs of dyslexia as an older sibling with dyslexia. However, weak verbal working memory leading to difficulty following oral directions with two or more steps is prevalent among children with dyslexia. Many dyslexic children also display early handwriting issues (dysgraphia) that may include a noticeably awkward pencil grip, and some dyslexic children also find simple math concepts difficult (dyscalculia). Additional interventions may be needed for each of these co-occurring conditions. If the dysgraphia is severe, it might be helpful to consult with an occupational therapist.

They may each need a different level of support and intervention. One of your dyslexic children may be a very quick learner and even be considered "gifted," (often referred to as "twice exceptional" or "2E"), while others in the family with dyslexia may be of average intelligence and aptitude. ADHD frequently coexists with dyslexia, and this condition can interfere with the progress of any reading intervention. If one of your dyslexic children also has ADHD, you will want to find the best way of addressing it, so that the intervention can be successful. For more information, visit the International Dyslexia Association's discussion on this topic **https://dyslexiaida.org/attention-deficithyperactivity-disorder-adhd-and-dyslexia**. Of course, great things can be accomplished by each of your children regardless of their profile.

Interestingly, the errors made by dyslexic children are not the same errors made by beginning readers, although it may appear that way at first. As they begin to read whole paragraphs or pages of a book or short story, you will see a myriad of unusual reading behaviors emerge, that are not typical of other young readers. To learn more about these reading behaviors, you might find the following resource helpful in *Exceptional Parent Magazine*'s Archive for September 2022: "What Dyslexia Looks Like by Grade Level" at **www.epmagazine.com/archive**.

TIP #5: ADVOCATE FOR EACH CHILD

Make sure the younger siblings are tested/screened for dyslexia before they fail. This means, as early as possible, either PreK or Kindergarten. If the screening or testing finds that the child has deficits associated with dyslexia, waste no time in advocating and pressing the school for an IEP (Individualized Educational Program) for this child. Without the IEP in place, there is no guarantee that your child will receive an evidence-based reading intervention that is dyslexia-specific. Instead, they are likely to receive more of the core reading curriculum that has already failed them. For more information on the IEP process, visit Dyslexia Help at the University of Michigan **https://dyslexiahelp.umich.edu**.

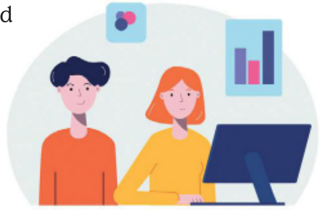
Stay vigilant to be sure the IEP is being followed and that appropriate accommodations are in place for tests and other challenges. An example would be spelling tests. Until your child has made significant progress in spelling, weekly spelling tests should be reduced to a few words, and grading should accommodate your child's level of progress. Certain standardized tests may also require the teacher to read the test questions orally, to give your child a fair chance at a successful outcome. Remember that the law is on your side. To learn more about your rights, visit Dyslexia Help at the University of Michigan. **http://dyslexiahelp.umich.edu/parents/living-with-dyslexia/school/know-your-rights**.

The greatest challenge in dyslexia intervention is helping each child reach grade level reading fluency norms. Fluency training provides a shortcut to gains in every reading measure, not just fluency. So, no matter what their unique dyslexia profile is, make sure that intensive fluency training is included in the intervention for each of them. This means that the intervention should include timed repeated reading, and timed repeated handwriting tasks with word lists and sentences, that are based on instruction that they have been explicitly taught. Handwriting fluency facilitates reading fluency, so timed repeated handwriting tasks are just as critical to achieving reading proficiency as timed repeated reading tasks.

TIP #6: TAKE ADVANTAGE OF NEW TECHNOLOGIES AND RESOURCES

While your children are working to improve reading proficiency, take advantage of the many learning resources on YouTube and audio book resources, such as Learning Ally at **https://learningally.org**. Audio books will give each child opportunities to explore their own individual interests, acquire vocabulary, and develop comprehension skills.

There are a host of assistive technologies that will make schoolwork and homework so much easier. To learn more about them, visit the Yale Center for Dyslexia & Creativity **https://dyslexia.yale.edu/resources/tools-technology**.



Again, help each child discover and focus on their strengths. Provide time every week for them to build on these strengths, which can appear in the form of a hobby, sport, academic interest, or special talent. Giving them time to develop their gifts individually will create resilience, build confidence, and improve self-esteem as they tackle and conquer reading, writing, and spelling skills.

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

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SUPPORTING YOUR CHILD'S READING JOURNEY

BY DR. PRARTHANA FRANKLIN-LUTHER, PH.D.

It is tough to see your child struggle with reading. It can be overwhelming to figure out what's going on and how to help.

You should know you are not alone in this. Reading challenges are one of the most common learning difficulties, and it has nothing to do with how smart a child is. The good news is that over the last twenty years, researchers have identified effective strategies to help children with reading challenges. Let's explore these strategies alongside common questions that parents have.

1. HOW CAN I SUPPORT MY CHILD WHEN THEY ARE STRUGGLING WITH SCHOOLWORK BECAUSE OF READING DIFFICULTIES?

When reading is challenging, your child might find it hard to keep-up in school. While you're waiting for extra help from their teacher or school, there are assistive tools your child can use at home and in school, that can make a big difference. While these are not a replacement for specialized reading intervention, they can play a crucial role in keeping pace with classmates and staying engaged with schoolwork.

- *Physical reading aids like finger pointers or colorful magnetic letters can help your child track words on a page to make reading more interactive and hands-on.*
- *Text-to-speech software reads the words on the screen out-loud. By hearing the content, your child can better understand the information.*
- *Speech-to-text software allows children to say their thoughts out-loud, and the software will write it down. This can help your child manage writing-based tasks.*

These tools can help bridge the gap until the school can offer more tailored support. Plus, they can make learning fun.

2. IF ONE OF MY CHILDREN IS FACING READING STRUGGLES, SHOULD I BE WORRIED ABOUT MY OTHER CHILD'S READING ABILITIES?

If one of your kids is having a hard time with reading, you might wonder about your other kids. It is normal to think this way. Reading problems can run in the family, but it is important to remember that each child's reading journey is unique. Here are some ways to make sure your other child is on the right track:

- *Keep an eye on your child's reading behaviors for clues. Do they usually avoid reading? Can they understand what they read? Closely observing these behaviors can provide some insight into whether your child is struggling with reading.*
- *Talk to your child's teacher about how they are doing with reading at school. You can ask questions like "Does my child seem engaged and interested during reading activities?", "How is my child doing with letter-sound relationships?", "Are they willing to read out loud in class?", "How are they doing with this skill?". Teachers can tell you a lot about your child's reading behavior and engagement.*
- *Get a reading assessment for your child. An assessment could give you important information about your child's reading skills. This does not mean you are expecting problems. Rather, it is about being informed and prepared to help. Catching any reading issues early can make it easier to help them get better at reading.*

These are some of the positive steps you can take to ensure each of your children receive the support they need to be successful in reading.

> “Every child has their own pace when it comes to reading. Reading challenges don’t reflect on your child’s intelligence or potential.”

BY THE BOOK: Get a reading assessment for your child. An assessment could give you important information about your child’s reading skills. Catching any reading issues early can make it easier to help them get better at reading.

3. HOW CAN I HELP MY CHILD WHILE WAITING FOR SCHOOL INTERVENTION SUPPORT?

Research shows that a supportive home environment can be very beneficial for children’s reading development. While you're waiting or advocating for the school to step in, here are things you can do at home.

- *Create a supportive and engaging reading environment at home. You can set aside a specific reading time and cozy reading space at home. This will show your child that reading is an important part of their daily activities.*
- *Another great way to motivate your child to read is to help them find books they are interested and excited about, but are still easy enough for them to follow and read on their own or create and tell you their own story out of the pictures. You can also pick some of these simpler books to read together, doing repeat readings or asking them questions about the pictures, to help build their skills. This balanced approach can boost their excitement for reading and improve their reading ability.*
- *You can encourage your child to create their own stories. They can tell you a story out loud and you can type it out for them, and then read the stories together. Afterwards, let them try reading these stories independently. This activity is not only fun, but also boosts their engagement, gives them a sense of control over what they're reading, and helps adjust the reading level to their comfort.*
- *There are various online programs that turn reading practice into fun activities. This can be an interactive and engaging way for your child to practice reading and build competency.*
- *Avoid pushing your child to read excessively, as it can lead to more avoidance. Remember, reading should feel like fun, not a chore. Let them choose when to pick up a book, and they will likely enjoy it.*

Every child has their own pace when it comes to reading. Reading challenges don't reflect on your child’s intelligence or potential. Simple steps like utilizing assistive and digital technology, monitoring your children’s reading habits, and fostering a love for reading at home while waiting/advocating for school support, can work wonders. Your role as a supportive parent is invaluable in your child’s journey towards reading mastery and a love for learning! •

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Dr. Prarthana Franklin-Luther is a scholar and researcher with over 20 peer-reviewed publications in the areas of parenting, child health, and developmental outcomes. She is the Senior Research Scientist at Sharpen.com She received her Ph.D. in Child and Youth Studies from Brock University and then completed a Postdoctoral Fellowship at McMaster University, where she researched cognitive, behavioral, and social outcomes of preterm-born children. Dr. Franklin-Luther has presented her research findings at various conferences and has been cited in media outlets like CBC.ca. Clinically, she has worked as a psychometrist and psycho-educational evaluator for several years, applying her academic insights in a practical context.

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THE RELATIONSHIP BETWEEN READING DISABILITIES AND EMOTIONAL/BEHAVIOR DIFFICULTIES IN EDUCATIONAL SETTINGS:

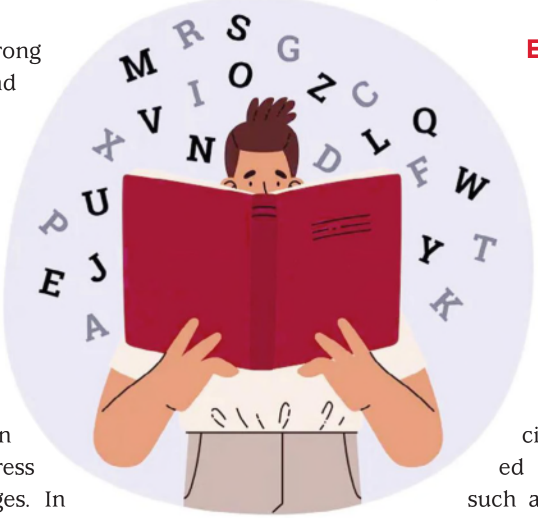
INSIGHTS AND UNDERSTANDING FROM CURRENT RESEARCH AND CLASSROOM EXPERIENCE

BY MARIA TORRES, MA., LDT-C

Reading disabilities, such as dyslexia, pose significant challenges for students in educational settings. These difficulties not only affect a student's academic progress, but frequently also impact their behavior in the classroom. Understanding the relationship between reading disabilities and behavior is crucial for educators, parents, and researchers in order to develop effective strategies and interventions.

THE LINK BETWEEN READING DISABILITIES AND EMOTIONAL/BEHAVIOR DIFFICULTIES

Numerous studies have demonstrated a strong association between reading disabilities and behavioral issues in educational settings.[1] Children with reading disabilities often experience frustration, anxiety, and low self-esteem due to their struggles with reading comprehension, decoding, encoding and fluency. These emotional and psychological challenges frequently manifest in disruptive or withdrawn behaviors, attention difficulties, and academic disengagement.



In some cases, these responses are shown to stem solely from the frustration and stress associated with students' reading challenges. In others, ancillary social and clinical circumstances and issues prompt inhibiting behaviors.[2] Recent research has also revealed that there are significant differences in the ways both reading disabilities and resulting behavioral responses manifest in boys and girls.

A few of the findings from recent studies, which are borne out in our own students, follow below:

- **Social Interactions:** Reading difficulties can affect a student's social interactions.[3] They may be bullied, feel embarrassed, and become isolated due to their struggles. This may result in social withdrawal, difficulty making friends, and lower self-confidence.
- **Academic Self-Concept:** Students with reading disabilities may develop lasting negative perceptions of their general academic abilities, impacting their motivation and engagement in other subjects, or in the overall learning process.[4]
- **Attention and Sensory Processing Difficulties:** Reading disabilities are sometimes accompanied by comorbid sensory processing issues, attention deficits, and other conditions which can contribute to inattentiveness and distractibility, and sometimes a variety of behaviors in the classroom.[5]

As a result of these responses to their situation, students with reading disabilities may have difficulty regulating their emotions, which typically leads to the expression of impulsive or disruptive behavior.

EFFECTIVE SOLUTIONS AND INTERVENTIONS

To address the relationship between reading disabilities and behavior in educational settings, a multi-faceted approach is essential. Following are some effective practices supported by current research.

- **Early Identification and Intervention:** Early assessment and identification of both reading disabilities and comorbid conditions is crucial for implementing timely and targeted interventions.[6] Screening programs, such as universal reading assessments, can help identify struggling students at an early stage, enabling timely support. Similarly, early assessment for commonly occurring comorbid conditions helps focus program design on the individual student's particular needs. Being able to simultaneously address the issues each student faces is crucial to reducing behavioral interference and addressing reading deficits quickly.[7]
- **Individualized Instruction:** Providing individualized instruction tailored to the specific needs of students with reading dis-

ONE TO ONE: Providing individualized instruction tailored to the specific needs of students with reading disabilities is highly beneficial.

abilities is highly beneficial. Strategies such as evidence-based reading and structured literacy programs, which include explicit instruction, and multisensory teaching techniques have shown promising results in improving reading skills and reducing behavioral issues.[8]

- **Assistive Technology:** Incorporating assistive technology tools, such as text-to-speech software or audiobooks, can support students with reading disabilities by providing alternative ways to access and comprehend text. These tools can also enhance students' independence, confidence, and engagement in the learning process.[9]
- **Social-Emotional Support:** Creating a supportive classroom environment is essential for students with reading disabilities. Implementing social-emotional learning programs and fostering a positive teacher-student relationship can help address emotional challenges, build resilience, and promote positive behavior.[10]
- **Collaboration Among Educators, Parents, and Professionals:** Collaboration among educators, parents, and relevant professionals, such as special education teachers, reading specialists, speech and language therapists, and school psychologists, is vital for understanding and addressing the needs of students with reading disabilities.[11] Regular communication, sharing of strategies, and coordinated efforts can maximize support and intervention effectiveness.

The relationship between reading disabilities and behavior in educational settings is a significant and sometimes complex one, and it demands attention from all stakeholders involved in the special education process. By understanding and actively addressing the emotional and behavioral challenges faced by students with reading disabilities, and implementing evidence-based interventions, educators can create a learning environment that supports their academic growth, emotional well-being, and overall success in and out of the classroom.•

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PHOTO PROVIDED BY MARIA TORRES

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The stress of caring for a child with disabilities goes beyond the caregiving itself. Navigating the complexities of the medical system, disability programs, public benefits and special education can be overwhelming, and can be even more if a caregivers' first language isn't English.

HOW FAMILIES OF CHILDREN WITH DISABILITIES CAN FIND SUPPORT

BY CLAUDIA BOYD-BARRETT

PHOTO BY MANUEL RUIZ

Susana Ruiz sat in the doctor's exam room, unable to smile, open her right eye, or even take a sip of water.

"The only way this is going to remedy is if you take care of yourself," the doctor told her sternly. "You can't take care of anybody else right now."

It was 2014, and for several months, Ruiz' sole focus had been on her 2-year-old son, Santiago. Ruiz wanted to do everything she could for her little boy, who had recently been diagnosed with autism. She sought out services, drove him to specialists, pored over autism research, and tried to manage his challenging behaviors, while also caring for her older son. She felt sad and exhausted, but pushed herself to keep going.

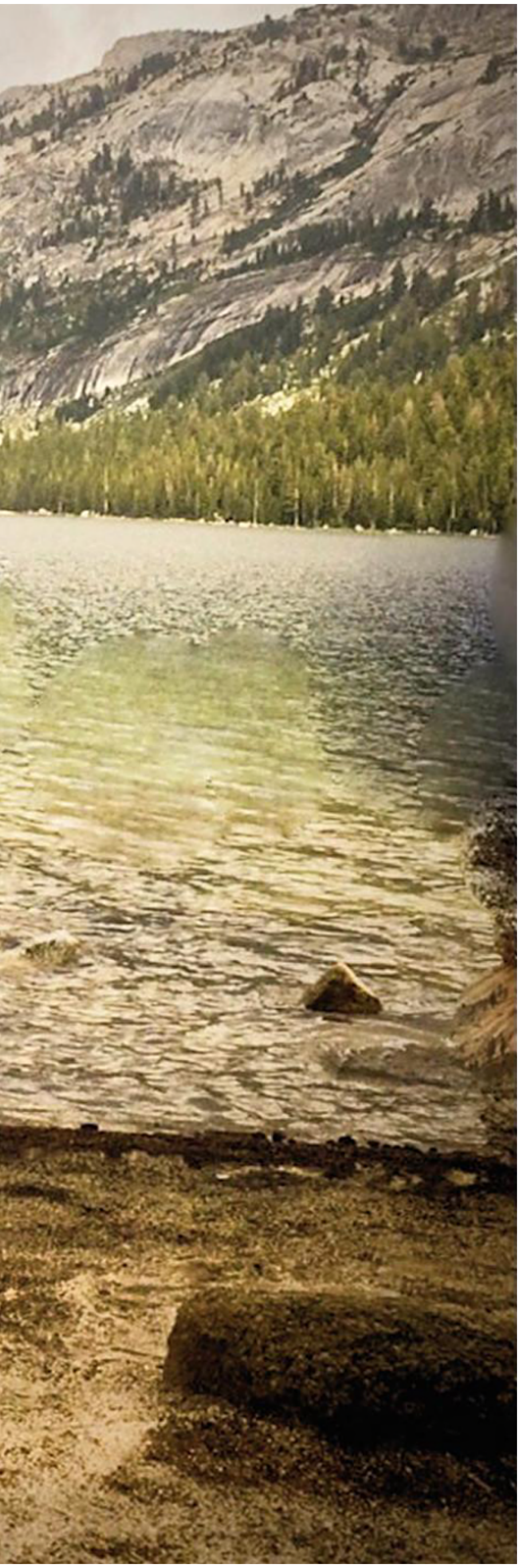
That is, until the right side of her face became paralyzed, a temporary condition known as Bell's Palsy. The doctor attributed it to stress.

"That pivoted my experience," Ruiz said. "I had to get tools to learn how to manage the stress that I was dealing with."

Caring for children with special needs, whether they have a developmental disorder like autism, a physical disability, a chronic medical condition or a combination of these, is demanding work. Without adequate support or rest, parents can end up feeling depleted and alone. Some, like Ruiz, develop physical or mental health problems. The solution, according to experts who work with families and parents who have faced these challenges, is to reach out for help, connect with other families of children with disabilities, and prioritize self-care.

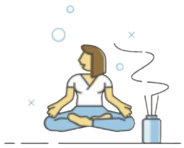
"The buildup of stress and care exhaustion is really very common," said Maria Daane, executive director of Parents Helping Parents, a support center for parents of children with disabilities, "Raising a child with a disability is a marathon. If we as caregivers don't practice self-care, it's very difficult to do what we do for our children."

The stress of caring for a child with disabilities goes beyond the caregiving itself. Navigating the complexities of the medical system, disability programs, public benefits and special education can be overwhelming, and can be even more if a caregivers' first language isn't English. Many parents



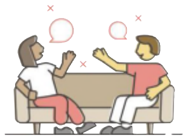
SHORING UP UNDER PRESSURE: Susana Ruiz with her youngest son Santiago. Santiago's condition has made her family and others around him more accepting of differences, and his outgoing demeanor brightens up people's day.

TAKE IT EASY : TIPS FOR MANAGING STRESS



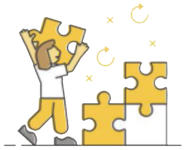
PRACTICE SELF-CARE

This means taking care of your own wellbeing by doing things that help you feel more rested and energized. This includes eating well, getting enough sleep, and doing restorative activities. This can include taking a few moments to breathe and be still during the day, or moving your body by going for a walk, dancing around your living room or practicing yoga. "Take it easy on yourself," Daane advises. "Stop and take a breath. None of us can do it all, all the time."



FIND SUPPORT

There are organizations across the country that offer resources and information for families caring for children with disabilities. Some, such as Parents Helping Parents, offer one-on-one guidance, often from parents who have raised a child with disabilities. Many also run in-person and online support groups for parents.



SHIFT YOUR MINDSET

Ruiz offered this recommendation for parents who feel stuck in negative thoughts about their child's condition or their ability to care for them. She recommends trying to find positive things to focus on, such as a small improvement in your child or small accomplishments. Think about the gifts that your child brings to your family and community. For example, Ruiz said Santiago's condition has made her family and others around him more accepting of differences, and that his outgoing demeanor brightens up people's day.

A WAY THROUGH: Susana Ruiz with her husband, Manuel Ruiz and their two sons. "Finding community, finding communication and advocacy is key to reducing some of the challenges parents encounter."

wrestle with strong emotions such as grief, and may even blame themselves for their child's diagnosis. Financial pressures mount if one spouse has to quit work to take care of the child or medical bills aren't covered by insurance. Marriages can become strained. Siblings may act up because the child with disabilities gets so much attention.

HELP IS HERE : RESOURCES FOR PARENTS

PARENT CENTERS

These centers offer support, services and information for families of infants, toddlers, children and youth with disabilities, from birth to age 26. There are nearly 100 Parent Training and Information Centers and Community Parent Resource Centers in the U.S. and territories.

parentcenterhub.org/find-your-center

PARENT TO PARENT USA

A network of organizations across most of the country that can match you with a trained Support Parent who has faced similar challenges raising a child with disabilities or special health care needs.

p2pusa.org

THE AUTISTIC SELF ADVOCACY NETWORK

The Autistic Self Advocacy Network has information and resources for parents of children with autism, including a guide to autism and therapies.

www.autisticadvocacy.org

Other helpful autism-related resources can be found at the Autism Society autismsociety.org and the National Autism Association at nationalautismassociation.org

For many parents, including Ruiz, one of the most powerful ways to handle these stressors and reduce feelings of isolation is to find a support group. After her Bell's Palsy diagnosis, Ruiz signed up for a research program at Stanford University designed to help parents of children with autism build their resilience. The program included group therapy sessions with other parents who shared the struggles they were going through.

"I understood that what I was experiencing was common," said Ruiz. "Being able to hear other parent's stories and have them share their resources and stories was very inspiring."

Ruiz also began carving out more time for herself to rest, go for walks and do other things she enjoyed. She shared more of the caregiving responsibilities with her husband. She attended yoga classes and learned to meditate. Today she's a volunteer advocate for other parents of children with disabilities through Parents Helping Parents. Her top advice for parents whose child has a new diagnosis? Find a support group before getting fully absorbed in finding resources for the child. "There are a lot of families that I encounter that are in that chronic stress mode," she said. "Finding community, finding communication and advocacy is key to reducing some of the challenges parents encounter."

This story was produced in collaboration with the California Health Report www.calhealthreport.org

ABOUT THE AUTHOR:

Claudia Boyd-Barrett is a long-time journalist based in Southern California. Her investigative stories on domestic violence and access to mental health care have resulted in legislative and policy changes, on both the state and county level. Her stories have won dozens of awards and appeared in the *Los Angeles Times*, the *Sacramento Bee* and the *San Francisco Chronicle*, among others. She is a two-time USC Annenberg Center for Health Journalism fellow and a former Inter American Press Association fellow. She is fluent in Spanish. As a single parent who has experienced financial insecurity, Claudia understands the challenges facing low-income families in California and the role of public health care and other safety-net programs. She is passionate about using journalism to elevate the voices and perspectives of people and communities disproportionately impacted by inequality.

PHOTO TOP LEFT BY JAISON BANGA; PHOTO TOP RIGHT BY KENNETH DRACHNIK


From Red Hawk to Financial Professional
Madison Surgent
Class of 2022
#1
SOCIAL MOBILITY
in New Jersey
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iPads are wonderful tools for discovery. Use these devices or others to facilitate discussion and pursue lifelong learning opportunities in a person-to-person or group situation.

IPADS AS TOOLS FOR DISCOVERY

BY JORDAN JANKUS

Since they were first released in 2010, iPads have revolutionized personal computing. The tablet brought with it a library of apps that can provide assists for daily tasks, communication, and more.

When my adult daughter, Jessica, got her first iPad, it truly opened a new world to her. She is challenged with ataxic cerebral palsy and cognitive delays. With PCs and Macs, she always struggled using a mouse and keyboard, handling CD-ROMs and DVDs, and navigating complex computer menus. Now, just through finger gestures on the tablet screen, she gains access to apps, movies, and music. It's portable and travels with her to her day habilitation program and to visits with her family.

Jessica is now forty-five, but mentally much younger. While her literacy levels are low, she has good receptive skills, and we have gotten used to her unique speech patterns. She doesn't understand calendars or calculators, but she enjoys people and life. There are those with more cognitive abilities whose use of a tablet or smartphone is essential for helping them manage their life and work, but for Jessica, an iPad provides opportunities for connection, fun and basic learning.

Providing Jessica with an iPad was just the start of an ongoing learning process. We would explore Apple's App store, download apps that we thought she might like and demonstrate how they worked. Some she liked, some we discarded, and then we'd try again. It's challenging to find the apps that are interesting, have low literacy requirements, are easy to manipulate, provide encouraging feedback, and aren't too childish. Movies and music were an easier decision, as for years she had pointed out the VHS and DVD's she liked, and she had an extensive collection. However, they were still physical media that required handling. Many a VHS tape was digested by the video player and DVDs could be easily scratched, smudged, or easily become stuck in the machine. Once we downloaded the digital movie or audio file onto her iPad, Jess could open it by tapping its picture icon and it couldn't be broken or misplaced! For those people with more significant cognitive challenges, the iPad can be a great tool for encouraging conversation, discovery, and learning. The magic of this digital tool is how it provides opportunities for engage-

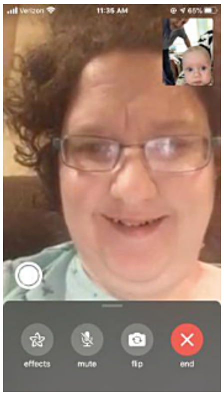
DIGITAL TOOLS AND THE IMAGINATION : OPPORTUNITIES FOR CONNECTION, BASIC LEARNING, AND FUN

FACETIME

Apple, Inc. | Free (included with iOS)

https://apps.apple.com/us/app/facetime/id1110145091

This free Apple app allows Jessica to connect from her group home to relatives around the country. We set up her FaceTime call list with pictures of her family, and we now have regular daily video calls with her during which she shares her day, and we talk about family members and upcoming events, like our annual trip to Florida. If she can't get us immediately, it's no problem, she just goes down the line of family pictures until her brother, uncle, aunt, or cousin, picks up (She is relentless!). For us, it's a comfort knowing how she's doing. During the COVID-19 pandemic, when her residence wasn't open for visits, it provided us with the assurance that she was well and receiving the best of care. FaceTime also provided her with the connection to continue her important speech therapy lessons.



SENSORY LIGHT BOX

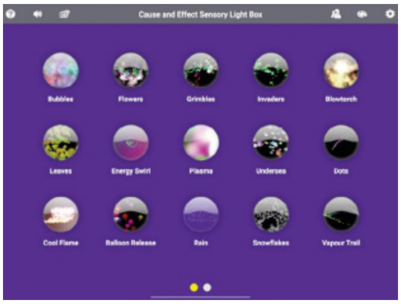
Cognable | $3.99

https://apps.apple.com/fm/app/sensory-light-box/id533976433

When this app starts, you're presented with several screens containing thirty circular icons. Each icon has a description of "leaves," "undersea," "balloon release" and more. Press on any of these circles and you might at first be disappointed, as you're presented with a blank screen. But wait, just press one finger to the screen, then another and finally, all your fingers and the results are swirling icons and sounds that you can draw across the screen in infinite patterns. The images, color and sounds are fabulous, but they also provide you with opportunity for conversation!

For example: *Look what you did! It was your fingers that made those beautiful pictures and sounds! That's amazing! There are leaves swirling on the screen! What time of year do you think of when you see this? What holidays happen around this time of year? Have you ever "crunched" your way through a pile of leaves? Now it's snowing across the screen! Do you like the snow? What season brings snow? What season comes after winter? Do you have a favorite season? Would you rather throw a snowball or splash in the warm water at the beach?*

That's just the beginning! With thirty icons to choose from, there's a lot of material to talk about!



ment between people. Here are a few examples of how I've used apps and an iPad for engagement with Jessica and other people I've supported through my years of service in the disability community.

These are just a few of the millions of apps our there. While our focus in this article is on Apple devices, there are similar apps that are available on Android devices. A good place to search for apps that may benefit people with disabilities is Bridging Apps (**https://bridgingapps.org**), a program of the Easter Seals of Greater Houston, that provides an app database with extensive reviews. They have a great message on their web page that really connects with me. "We believe that it is more important to focus on the person who will be using the technology, than the device itself."

It's encouraging that in the spirit of universal design, many useful apps have been created that are more accessible than ever before. They may not have been originally targeted for the special needs community, but they nonetheless hold great potential for everyone. When searching for apps, don't just confine your search to "special needs;" there's a world of possibilities to discover in the vast offerings of apps.

iPads are wonderful tools for discovery. Use these devices or others to facilitate discussion and pursue lifelong learning opportunities, in a person-to-person or group situation. All of us are learning each day; no matter our disabilities; it's a lifetime activity. Let's use these digital tools and our imaginations to enhance the learning process. •

ABOUT THE AUTHOR:

Jordan Jankus is the proud father of Jessica, his adult daughter who was born with multiple developmental delays. In addition to his role as a parent, Jordan has worked in human support services for twenty-three years as a case manager, employment specialist, self-advocacy trainer and assistive technology specialist. You can read more of Jordan Jankus' writings on the world of disabilities, parenting, lifelong learning, and technology at his Substack blog, "Plastic Learning"
https://plastlearn.substack.com

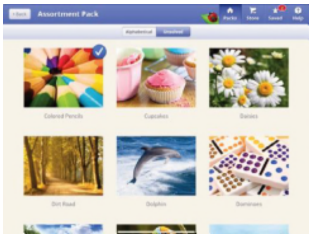
JIGSAW BUG: HD PUZZLE GAME

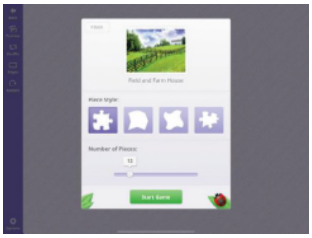
Digital Strawberry | Free with in-app purchases

https://apps.apple.com/us/app/jigsaw-bug-hd-puzzle-game/id804982722

Puzzles apps are fun, but most can be overwhelming in their complexity. This app comes with thirty-six free puzzles (additional puzzle sets can be purchased) that have interesting pictures with vibrant colors. The magic of the app is that you can pick the complexity of the puzzle, choosing from four pieces to three-hundred pieces, then opt to have a "ghost" outline of the picture on the screen to help with the placement of the pieces. The app features thousands of high-resolution jigsaw puzzles, based on beautiful images from professional photographers. As the puzzle is being completed, there are a variety of topics to discuss!

Why did you pick that puzzle? What do you see in the picture puzzle? Which is the left and right of the screen? Would you like to reduce the number of pieces to make it easier? Using the slider control, can you move it to "6" pieces? What tricks have you learned to complete a puzzle?





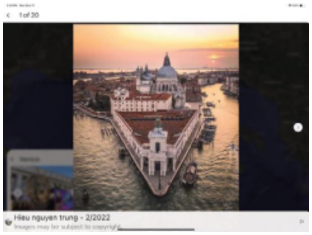
GOOGLE EARTH

Google, Inc | Free

https://earth.google.com

Not everyone gets to travel the world in person, but this app gives everyone a chance to explore a digital version of the world. You can type in any location, or a specific site of interest, like the White House. The globe turns and you're taken to that location. You're provided with pictures of the location, a brief description, and links to Wikipedia information. Your exploration can be captured in a file that can be stored on your free Google Drive, in case you want to revisit your trip. In many places, you can get a street view of the location. For example, you could take a stroll in front of the White House!

So a conversation could start with.... *Where did your ancestors come from? Italy? Have you ever been there? Well, let's take trip! Let's type I-T-A-L-Y in the search box. There it is! Do you know there's a city in Italy where the buildings are surrounded by water? Let's look for the city Venice. How would get around a water city if you couldn't take a bus or car?*



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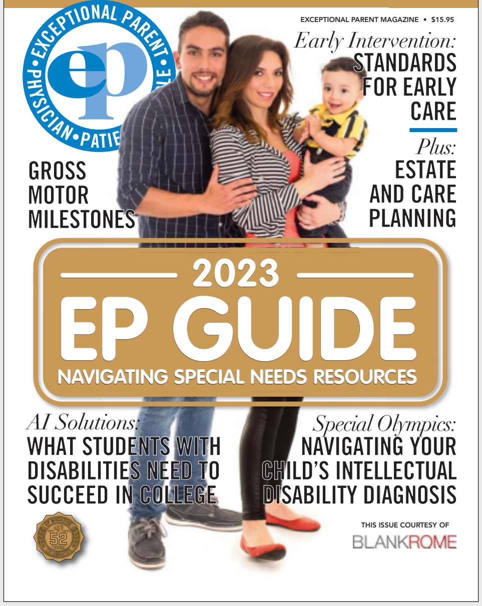

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EP MAGAZINE: THE JOURNAL FOR SPECIAL NEEDS FAMILIES AND PROFESSIONALS

Alexa's Gift

BY KARA AYIK

My older brother Mark and I, born just over two years apart into a military family of four, are as different as night and day. Our starkly different personalities were evident to our mother, even prenatally.

Mark was so vigorously active in the womb that he made my mother shed tears, whereas, I was so still she often grew worried and pressed on me to make me move and reassure her that I was still viable. As adults, Mark and I share some values and our family history, but we don't have a lot in common. Now, we are both middle aged, and he is still active and gregarious, and I am still quiet and reserved. We travel in different social circles and have different standards of living. But despite our nearly polar opposite personas, my brother and I have something in common that has shaped our adult lives, albeit from different lenses. That is the exceptional parenting experience.

Mark's firstborn, his daughter Alexa, who is now 19 years-old, lives with autism, ADHD, and intellectual disabilities. She requires round-the-clock supervision, and at times, abundant

GOING WITH THE FLOW: Alexa enjoys rafting down the American River in Sacramento; "Alexa has deepened my empathy and patience for myself and for others in our unique sensitivities."

PHOTOS PROVIDED BY KARA AYIK

FAMILY TIES: *(Above left)* Alexa's father's family pose for a family picture – (left to right) Alexa's Grandma, Erol, Kara, Mark, Evren, Alexa, and Alexa's Grandpa; *(Above right)* Alexa takes a break from the iPad to take a picture with her Aunt Kara.

patience to help her cope with sensory overload and the overwhelm that accompanies her struggles to process the ever-changing world around her. My firstborn son, Evren, Alexa's cousin, is now 21. He lives with acid sphingomyelinase deficiency, or ASMD, a rare genetic disease, which, like autism, is a spectrum disorder. ASMD is multi-systemic and progressive, meaning that it impacts multiple organ systems, such as the liver, heart, bones, and blood, and becomes worse over time.

Evren is a gentle sort, and most everyone who gets to know him admires his kind and positive nature. While he is cognitively unaffected by his disease, raising Evren has involved vigilance and countless interventions because of the nature of ASMD. We spent quite a bit of time at the children's hospital as he was growing up. Still today, I actively help him navigate his complex care. On the other hand, Alexa has a remarkably healthy body: she has a strong heart and lungs, excellent eyesight and hearing, and even a set of powerful vocal cords like her dad's. She has a sturdy, muscular build, swims like a fish, and has no qualms about drinking water straight from a hose. If no one intervenes to stop her, she will pluck fresh lemons off a tree in the backyard and eat them with gusto.

Mark and I are both familiar with chronic sorrow. It is a recurring grief, commonly experienced by parents of children with serious and life-long diagnoses, as well as disenfranchised grief, a form of grief over a loss that many are unable to comprehend, as our children are still with us. We have both traveled the soul-shaking journey through diagnosis and the associated grieving process that comes with the ending of the dream we had envisioned for our children's lives. Each of us raised a child with exceptional parenting needs, and observing each other's trials as parents has given us insight and perspective about parenting. Despite the hard parts, both Mark and I have no trouble finding reasons to admire and enjoy our children. The pity narrative that sometimes accompanies special needs parenting holds little relevance to us.

> **"Alexa has helped me learn why language is so important, and to have compassion for those who don't have it."**

I admit, though, that the challenges Mark has faced as Alexa's dad, have sometimes boggled my mind. Likely, he would say the same about my experience raising a child with a disease as serious as ASMD. Often the response from onlookers is indeed pity, and in some cases an intentional distancing. Regardless of these reactions, I make it a point to illuminate the remarkable and powerful ways children like Evren and Alexa enable us to bring our character to fuller fruition, and how they enrich our lives beyond measure. I cannot speak for my brother in terms of what he has learned from Evren's life, but I can definitely speak to my experience being Aunt Kara to my niece Alexa. What she has taught us that has enriched our lives and carved out new dimensions in our worldviews, is her gift to our family.

Like some, but certainly not all, who have autism, Alexa's language and her ability to express thoughts are limited to formulas, for the most part. An example of her formulaic speech with a predictable intonation pattern is something like this:

Aunt Kara: "Alexa, what is this?"

Alexa (pauses, then pipes up): It's a balloon!

Aunt Kara: "What color is it?"

Alexa: "It's purple!"

But in addition to formulas, Alexa speaks her own little language, sometimes repeating her favorite words and phrases over and over, in what is called *echolalia*, a calming form of self-stimulation, or "stimming." Sometimes, she will enthusiastically repeat a phrase like, "Do you want?" with a big jolly grin, to prompt us to ask her that same question so that she might fill in the formula with whatever she wants, often a food or drink item, sometimes an activity. Over the years, Mark, Evren, and I have delighted in her verbal pearls of creativity

RELATIVE STRENGTHS: Cousins Alexa and Evren on a weekend at Grandma's house; "I actively help Evren navigate his complex care. On the other hand, Alexa has a strong heart and lungs, excellent eyesight and hearing, and even a set of powerful vocal cords like her dad's."

such as, "S-U-L-E spells I want more Goldfish please!" or one of Mark's favorites, "Put away the snowman... nickel!" She rattles off these linguistic confections masterfully, and my background in language studies helps me to appreciate these novel creations from an intellectual standpoint.

Alternatively, Alexa expresses unbridled happiness without actual words, as she makes what Mark calls *happy sounds,* usually quite loudly, sometimes during the day and often into the wee hours of the night. Though Alexa's happy sounds might drown out a conversation or wake us at night, they also "teach us delight in simple things, and mirth that has no bitter springs," as poet Rudyard Kipling describes it.

Alexa also uses echolalia interactively to communicate more urgent needs. For example, when Alexa speaks adamantly in a slightly monotone and staccato voice of wanting to "play in the sparkly grass," or states ominously that "the lamp *is* dangerous," that is her way of warning us that her anxiety is heightening rapidly. Her latest yellow light warning is "Snap that money out of the tree!"

In my observing the connections between her language and behavior, Alexa has helped me learn in a vivid way why language is so important, and to have compassion for those who don't have it. When we have abstract or symbolic language, we can think *about* something rather than solely *of* something. With abstract thought, we are no longer limited to understanding the concrete world, or that which can be seen, heard, touch, felt or smelled through one of the five senses. Abstract thought is what enables us to access memories of our past experiences, reflect on them, and then use our reasoning to make predictions about the present and the future. We can then make sense of the ever-evolving circumstances of our daily lives and respond adequately. It is no wonder then, that someone like Alexa with limited cognition or no abstract language, would perceive anything new as a possible threat to her safety, and then react to the mental and emotional chaos with fight or flight behaviors that are instinctual for survival. At times, that has involved Alexa's striking out with her hands or throwing objects, and at other times, assertive attempts to escape or avoid the unfamiliar situation. Having observed her distress on several occasions, Alexa has taught me to have compassion for anyone who cannot utilize abstract language and thought. Everyday sights and sounds can overwhelm Alexa. While wearing noise-cancelling headphones, flapping her hands, and squinting her eyes help her shut some of the input out, sensory overload is something she will always battle. Because of my love for her, I cannot help but seek to comprehend her sensory processing trials, and doing so has led me to reflect on my own trait of high sensitivity, which gave birth to a lifelong source of self-doubt and frustration.

> **"Alexa has modeled for me a pristine character with an absence of dark motives. She embodies unconditional love."**

I think back to my childhood when I dreaded the times my mother decided it was necessary to run our 1970s brown Hoover vacuum. Its roar was so loud and harsh that it made me feel a mix of emotional and physical stress, a distinct sort of low-grade pain. Added to the list of what makes me experience that discomfort are bright lights, like the fluorescent light fixture over my parents' kitchen sink, or even direct sunlight shining through a window. Odors that emanate from scented laundry products and deodorizing fragrances distract my thinking and trigger headaches, much to the irritation of those in my orbit who adore them. I think about how uncomfortable I feel when exposed to these stimuli and tell myself to multiply the feelings by ten. That gives me an inkling of what Alexa might be facing. In this regard, Alexa has deepened my empathy and patience for myself and for others in our unique sensitivities.

Perhaps the greatest lesson Alexa has modeled for me is a pristine character with its absence of dark motives. She embodies, and thus models, unconditional love. My younger son Erol once said that Alexa taught him that a person can just be happy, plain and simple, with nothing: no material wealth or power, none of the abilities or skills that mainstream society tends to idolize. Alexa lives effortlessly in the moment, just as Eckhart Tolle teaches us to do in his book, *The Power of Now.* When I am with her, I am reminded of the importance of living in the moment. She also motivates me to think about how a person of golden character might behave. Never will Alexa be tempted to utter a snarky remark about someone's appearance or spread any gossip, nor will she look down her nose at someone's social status or personal choices. Though she will live, laugh, and celebrate with us, Alexa will never manipulate, deceive, or betray. She is immune to the sin of all of the -isms (such as racism, sexism, and materialism) and has no motives that are not honest and pure in nature. Her subtle and sincere expressions of love are given freely and unconditionally. As my father notes, Alexa loves her people. "You can see it in her eyes, especially when she's with her mommy," he says.

> **"Alexa has no motives that are not honest and pure in nature. Her sincere expressions of love are given unconditionally."**

Alexa actually did give me a material gift once, when she was a teenager, probably the only one I will receive from her in our shared lifetime. It is a piece of art. The medium is black crayon on a sheet of white copier paper. Clearly, she worked hard to decorate the page from edge to edge with bold and intentional strokes in such a dramatic color. One of the aides in her special educational classroom prompted her to say the name of someone to whom she wanted to give the drawing. "Aunt Kara," Alexa must have said, because the aide wrote it down on the paper, even though she had no idea who Aunt Kara was. *But Alexa did.* Somewhere in the mysterious workings of her mind, Alexa thought of me, chose me, and wanted me to have something she had created with her own hand. My mother brought it to me after one of her respite visits to Northern California where Mark and his family live. She came to my house and announced that she had something to deliver to me from Alexa. I could tell from her tone that whatever she had was something extraordinary. And indeed, it was. It was not just the artwork itself, but Alexa's gift in choosing to give it to me that broke my heart open in the most beautiful way. •

ABOUT THE AUTHOR:

Kara Ayik is mother to sons Erol, age 19, and Evren, age 21. Evren lives with Acid Sphingomyelinase Deficiency (ASMD), an ultra-rare genetic disease. In 2021, Evren and Kara published the book *Extraordinary! A Book for Children with Rare Diseases* to uplift and encourage children around the world who live with rare diseases. Kara has also published a number of blog articles about rare disease advocacy and rare parenting. Her interests include native flowers and hummingbirds, world cultures and languages, health literacy, and advocacy for children and the environment. Currently, Kara works as a lecturer at the University of California, Merced.


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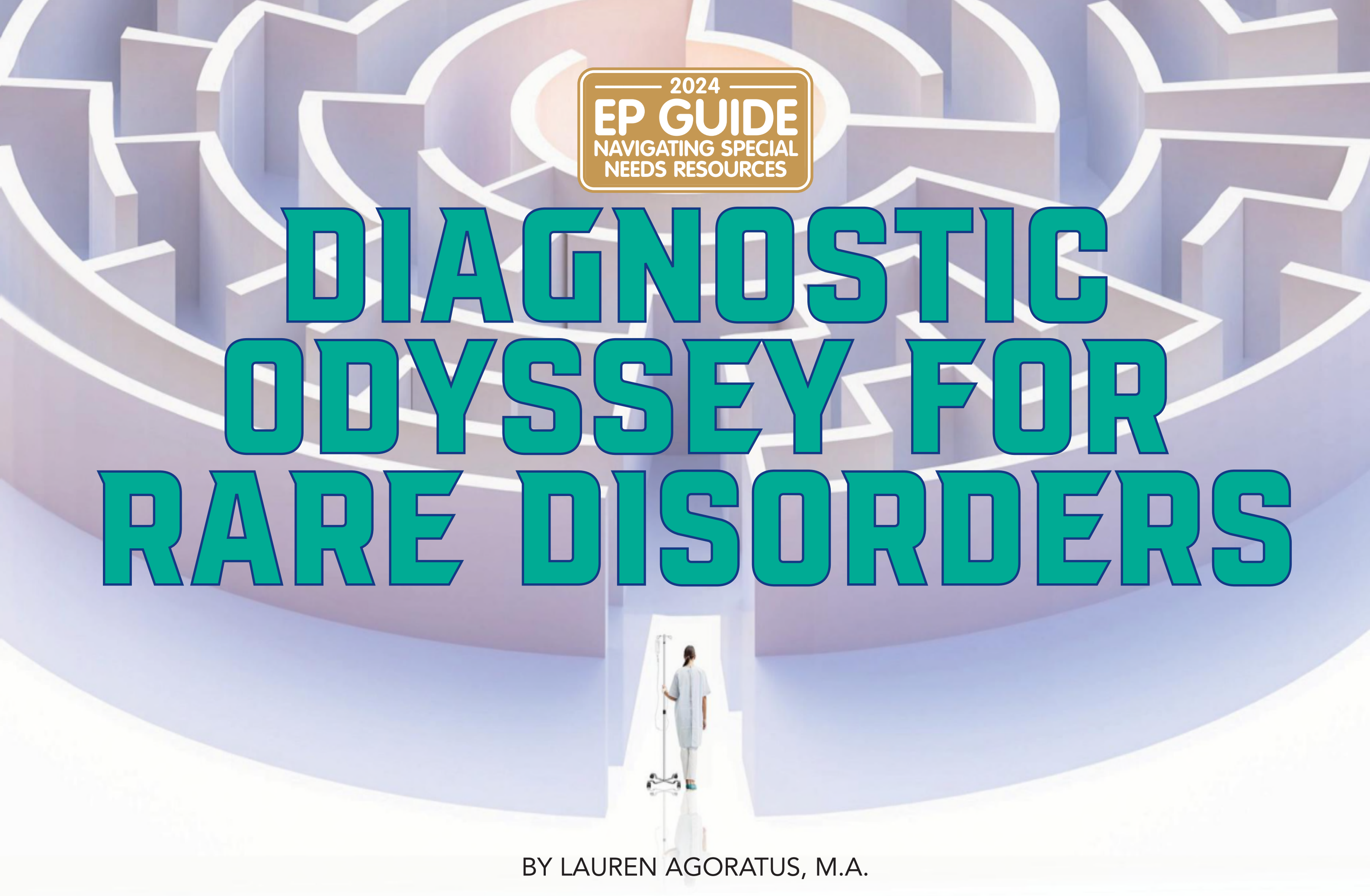


BY LAUREN AGORATUS, M.A.

It can take many years, doctors, hospitalizations, and increased costs to get a diagnosis for a rare condition.

CHALLENGES IN GETTING A RARE DIAGNOSIS

According to Rare Disease Legislative Advocates convened by Every Life Foundation, it can take up to 6 years, 17 doctors, and 41 hospital stays on average to get a diagnosis. The economic cost of rare diseases is $1trillion and the impact per patient can be over $200,000 in avoidable costs, and over $500,000 systemically *(see Resources).*

Every Life Foundation's report, entitled "The Cost of Delayed Diagnosis in Rare Disease," states that an estimated 10,000 rare diseases (RDs) affect 25-30 million Americans and that "Timely diagnosis is important when there are potentially disease-altering or life-saving treatments available."

COST BEYOND MEDICAL

Direct medical costs can include doctor visits, prescriptions, DME (durable medical equipment), and hospitalization. Indirect costs include productivity impact including:

- ✓ *early retirement*
- ✓ *absenteeism*
- ✓ *presenteeism (working while sick)*

Other non-medical costs include:

- ➢ *home/vehicle modification*
- ➢ *alternate transportation*
- ➢ *paid home care*
- ➢ *items not covered by insurance such as special diets, etc.*

WHAT FAMILIES CAN DO

First and foremost, families need information and support. Newborn screening and genetic testing may be helpful.

The National Organization for Rare Disorders has a disease directory, patient assistance (e.g. medications), and online community. The National Institutes of Health also has good information describing rare diseases and treatment in family-friendly language. For

A STITCH IN TIME : BENEFITS OF TIMELY DIAGNOSIS

Timely diagnosis improves health outcomes by:

- Providing earlier access to supportive therapies and treatment
- Reducing or eliminating expensive and unnecessary services, tests, and treatments
- Preventing deaths and delaying disease complications and physical disabilities
- Enabling opportunity to evaluate future family planning based on diagnosis

GRAPHIC ADAPTED FROM EVERY LIFE FOUNDATION genetic conditions, the Genetic Alliance has a searchable database of diseases and support groups.

Later in their journey, families can share their stories, contact legislators, and get involved in advocacy. The Every Life Foundation has a section on the study website on how to submit personal stories, infographics, the full report, and links to contact their representatives. Doing this will help raise awareness and create systemic change for all families affected by rare disorders. •

ABOUT THE AUTHOR:

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

RAISING AWARENESS : RARE DISEASES RESOURCES

EVERY LIFE FOUNDATION

https://everylifefoundation.org/delayed-diagnosis-study

NATIONAL ORGANIZATION FOR RARE DISORDERS

https://rarediseases.org

NATIONAL INSTITUTES OF HEALTH

https://rarediseases.info.nih.gov

GENETIC ALLIANCE

https://geneticalliance.org/disease-infosearch

making sure everybody has the same opportunities to participate in every aspect of life to the best of their abilities and desires.

2024
EP GUIDE
NAVIGATING SPECIAL NEEDS RESOURCES

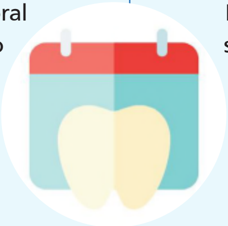
ENSURING OPTIMAL ORAL CARE FOR DISABLED AND AUTISTIC CHILDREN

BY SCOTT RUVO, DDS

Caring for the oral health of children with autism and other disabilities requires special attention and tailored strategies. Good oral hygiene not only prevents immediate dental issues, but also contributes to long-term well-being.

ENSURING OPTIMAL ORAL CARE : KEY CONSIDERATIONS AND PRACTICAL STEPS

1. INDIVIDUALIZED APPROACH



Recognize that each child is unique, and their oral care needs may vary. Tailor oral hygiene routines to accommodate sensory sensitivities, motor challenges, and communication differences. Understanding the child's preferences and limitations is crucial.

2. ESTABLISH ROUTINE AND CONSISTENCY

Create a predictable oral care routine, incorporating it into the child's daily schedule. Consistency helps build familiarity, reducing anxiety and resistance. Use visual schedules or social stories to prepare the child for each step in the routine.

3. ADAPTIVE TOOLS AND TECHNIQUES

Explore adaptive tools such as toothbrushes with soft bristles, electric toothbrushes, or tools designed for easy grip. Experiment with different toothpaste flavors to find one the child prefers. Introduce these tools gradually, to make the child comfortable.

4. DESENSITIZATION STRATEGIES

Gradually expose the child to oral care activities to desensitize them. Start with short sessions, and gradually increase the duration. Use positive reinforcement and praise to create a positive association with oral care.

5. PROFESSIONAL SUPPORT

Collaborate with a dentist experienced in treating children with special needs. Regular dental check-ups are crucial for preventive care. Discuss any specific challenges your child faces, to ensure the dental team can provide the most effective support.

6. NUTRITION AND HYDRATION

Emphasize a balanced diet that supports oral health. Limit sugary snacks and beverages that can contribute to dental issues. Encourage water intake, as hydration is essential for overall health, including oral health.

7. COMMUNICATION STRATEGIES

Establish effective communication channels. Use visual cues, simple language, and positive reinforcement during oral care routines. Foster open communication with the child's healthcare team to address any concerns or adjustments needed.

8. TEAM INVOLVEMENT

The dental team should engage parents and caregivers in the oral care process. They should provide guidance on maintaining oral hygiene at home and encourage them to reinforce positive oral care habits.

9. BEHAVIORAL SUPPORT

Seek behavioral support when necessary. Behavioral therapists can offer strategies to address challenging behaviors related to oral care and help the child develop coping mechanisms.

10. CELEBRATE SMALL ACHIEVEMENTS

Acknowledge and celebrate each step of progress, no matter how small. Positive reinforcement boosts confidence and encourages continued cooperation with oral care routines.

Ensuring optimal oral care for children with disabilities involves a holistic, patient-centered approach. By combining adaptability, consistency, and support from both caregivers and dental professionals, we can pave the way for a lifetime of good oral health and overall well-being for these special individuals.•

ABOUT THE AUTHOR:

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

29
FEB
2024

RARE DISEASE DAY

SHARE YOUR COLOURS

Raise awareness for the 300 million people living with a rare disease and their families worldwide, together with EURORDIS-Rare Diseases Europe and 72 national alliances for rare diseases.

#RAREDISEASEDAY®

SET YOUR CHILD UP FOR SUCCESS WITH A VISION STATEMENT

BY KELLEY COLEMAN

GOLD STAR: The author's son, Aaron, stands at the front of his classroom, receiving an award and smiling triumphantly.

PHOTO BY ANDREA CASILLAS

Parents of disabled children are no strangers to paperwork. With so many forms, assessments, intakes, and applications, I've had to ice my hands on more than one occasion because they hurt from filling out the latest stack of paperwork. My son (who has multiple disabilities) is amazing. But the paperwork? Not so much.

While much of the paperwork can't be avoided, there are ways to make it feel like less of an uphill climb. Enter the vision statement. We first crafted a vision statement to accompany our child's IEP, and soon found that it informed the extensive future care plans we were mapping out for him. It also helped us when filling out the application for his service dog, determining the best therapy goals, and even making the most of our child's free time. We built on his strengths, and found ourselves using the same language, as we filled out many of the forms – language that best suited our son's journey of working towards a meaningful future.

VISION QUEST : WORKING TOWARDS A MEANINGFUL FUTURE

WHAT IS A VISION STATEMENT?

A vision statement is a long-term plan for your child's future. Your child's vision statement can involve your family, any members of your child's team, and anyone significant to your child's life. Ideally, a vision statement should involve the child to the fullest extent possible, and should grow and change as your child develops.

WHY PUT THE VISION STATEMENT IN WRITING?

While we may know in our minds how our children envision their future, or how we, as parents, envision that future. Putting the vision statement in writing allows us to incorporate it into all of the planning, and across all areas of our child's life. As our child grows, the vision statement will evolve. Having a record of the progressive vision statements can be a way to track our child's development, wants, needs, and supports over the years.

HOW TO APPROACH THE VISION STATEMENT?

Many parents find that evaluations and reports focus on the things a child cannot do. A vision statement is your opportunity to shift the conversation, by focusing on the things your child can do and building from there.

HOW DO YOU CREATE A VISION STATEMENT?

- **Start with your child.** Involve your child to the fullest extent possible. Know that the vision statement will evolve as your child grows.
- **Think big picture.** What is the vision for your child's future, even beyond the next year, and even beyond graduation? How does your child move through life as an adult?
- **Consider home, work, and play.** Are you working towards independent living, employment, continued education, social and/or recreational outlets? Build from your child's strengths and what they love. Think about how these will be built into their future.
- **Build in supports and accommodations.** What will your child need in order to achieve their desired level of independence? Will toilet training be a long-term goal? Will they need alternative means of communication? What will they need in order to set them up for success within the community and with peers?
- **Aim high.** Instead of all of the cant's that we always hear, what is the optimum future that your child is working towards?

WHY DOES A VISION STATEMENT WORK?

First, it takes into account your child's autonomy, personal preferences, and support needs, and all of the things that your child will do. Second, it takes a big picture view, which allows you to ask how your planning for your child will serve this vision. This goes for all areas of planning, from the IEP, to the future care plan, to the ways that a service dog (or other supports) will be incorporated into daily living.

HOW DOES THIS MAKE ALL OF THE PAPERWORK EASIER?

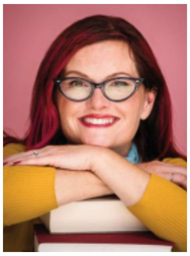
In addition to being able to copy and paste the vision statement into documents, it gives us a baseline for our planning and conversations. For us this has looked like:

- **More productive IEP meetings.** In advance of our IEP meetings, we meet with our son's teacher and service providers to discuss: how his progress, goals, supports, and services build on where he is now, so that he may achieve this future vision.
- **Therapy goals geared towards a big picture future.** We work backwards from our future vision to create therapy goals, so that our child is working towards the things that will matter most to him in the big picture of his life.
- **Future care plans that can be shared with family and friends who may be involved in our child's care.** Familiarizing our friends and family with our son's care and future care plans becomes a conversation about empowering him for a meaningful future, when everyone is on board with the meaningful future that he will have.
- **Advocacy for our son and others with an eye towards fostering self-determination.** As we advocate for our son, and for other individuals with disabilities, we are both teaching him to advocate for himself, as well as advocating for the supports and services that will be necessary for him to lead a fully included, self-determined life.

Of the specific ways that our son's vision statement has shaped our planning, the renewed focus on his communication has become the most essential. Because of his vision statement, we considered and reconsidered how his communication is building towards an optimum future. We realized that his limited communication allowed him to communicate only with people familiar to him and who were familiar with his unique communication style (primarily gestures, with some vocalizations). He is a very social person who enjoys his time in the community, including greeting many new people, out in the world. When we built that into his future plan in earnest, we realized that it was time to expand his communication beyond his current levels. We committed to AAC (Alternative and Augmentative Communication, aka a communication device), despite our past frustrations with introducing it as a viable option. We tried many AAC programs, worked with several therapists, and brought the necessary training to everyone working with our son.

Thanks to the vision statement and our work to set our son up for success with that vision, he is now telling us things like "excited go school" and "tired go bed" and "watch different movie." We look forward to a future where our son will craft a vision statement for himself, totally on his own. For now, "excited go school" seems like an excellent start. These days, I spend less time icing my hands and more time seeing my son develop into the rather amazing future self that we have all envisioned. •

ABOUT THE AUTHOR:



HEADSHOT PHOTO BY JTC PHOTOGRAPHY

Kelley Coleman is the author of the book *Everything No One Tells You About Parenting a Disabled Child: Your Guide to the Essential Systems, Services, and Supports.* Her writing draws upon over a decade of advocating for parent caregivers and individuals with disabilities, including her own rather amazing son.

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EARLY INTERVENTION, APPLIED BEHAVIOR ANALYSIS, AND A GROUP LEARNING EXPERIENCE

BY KELLY BERMINGHAM

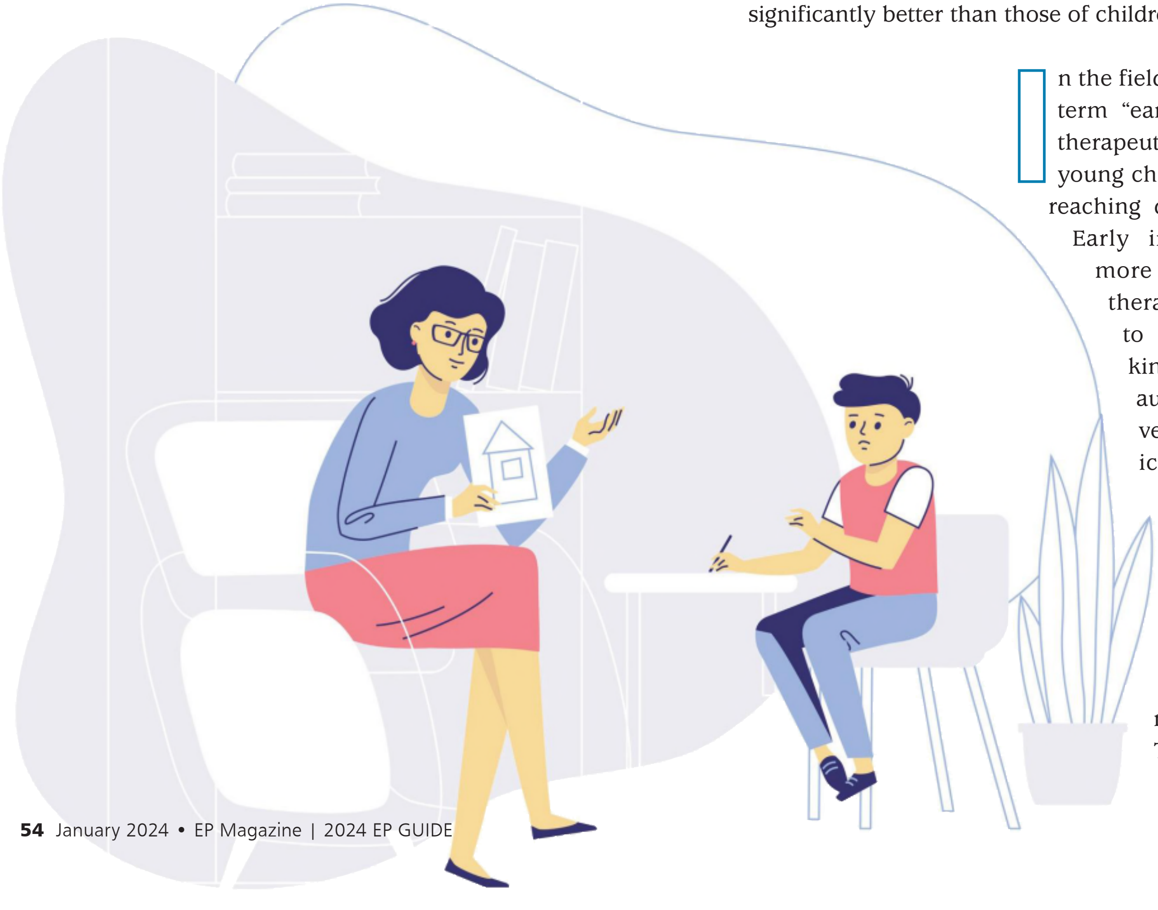
There is a long history of evidence and research indicating that early intervention is one of the most successful measures of autism spectrum disorder symptom reduction (ASD).

In 2001, The National Research Council convened a panel of many of the most well-recognized national experts in the treatment of autism at the time. This panel was charged with integrating scientific literature and creating a framework for evaluating the scientific evidence concerning the effects and distinguishing features of the various treatments for autism. One of the significant recommendations for children on the autism spectrum is the need for early entry into an intervention program.

In 2001, the American Academy of Pediatrics issued a policy statement entitled, "The Pediatrician's Role in the Diagnosis and Management of Autistic Spectrum Disorder in Children." As part of this policy statement they noted, "There is a growing body of evidence that intensive early intervention services for children in whom autism is diagnosed before 5 years of age may lead to better overall outcomes. Behavioral training, including teaching appropriate communication behaviors, is effective in decreasing behavior problems and improving adaptation."

In 2007 The California Blue Ribbon Commission on Autism found: "Early identification and intervention for ASD is critical for children to reach their full potential and reduce their level of disability and dependence. Although the outcomes of interventions and treatment for ASD vary with each child, there is widespread agreement in the field based on a large body of research that children with ASD need to receive intensive interventions during early childhood."

In a second Clinical Report of the American Academy of Pediatrics Council on Children With Disabilities, the report noted, "The effectiveness of ABA-based intervention in ASDs has been well documented through 5 decades of research by using single-subject methodology and in controlled studies of comprehensive early intensive behavioral intervention programs in university and community settings. Children who receive early intensive behavioral treatment have been shown to make substantial, sustained gains in IQ, language, academic performance, and adaptive behavior as well as some measures of social behavior, and their outcomes have been significantly better than those of children in control groups."



In the field of child development, the term "early intervention" refers to therapeutic services for infants and young children who have a delay in reaching developmental milestones. Early intervention often refers more specifically to intensive therapeutic services provided to children before entering kindergarten. In the field of autism and ABA, early intervention often refers to services that are delivered "early," typically from the ages of under 2 to 5 or 6 years old. This term also tends to refer to the concept of "intensive," meaning the hours provided to the child are significant and impactful. These programs are often also called EIBI programs, Early Intensive Behavioral Intervention. In the field of ABA, this is often referred to as a “Comprehensive ABA program” that asses for and seeks to teach and develop skills that are needed across all developmental areas. Additionally, according to the National Research Council, Committee on Educational Interventions for Children with Autism, the committee noted that research shows that early diagnosis of, and interventions for, autism are more likely to have major long-term positive effects on symptoms and later skills.”

A young child’s brain is still forming, meaning it is more “plastic” or changeable than at older ages. Because of this plasticity, treatments have a better chance of being effective in the longer term. Early interventions not only give children the best start possible but also the best chance of developing to their full potential. Recent guidelines suggest starting an integrated developmental and behavioral intervention as soon as ASD is diagnosed or seriously suspected. ABA therapy programs should be designed for these crucial skills related to language and social communication deficits, including responsivity to social stimuli, which supports skills including imitation and joint attention as mentioned previously.

The Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition, Text Revision (DSM-5-TR) was published in 2022. The DSM-5-TR is used to diagnose a person on the autism spectrum based on two primary domains.

A. Persistent deficits in social communication and social interaction across multiple contexts, as manifested by the following, currently or historically:

1. Deficits in social-emotional reciprocity, ranging, for example, from abnormal social approach and failure of normal back-and-forth conversation; to reduce sharing of interests, emotions, or affect; to failure to initiate or respond to social interactions.
2. Deficits in nonverbal communicative behaviors used for social interaction, ranging, for example, from poorly integrated verbal and nonverbal communication; to abnormalities in eye contact and body language or deficits in understanding and use of gestures; to a total lack of facial expressions and nonverbal communication.
3. Deficits in developing, maintaining, and understanding relationships, ranging, for example, from difficulties adjusting behavior to suit various social contexts; to difficulties in sharing imaginative play or in making friends; to the absence of interest in peers.

B. Restricted, repetitive patterns of behavior, interests, or activities, as manifested by at least two of the following, currently or historically:

1. Stereotyped or repetitive motor movements, use of objects, or speech (e.g., simple motor stereotypies, lining up toys or flipping objects, echolalia, idiosyncratic phrases).
2. Insistence on sameness, inflexible adherence to routines, or ritualized patterns or verbal/nonverbal behavior (e.g., extreme distress at small changes, difficulties with transitions, rigid thinking patterns, greeting rituals, need to take the same route or eat the same food every day).
3. Highly restricted, fixated interests that are abnormal in intensity or focus (e.g., strong attachment to or preoccupation with unusual objects, excessively circumscribed or perseverative interest).
4. Hyper- or hypo-reactivity to sensory input or unusual interests in sensory aspects of the environment (e.g., apparent indifference to pain/temperature, adverse response to specific sounds or textures, excessive smelling or touching of objects, visual fascination with lights or movement).

As we can see, the core symptoms of autism are heavily related to language and social communication deficits. Conversely, we know that in neurotypically developing children, social and communication skills develop inherently. As these social and communication skills emerge, they are reinforced by people in their world and the environment they live in, further strengthening these skills. Let’s look at how these skills emerge and develop.

As young children age, they begin to look around and become aware of their surroundings. They smile or frown, or even cry based on what they see. They begin to imitate and respond to their environment based on what happens, or the consequences of their responses. They begin to point to ask for things or to show you things they see. They respond to the attention they receive when doing these things. During the first year of life, children start to develop close connections with their parents and other caregivers. They begin to observe, imitate, and show pleasure and displeasure. During the second year of life, children begin to notice other children and seek interactions with other children. They may begin to show pleasure with others, as well as conflict, and begin to recognize emotions in others. During the third year of life, children expand their play skills and explore more. They begin to develop friendships with those in their proximity and engage in common play actions. They begin to cooperate,

imitate, and learn to accept compromise during conflict, with adult support. During the fourth year of life, conversation skills improve and become robust. Their social interactions with others advance through shared play and conversations. They begin to show support and help toward others.

As children age, they may interact with other children or more people in their environment. They may go to daycare or preschool, then on to kindergarten. In preschool, children are taught and reinforced to use language to communicate. They are taught to play, share, and play together, cooperatively toward a common goal. They are taught to wait. They use their imitation skills to learn how to dance and sing and observe and learn new skills from other children. They move on to kindergarten and are taught even greater communication and social skills that include learning how to negotiate and play a friend's choice. They learn how to regulate their feelings and behaviors. They learn these in a group experience. During the fifth year of life, children can more comfortably create and maintain friendships through common interests and play. They can engage in more complicated games that require more attention and are guided by rules. There is a wide variety of words and actions in play and interactions, and they can directly express concern and help. As they move on to an educational setting, they are ready and able to learn in a group format. They can follow along with an adult leading the group, follow the directions, and manage themselves around others.

> **"BY PROVIDING EARLY INTERVENTION IN A GROUP, ABA-BASED FORMAT AS SOON AS POSSIBLE, WE CAN BETTER PREPARE THE CHILD WITH AUTISM FOR GROUP LEARNING."**

Children diagnosed with autism are not likely to demonstrate these skills and they are not coming into contact with reinforcement. Going back to the diagnostic criteria and symptoms of autism, we see that deficits in social communication and social interaction across multiple contexts result in challenges with interacting with others in a social setting and these crucial milestones being missed.

A new study by Blacher et. Al, 2022 found that nearly one in six kids with autism are expelled from preschool and daycare. Many of them, in the sample, were expelled more often from a private than a public program. Most of the children were expelled due to their behavior which included temper tantrums, hitting, and yelling. The study found that often the teachers were not trained or credentialed and didn't have the required courses in autism. to be fixed or eliminated.

Applied Behavior Analysis, ABA, is a science devoted to the understanding and improvement of human behavior. Applied behavior analysts focus on objectively defined behaviors of social significance; they intervene to improve the behaviors while demonstrating a reliable relationship between the interventions and the behavioral improvements. In the field of ABA, as it relates to supporting children on the autism spectrum, most people think of ABA instruction being delivered in a 1:1 format. The concern often happens when a child transitions to a daycare or classroom setting. The child learning in the 1:1 format may not have the skills to learn in a group format or learn alongside other children. Now we are back to the statistic of one in six kids with autism being expelled from preschool and daycare. By providing early intervention in a group, ABA-based format as soon as possible, we can better prepare the child with autism for group learning. If you think of the very best teacher, you ever had in school, the teacher likely employed ABA strategies, such as: including environmental arrangements, priming, using visual supports, reinforcement/reward strategies, and using first this. That teacher likely considered motivation and created activities that were interesting and motivating to you while you learned. That is using ABA in a group format.

For many children diagnosed with ASD, a comprehensive program would look across all of these developmental areas, identify what skills are missing, and identify appropriate teaching methods to teach those skills. This comprehensive program would likely be heavily based on play and natural environment teaching. It would include caregivers in the programming as well as siblings and possibly other family members. It would include consultation with other therapies or providers the child may be receiving and coordinating care with those services. It would be intensive in the hours provided in the beginning, often 27-40 hours of ABA recommended according to research. This program would include opportunities to include peers and would be focused on teaching the child with autism how to learn. It would focus on teaching the child to be able to attend to, respond to, and participate in group environments as they prepare to attend daycare, preschool, or Kindergarten. The ultimate goal of the ABA-based, Early Intervention program should be to move from 1:1 therapy to a group learning experience, focusing on the developmental milestones described earlier, and allowing these skills to come into contact with reinforcement from other children. •

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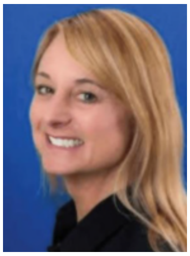
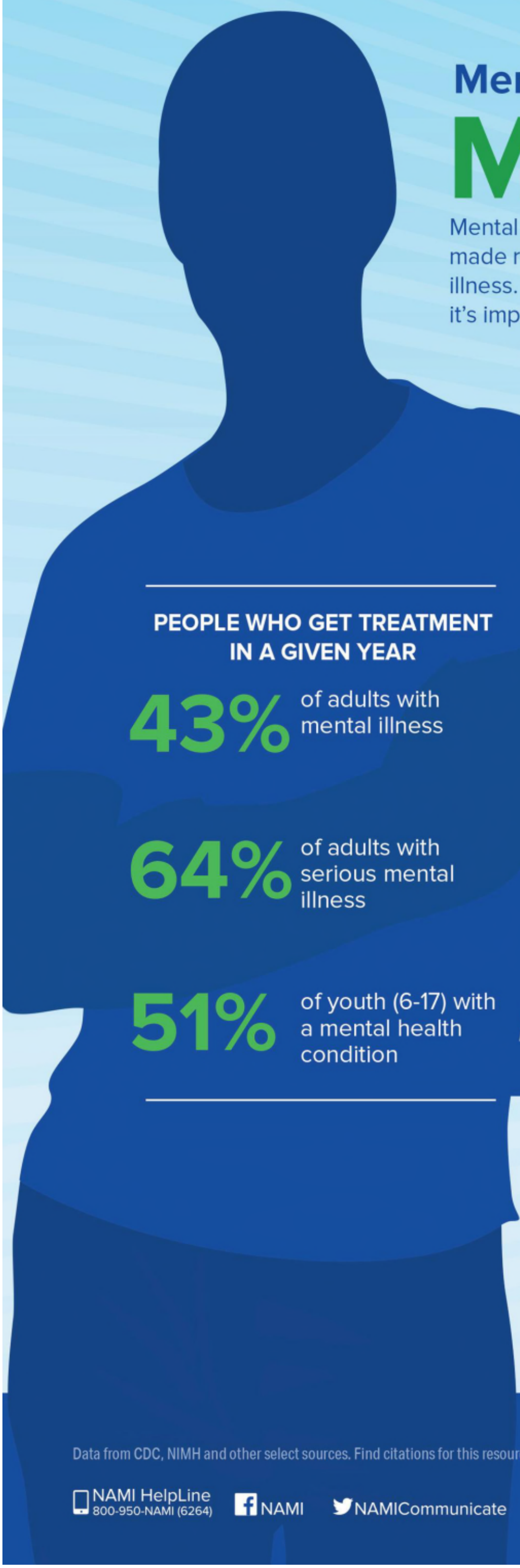


With over 27 years of experience in the field of autism and ABA, Kelly Bermingham is a respected expert in the field. She's a certified BCBA and ESDM therapist, a published author, and a sought-after speaker at national conferences. She is the author of *Social Skills Solutions* Tune into her podcast "A 25 Year Look Across the Spectrum" for valuable insights and advice.



Mental Health Care
MATTERS

Mental health treatment — therapy, medication, self-care — have made recovery a reality for most people experiencing mental illness. Although taking the first steps can be confusing or difficult, it's important to start exploring options.

The average delay between symptom onset and treatment is

11 YEARS

PEOPLE WHO GET TREATMENT IN A GIVEN YEAR

43% of adults with mental illness

64% of adults with serious mental illness

51% of youth (6-17) with a mental health condition

Adults with a mental health diagnosis who received treatment or counseling in the past year

25% of Asian adults

31% of black adults

32% of adults who report mixed/multiracial

33% of Hispanic or Latinx adults

49% of white adults

49% of lesbian, gay and bisexual adults

> *For therapy to work, you have to be open to change. I'm proud to say that I changed.* ***Therapy saved my life.***
>
> – NAMI Program Leader

Data from CDC, NIMH and other select sources. Find citations for this resource at nami.org/mhstats

NAMI HelpLine 800-950-NAMI (6264) NAMI NAMICommunicate NAMICommunicate www.nami.org

NAMI
National Alliance on Mental Illness

HELPING YOUTH WITH LOW VISION AND BLINDNESS TRANSITION INTO THE WORLD OF WORK

BY ERNST VANBERGEIJK, PH.D., M.S.W AND ALEXANDRA LAVOIE, M.S.O.T.

A common misconception is that individuals with low vision or blindness are unable to work or live independently due to the nature of their disability. Employers are often reluctant to hire these individuals because they incorrectly assume that accommodations for these employees will be costly.

Others fear the employee with low vision will be injured on the job and the business will be held liable for an accident. These misplaced fears impact the possibility of individuals with disabilities to find and keep employment.

As part of a comprehensive strategic planning process, Perkins School for the Blind engaged with stakeholders from across the country to better understand the nuanced challenges that exist for students with low vision or blindness, as they navigate the complex transition from high school to adult services. This research uncovered significant gaps in transition programming, opportunities for meaningful career exploration and skill development for students who are blind or visually impaired, including some who have additional disabilities and complex learning profiles. As a result, these students are graduating with minimal work experience, gaps in independent living skills, emotional immaturity, and inability to navigate public settings. Traditional classroom and school-based work experiences alone, do not adequately prepare students with disabilities to establish community connections and build the pre-employment skills that are needed to navigate real-word experiences. The complexity of disabilities within this student population necessitates individualized transition planning, and job placement experiences that are tailored to their unique strengths and interests. These opportunities help students to generalize their skills and enhance the development of problem-solving and critical thinking skills needed to be successful in a work setting.

WORLD OF WORK: The Perkins Transition Center strives to ensure that every student has equal access to the support they need, to transition to an active role within their communities and to a fulfilling adult life.

PHOTOS PROVIDED ERNST VANBERGEIJK/ALEXANDRA LAVOIE

WHAT THE RESEARCH TELLS US ABOUT YOUTH WITH DISABILITIES

"There are approximately 239,700 transition-age youth who have VI, ages 16 to 20 years" (Erickson, Lee, & von Schrader, 2019 as cited in Lund & Cmar, 2020).

Employment disparities are evident among transition-age youth with disabilities, who have lower employment rates than youth without disabilities. 35.9% of working-age people with disabilities were employed compared to 76.6% of those without disabilities (Kraus, Lauer, Coleman, & Houtenville, 2018). In 2017, 18.1% of youth with disabilities ages 16-19 years were employed versus 30.8% of those without disabilities. Similarly, 36.9% of young adults with disabilities ages 20-24 years were employed compared to 67.3% of their peers without disabilities (Bureau of Labor Statistics, 2018).

More recent research found that:

- *50.9%, or roughly half of working age people with visual impairments are not in the labor force.*
- *The rate of visually impaired individuals not in the labor force is almost triple the rate of individuals without disabilities who are not in the labor force*
- *Youth with visual impairments are more likely to be out of the work force or never even enter the workforce because of employer discrimination or negative attitudes associated with visual impairments*

(Crudden, McDonnall, & Tatch, 2023).

WHAT WORKS WHEN HELPING STUDENTS WITH DISABILITIES FIND EMPLOYMENT

We know education matters. Students with disabilities who participate in a degree bearing program, a vocational training program or even one college course, are more likely to find employment than their peers with disabilities who do not pursue these options (Getzel & Wehman, 2005 as cited in VanBergeijk, 2019). Research shows that students with disabilities who received services from their local Vocational Rehabilitation Services Office while still in high school, were more likely to be employed (Miligore, et al., 2012; Roux, 2018 as cited in VanBergeijk, 2019). Having paid employment while in high school is another predictor of employment post high school for students with disabilities (Chiang, Cheung, Li, & Tsai, 2013).

Specifically, post-secondary vocational and transition programs do make a difference for students with disabilities. Moore and Schelling (2015) analyzed the National Longitudinal Transition data and found that 9 out of 10 students with ID who graduated from a transition program were employed within 2 years of the study (as cited in VanBergeijk, 2019), compared to only 5 out of 10 who did not participate in such programs.

In their systematic review of factors related to employment in transition aged youth with visual impairments, Lund & Cmar (2020) found that "…previous work experience, and post-secondary education were consistently significant positive predictors of employment across studies with previous self-initiated work experience being the strongest predictor." They also found some evidence of transportation and travel skills being an important factor in finding employment. Interestingly, "…demographic and disability characteristics were NOT significant predictors of employment" (Lund & Cmar, 2020).

A NEW MODEL OF INTERVENTION

Perkins School for the Blind has been educating children and young adults for almost 200 hundred years. Among their notable alumni are Helen Keller and her teacher, Anne Sullivan. Perkins believes every child can learn, and that real change is global change. Their training programs work with not only students, but families, teachers, schools, medical professionals, hospitals, community leaders, universities, and governments, to make education accessible to all children.

COUNTDOWN TO LAUNCH: The Life Launch Program is a work-based, residential transition program designed for students who are blind or visually impaired who have goals of meaningful work and community participation after high school.

Perkins School for the Blind is committed to conducting empirically based research and sharing the latest best practices with families and educators globally. Recognizing that youth with low vision and blindness are not employed at the same rates as their peers without disabilities, Perkins drew upon the latest research and best practices in the field, to create The Perkins Transition Center. The Transition Center strives to ensure that every student has equal access to the support they need, to transition to an active role within their communities and to a fulfilling adult life. It offers a range of services for families and young adults with disabilities, including innovative programming, transition counseling, parent education opportunities, and access to an online caregiver support community.

The Life Launch Program is their latest offering to transition aged youth who are looking to transition into the world of work and independent living. This work-based, residential transition program is designed for students who are blind or visually impaired, with or without multiple disabilities, who have goals of meaningful work and community participation after high school. Recognizing that the final years of high school mark a critical juncture in a student's educational journey, the program is tailored for students in their final years of high school. The understanding that students with blindness, low vision and additional disabilities require specialized instruction, intensive transition planning, and individualized, experiential learning opportunities underpins the Life Launch curriculum. The coursework is designed so that participants will develop essential skills for successful workforce and community integration. Participants complete all academic requirements. The curriculum focuses on the Expanded Core Curriculum and encompasses a range of subjects, including assistive technology, interpersonal communication, independent living, financial literacy and advocacy and activism. Students are guided through immersive work experiences that equip them with the essential skills needed to secure and maintain employment, such as: job-seeking strategies, workplace etiquette and task-specific proficiencies. A program tailored specifically to the unique needs of this population promotes student empowerment and will maximize opportunities to achieve meaningful employment outcomes.

The Life Launch Program started accepting applications this month (January 2024). The Perkins School for the Blind will be welcoming the Life Launch students on campus Fall of 2024. For more information visit: **www.perkins.org/transition-center/life-launch**

Perkins also offers a range of impactful programming and resources designed to assist more academically oriented students with BVI, to transition to postsecondary higher education programs including colleges, universities, and Comprehensive Transition and Post-secondary (CTP) programs. For more information on these programs and resources visit: **www.perkins.org/college-success** •

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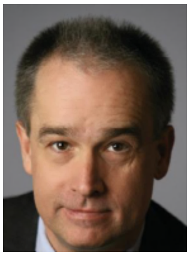

Ernst VanBergeijk, Ph.D., M.S.W. is the Founder and President of Ernst Equitable Education Solutions, a consulting firm that helps parents find appropriate educational settings and solutions for their children, and helps organizations evaluate and design programming for special needs children, youth, and young adults. He has over 35 years of experience in the special education field including working as the executive director/dean of two college-based transition programs for students with a wide variety of disabilities. **ErnstEES.com**

Alexandra LaVoie, M.S.O.T is the Director of the Transition Center at the Perkins School for the Blind and is a licensed occupational therapist and special education administrator. Alex has worked in the field of blindness education for over 10 years and has a deep understanding of the unique supports and accommodations that are needed for BVI students to achieve their post-secondary goals. She is passionate about Perkins' mission to empower students with disabilities to unlock their potential and live as independently as possible. **Perkins.org/Transition**

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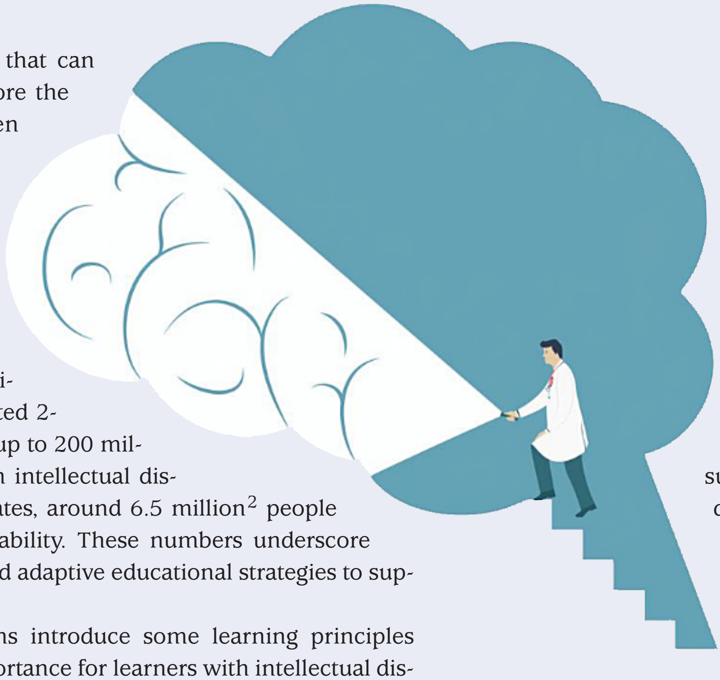
EMPOWERING CHILDREN WITH INTELLECTUAL DISABILITIES

BY ARTYOM ZINCHENKO, PHD

Intellectual disabilities (ID) represent a complex spectrum of conditions affecting cognitive functioning and skills, including language, social interactions, and self-care. Individuals with ID may develop and learn differently, often at a slower pace than those without such disabilities. The causes are diverse, ranging from genetic conditions like Down syndrome and Fragile X syndrome, to complications during pregnancy and birth, and even environmental factors like diseases or exposure to toxins.

It's a phenomenon that can occur anytime before the age of 22, even before birth, making it the most common developmental disability globally. Intellectual disability poses a serious challenge to individuals, families, and communities. Globally, an estimated 2-3%[1] of the population, up to 200 million people, live with an intellectual disability. In the United States, around 6.5 million[2] people have an intellectual disability. These numbers underscore the need for effective and adaptive educational strategies to support learners with ID.

The following sections introduce some learning principles that hold particular importance for learners with intellectual disabilities. These insights can be helpful for parents striving to support and enhance the learning experiences of their children with special educational needs.



THE RIGHT STEPS: Educators, parents, and caregivers are pivotal in crafting a supportive and enriching environment.

ELUCIDATION

Let's explore these strategies, beginning with the concept of elucidation. Elucidation is the practice of giving clear, precise, and slow explanations, and could be one of the keys to unlocking the world for children with ID. Breaking down challenging concepts into smaller, more manageable parts and using straightforward language, makes learning more accessible for these children. Incorporating visual aids such as picture schedules to help children anticipate daily activities, or storyboards to assist in understanding story sequences, can further enhance their understanding. These tools aid in comprehension and provide a sense of control and predictability for the child. It's crucial in this process to maintain the child's engagement, as their learning can be significantly affected by distractions.

For instance, in reading and language development, elucidation may entail reading a story aloud and pausing to explain the meaning of unfamiliar words or phrases. Simple repetitive sentences and visual cues like illustrations, can further aid comprehension. Elucidation is equally valuable for teaching social skills. When helping a child with ID learn about sharing, use real-life scenarios to illustrate the concept. Role-playing can be an effective tool, allowing them to practice sharing in a controlled and supportive environment.

FEEDBACK

Another critical aspect of education is feedback. It needs to be clear and kind. We're not just fixing mistakes, but showing children what they're doing well and how to improve. Saying things like "I noticed you worked hard on this part" makes a child feel good about their effort. Telling them, "Let's try this part another way," helps them see a challenge as a chance to learn something new. Giving feedback immediately is helpful because it connects what they're doing with their learning.

It's also crucial to find the *right balance with feedback*. Too much feedback can make a child feel watched constantly, which can be overwhelming. However, insufficient feedback might make them unsure about their performance. The trick is to check on their work periodically, especially at the start, to ensure they understand, and are on the right track. If you need to suggest improvements, pick a few important things to focus on. This way, they don't feel overloaded with corrections.

WE CAN ENABLE CHILDREN WITH INTELLECTUAL DISABILITIES TO NAVIGATE THEIR LEARNING JOURNEYS MORE EFFECTIVELY BY IMPLEMENTING ELUCIDATION PRINCIPLES, PROVIDING BALANCED FEEDBACK, AND FOSTERING SELF-REGULATION SKILLS.

SELF-REGULATION

Teaching self-regulation to children with intellectual disabilities is another integral part of their learning. Self-regulation is crucial to one's ability to manage behavior and emotions. Simple steps, such as assisting children in planning, tracking progress, and emphasizing the importance of patience, can have a significant positive effect. Strategies for enhancing socio-emotional self-regulation could involve: teaching breathing exercises for calming down, using feelings charts to help children identify and express their emotions, or establishing a 'safe space' in the home where they can go to feel secure and gather their thoughts. Parents need to recognize and respond to the individual emotional needs of their child, as children with ID might express their emotions differently. As parents and teachers, we can create environments that help children practice these skills. This means setting up routines and spaces that are structured and predictable, which helps kids feel more secure and focused.

Understanding self-regulation involves knowing about three essential parts: planning before doing something (forethought), controlling oneself while doing it (performance), and thinking about how it went afterward (self-reflection). Helping kids get better at these, can start with simple strategies. For example, we can help them set goals, evaluate their work, and manage their time well. Parents can also play a big role in this at home. For younger kids, it might be helping them understand and follow instructions, or set up a routine for homework. For older kids, it's more about assisting them to handle their emotions in different social situations, and giving them the right balance of guidance and independence.

Children with ID may experience sensory sensitivities, such as being easily overwhelmed by loud noises or certain textures. Parents must understand their child's unique sensory needs. Strategies like creating a sensory-friendly environment at home, using sensory toys for comfort, or gradually exposing the child to different sensory experiences can be beneficial. Understanding these needs helps prevent and manage meltdowns, often resulting from sensory overload.

In summary, by implementing elucidation principles, providing balanced feedback, and fostering self-regulation skills, we enable children with intellectual disabilities to navigate their learning journeys more effectively. Educators, parents, and caregivers are pivotal in crafting a supportive and enriching environment. Through these efforts, we facilitate our children's academic and personal growth, and lay a solid foundation for wise, lifelong learning. This holistic approach is crucial in preparing them to meet the challenges and opportunities of the future with confidence and resilience. •

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Artyom Zinchenko, PhD, is a cognitive neuroscientist passionate about teaching. He completed his PhD at the Max Planck Institute for Cognitive Human and Brain Sciences in Leipzig, Germany, focusing on how emotions and cognitive conflict are processed. He is a faculty member at Ludwig-Maximilian University in Munich, researching the interplay between cognition and emotion and the role of long-term memory in visual search. His research employs various neurophysiological techniques, including EEG, transcranial magnetic stimulation, and a combination of EEG and fMRI. Dr. Zinchenko is also an effective teacher, instructing cognitive neuroscience and EEG methodology courses. He extends his expertise to high school students, aiming to spark their interest in neuroscience. As a father, he finds joy in assisting his children with their education, a pursuit that fuels his continuous learning, e.g., in machine learning and app design. For more information, please visit **wisestlearners.com**

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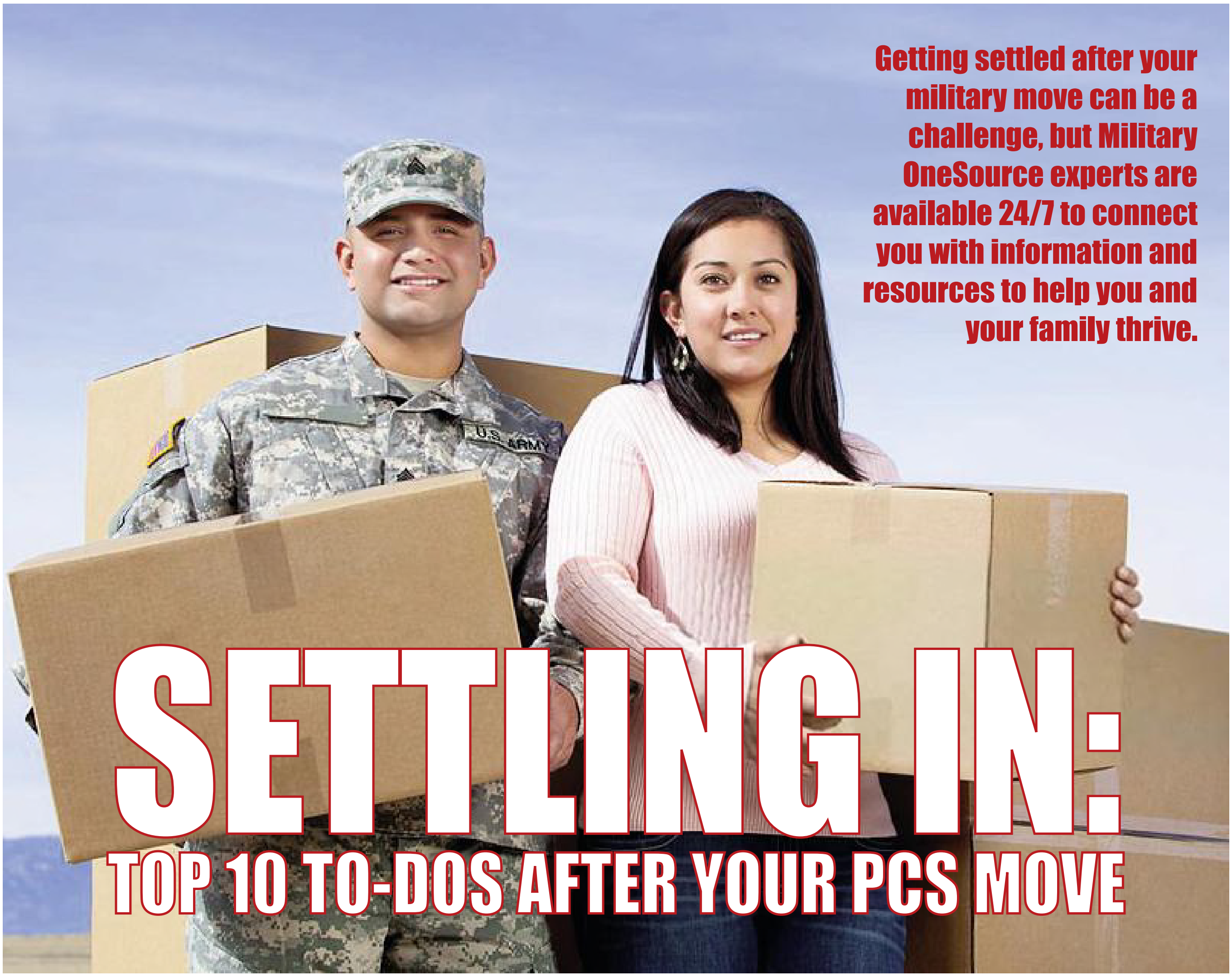

Getting settled after your military move can be a challenge, but Military OneSource experts are available 24/7 to connect you with information and resources to help you and your family thrive.

SETTLING IN:

TOP 10 TO-DOS AFTER YOUR PCS MOVE

Once you arrive at your new duty station, you'll have to tie up all the loose ends before you can get settled into your new community. Use these top ten "to-dos" to help you.

1. FILE YOUR TRAVEL VOUCHER

The Defense Department will pay for some things related to your move, including mileage expenses and Dislocation Allowance (**www.militaryonesource.mil/benefits/military-dislocation-allowance**). Learn how to submit your travel voucher online. at **https://corpweb1.dfas.mil/askDFAS/faqView?faq.faqId=13389**

2. CONNECT WITH YOUR RELOCATION ASSISTANCE PROGRAM

The military Relocation Assistance Program (**www.militaryonesource.mil/benefits/relocation-assistance-program**) offers key resources to help you adjust to your new location. Programs, briefings and other services are usually offered at your local Military and Family Support Center (**https://installations.militaryonesource.mil/search?program-service=26**), and may include:

- *Newcomers' orientations and welcome packets*
- *Free internet café, with printers, faxes and photocopiers*
- *One-on-one assistance from experts on topics ranging from settling into a new community to child care information and getting help with local schools*
- *Referrals to the installation Personal Financial Management Program or organizations that offer emergency financial assistance*

Programs vary by service and location, so contact your local Military and Family Support Center for more information.

3. CHECK OUT YOUR INSTALLATION LOAN CLOSET

If you arrived at your new location and your household goods aren't there yet, see if your installation has a loan closet or loan locker. You can borrow essential items for free – such as dishes, cooking utensils or coffee maker – until your goods arrive. Use MilitaryINSTALLATIONS to see if your new installation offers a loan closet (**https://installations.militaryonesource.mil/search?program-service=52**).

4. REGISTER FOR CHILD CARE

For parents with preschool children, contact your installation's child development center (https://installations.militaryonesource.mil/search?program-service=29) immediately to register because there can be a long waiting list for child care in some areas. You don't need official orders to request child care, so be sure to start that process as soon as you know where you'll be going.

Learn more about military child care programs (www.militaryonesource.mil/benefits/military-child-care-programs), including how to:

- *Search for and request child care through MilitaryChildCare.com* (https://militarychildcare.com)
- *Access a national database of caregivers through Military OneSource's Expanded hourly options* (www.militaryonesource.mil/parenting/child-care/military-child-care-services)
- *Learn about fee assistance available from ChildCareAware.org* (www.childcareaware.org/fee-assistancerespite)

5. ENROLL CHILDREN IN SCHOOL

If your child will attend a DOD Education Activity school, learn about eligibility and enrollment (www.dodea.edu/registration-process.cfm).

If your child will attend a public school, the Interstate Compact on Educational Opportunity for Military Children can (www.militaryonesource.mil/education-employment/for-children-youth/interstate-compact-for-military-children) make the switch easier for military families moving between states. The compact is applicable in all 50 states and helps children register for the classes they need and graduate on time.

If you have questions, a Military OneSource education consultant (www.militaryonesource.mil/specialty-consultations/education/plan-your-future-with-a-military-onesource-education-consultant) can help you locate schools on and off your installation and advise you on registration. If you have a child with special needs consultants can direct you to resources such as your installation's EFMP (https://installations.militaryonesource.mil/search?program-service=15).

Another great education resource is your installation school liaison (https://installations.militaryonesource.mil/search?program-service=12). School liaisons serve as a bridge between schools and military families and assist with education-related issues for children grades pre-K through 12. They know the local schools and community and can help make sure your child's educational needs are met. Learn more about the wide variety of services offered by school liaisons (www.militaryonesource.mil/resources/podcasts/military-onesource/school-liaisons-and-geo-dispersed-families).

6. COMPLETE YOUR MOVING CUSTOMER SATISFACTION SURVEY

Your feedback matters! After your shipment has been delivered, you will have an opportunity to evaluate your household goods or unaccompanied baggage shipment by submitting a customer satisfaction survey (https://download.militaryonesource.mil/12038/MOS/Factsheets/TRANSCOM-DP3CustomerSatisfactionSurvey-15March2021.pdf). Sharing your feedback could help other families benefit from your experience, as well as positively impact your own future moves.

The surveys are read by real humans, and if a transportation service provider has a negative trend, they can be suspended (temporarily or indefinitely) for providing poor service. On the flip side, if you find a TSP that did an excellent job, please put that in the survey as well, so we know who to continue to reward with more service contracts.

To access the survey, log in to the Defense Personal Property System (https://dps.move.mil/cust/standard/user/home.xhtml) and select the Customer Satisfaction Survey tab. If you are unable to log in to DPS you can call the System Response Center at 800-462-2176. Select option 2, next option 1, then option 1."

7. FILE A CLAIM FOR ITEMS DAMAGED DURING YOUR MOVE

Once your household goods have been delivered, you have up to 180 calendar days (75 calendar days for household goods shipments picked up prior to May 15, 2020) to inspect your property and provide a notification to the TSP that you plan to file a Loss and Damage Report. To be reimbursed, you must also file a Loss and Damage Report with your itemized claim in the DPS within nine months. Find out more about filing loss and damage claims (www.militaryonesource.mil/resources/millife-guides/moving-claims).

If you have questions about the claims process or need assistance, contact your local transportation office (https://installations.militaryonesource.mil/search?program-service=2). If they are unable to help, you may contact your service branch military claims office for further assistance. Visit the following service branch moving assistance pages for contact information:

- Army PCS Moving Assistance www.militaryonesource.mil/moving-pcs/plan-to-move/army-pcs-moving-support/
- Marine Corps PCS Moving Assistance www.militaryonesource.mil/moving-pcs/plan-to-move/marine-corps-pcs-moving-assistance
- Navy PCS Moving Assistance www.militaryonesource.mil/moving-pcs/plan-to-move/navy-pcs-moving-assistance
- Air Force PCS Moving Assistance www.militaryonesource.mil/moving-pcs/plan-to-move/air-force-pcs-moving-support
- Coast Guard PCS Moving Assistance www.militaryonesource.mil/moving-pcs/plan-to-move/coast-guard-pcs-moving-assistance

8. MAKE SURE YOUR HEALTH CARE MOVES WITH YOU

Contact TRICARE (www.tricare.mil/LifeEvents/Moving) and let them know you have moved, especially if you have relocated to a different part of the country or OCONUS. You'll want to be connected with a new primary care provider. TRICARE can also advise you on dental and vision care. Learn more about TRICARE basics (www.militaryonesource.mil/health-wellness/prevention-care/tricare-101-military-health-benefits-basics-in-five-minutes-or-less).

9. GET TO KNOW YOUR NEW INSTALLATION AND COMMUNITY

Don't' be afraid to get out and about. Use your sponsor. Ask about activities you and your family like to do so you can get connected to those activities in your new community. A good way to help children get settled is to reach out to your installation school liaison (https://installations.militaryonesource.mil/search?program-service=12) for information about youth sponsorship or visit your installation youth programs, schools and parks.

Your children will learn how to join in familiar activities and have an opportunity to meet other military-connected children. Keep in mind that children can have a wide range of emotions during the transition. They could have concerns about starting a new school and making new friends. Listen, support and be there for your children during the transition.

In addition to learning about the activities and programs available for you and your family at the new installation, it's also a good idea to look into what discounts are available for utility services such as phone, TV, internet and trash removal. If you live off the installation, you are responsible for arranging these services yourself. If you will live on the installation, basic services are provided by the installation. Some companies offer military families a discount, so always ask when you are setting up a new service.

Use MilitaryINSTALLATIONS (**https://installations.militaryonesource.mil**) to explore your new duty station. The website offers everything from base essentials to program and service contacts, community information and state resources. Find contact information for installation child development centers, youth programs, school liaisons and more. Learn how to explore your base and beyond with MilitaryINSTALLATIONS (**www.militaryonesource.mil/resources/network/militaryinstallations**).

10. START YOUR JOB SEARCH

If you're a military spouse looking for a new job after your PCS, use these helpful resources to jump-start your search.

The Spouse Education and Career Opportunities program (**https://myseco.militaryonesource.mil/portal**) provides comprehensive resources and tools for career development, education guidance and employment opportunities to military spouses worldwide. SECO resources include career coaching, the Military Spouse Employment Partnership (**https://myseco.militaryonesource.mil/portal/article/military-spouse-employment-partnership**), a free upgrade to LinkedIn Premium (**https://myseco.militaryonesource.mil/portal/article/linkedin-premium-for-military-spouses**) to assist with job searches and networking, and much more.

Installation spouse employment readiness specialists, (**www.militaryonesource.mil/education-employment/seco/installation-employment-readiness-specialists-a-valuable-resource-for-you**) accessed through your local Military and Family Support Center (**https://installations.militaryonesource.mil/search?program-service=26**) or service branch, offer hands-on assistance with everything from resume writing and preparing for interviews to resources for portable careers.

If you move due to a PCS and want to transfer your professional license, you can apply for up to $1000 for reimbursement of relicensure or certification fees from your service branch. Learn more about transferring your professional license (**www.militaryonesource.mil/education-employment/seco/transferring-your-professional-license-what-s-involved**).

Love working with children? Look into opportunities to work in child development programs (**www.militaryonesource.mil/education-employment/seco/careers-with-military-kids**).

Getting settled after your military move can be a challenge, but Military OneSource experts are available 24/7 to connect you with information and resources to help you and your family thrive. Call 800-432-9647, use OCONUS dialing options or schedule a live chat."

– Military OneSource

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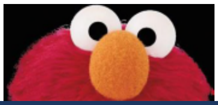
is available to help with your concerns regarding military life.



WE OFFER

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

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

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U.S. MILITARY ★ BOOK EXCERPT 14TH OF A SERIES

THE RESILIENT WARRIOR

PURPOSEFUL MOVEMENT

BY KATE HENDRICKS THOMAS

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

Mindful movement creates opportunities for mastery, experience, and a platform from which to build physical stability. When we talk about caring for our physical body, we often emphasize movement, movement off-the-couch, movement!

Yet balance is one of the most important things a person can plan into a training calendar. The physical practices that offer us stress reduction and a return to homeostatic balance are beneficial in a myriad of ways. It cannot all be about raising our heart rate and shrinking a derriere. Those things are fine, but balanced physical self-care with a keen focus on regulating an overstimulated nervous system must become priorities to anyone looking to cultivate resilience.

Here is the good news – there is more than one way to do this. You have the freedom to figure out which activities work best for your personality, resources, and preferences. Trying out mindful movement practices, and learning from the pros who teach them is my favorite hobby. For me, the most relaxing physical practice available, changes based on what is happening in my life. There have been times when the answer was trail running, yoga, swimming, or rowing. The fun part is trying new options, with an eye towards what you should be feeling, and deciding if it is a practice that is bringing you into balance. Remember: healthy practices are not abusive. When it is a balancing activity, you will feel yourself exerting, but still peaceful. You will sleep a bit better; you may notice your mind slow down a bit.

You'll pay attention to your body in new ways. *"Hey!' you'll think. 'I just noticed how much tighter my left hip is than my right! I wonder if I should spend some time stretching that side more?"* Self-care of this sort also provides a level of mental fitness training that can hone focus, improve performance, and increase resilience. Such training involves purposeful movement that brings attentive focus to the physical body and the racing mind. This attention trains the body in both a challeng-

WARRIOR TO THE END: United States Marine Corps Captain Katherine Hendricks Thomas lost her lengthy and courageous battle with Stage IV Breast Cancer in April of 2022. She is remembered for her dedication to bettering the lives of veterans and active-duty military.

ing and balanced fashion, while carving in space for activation of the parasympathetic nervous system. It is here that the body restores, improves, and evens out hormone levels in the blood, back to their optimal levels. That's the beauty of balanced training: it pushes your envelope and then hits the reset button!

Mindful movement is a unique way to build mental toughness. It creates opportunities for mastery, experience, and a platform from which to build physical stability. Interestingly, most of us are not physically stable without very intentionally working to become so. We sit too much, slouch a bit, and create muscular imbalances that we do not notice, because we often zip through our days without paying attention to present tense sensations in our tissues.

We all live in an obesogenic environment, where it is easier to find fast food than fresh vegetables, and we are all constantly overstimulated. It is easy to dismiss just how stimulating our environments typically are, because we get used to an unhealthy norm. That cell phone is really not supposed to be next to your pillow at night.

I recall sitting with a friend in a shopping mall a few years ago. We sat down at a little table near the food court and were trying to chat and catch up a bit, while she snuggled her toddler in her lap. We were surrounded by flat-screen televisions that were all blaring different stations to entertain food court patrons. Her little boy looked around in alarm, then buried his face in her shoulder and started weeping. I felt like joining him. His young system was not used to blaring techno-noise, and his reaction to the shrillness was to retreat to his mom.

I remember thinking that he was setting an example for the adults in the room, who had all gotten used to ten television sets blaring overhead while they ate a rushed meal of fast food. This is not normal for our physical bodies! The pace of modern life is frenetic. Our bodies read this "Go, go, go" message clearly, and the stress embeds itself in our minds and bodies. Our stress response is a completely natural phenomenon, and the human body operates intelligently to produce appropriate reactions to life's surprises.

Upon registering some sort of threat, the brain sends hormonal signals to the adrenal glands, which secrete cortisol and adrenaline to empower the body to handle it. In a healthy negative feedback system, the cortisol signals the hypothalamus to shut down the response provided the threat has disappeared. This stress response is supposed to happen at an intensity level in relation to the threat. It is instructive and animal, and is necessary for performance, self-preservation, and survival.

Everyone's response to stimuli differs, and what is stimulating to one person biochemically, may not be to another. That does not mean our systems aren't registering the stimulation, however. Those ten televisions were keeping my nervous system on the alert, even if I did not view them as threatening in the same way that my friend's toddler did. The problem with the human stress response does not become apparent until the stress becomes chronic, and the bloodstream contains too much cortisol. Chronic stress occurs when the brain's hypothalamus refuses to shut off the chemical signals it is sending, because it still perceives a problem.

In our modern society, with its constantly ringing phones, troubled interpersonal relationships, and an ever-increasing pace enabled by technology, chronic stress is rampant. When the body's stress response is constantly firing, blood cortisol levels are too high and inflammatory proteins become more present in the bloodstream. A host of illnesses and inflammatory conditions have been related to this chemical imbalance. The body's immune system becomes overactive and confused by the aberrant proteins. Unsure what foreign bodies to attack, autoimmune illnesses like rheumatoid arthritis and allergies become real health issues. Unchecked, unacknowledged stress is a killer in too many ways to count. Chronic stress has been linked to a host of physical maladies including abdominal weight gain, cancer, gastrointestinal illnesses, depression, and chronic pain.

We cannot always prevent surprises that send our bodies into reaction mode, but we can prepare them for stress and adopt a positive outlook towards challenge, in general. For me, time spent with my pet, a quiet walk in the woods, or a mindful yoga class are my means of preparing for the stress I know will always come. •

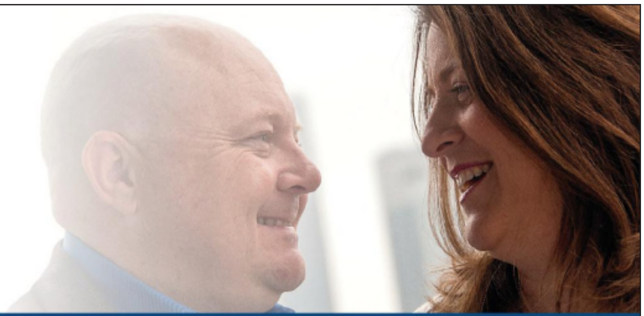
ABOUT THE AUTHORS:

United States Marine Corps Captain Katherine Hendricks Thomas lost her lengthy and courageous battle with Stage IV Breast Cancer on April 5th, 2022. Thomas was diagnosed with three types of breast cancer in 2018 at just 38 years old. The cancer is attributed to the exposure from the burn pits during Thomas' service in Iraq. Thomas was born into a military family and lived in several different bases throughout her life. She grew up with three siblings, and along with her brother, decided to follow in their father's footsteps of becoming a United States Marine. In 2005, Thomas was deployed to Fallujah, Iraq where she served as a military police officer. It was there that Thomas was exposed to smoke from burn pits, containing toxins now known to cause cancer and other service-related diseases. Thomas was a fierce advocate for those who suffered from illnesses attributed to burn pit exposure. On June 7th, 2022, President Biden signed into law the Dr. Kate Hendricks Thomas Supporting Expanded Review for Veterans in Combat Environments (SERVICE) Act, requiring the VA to provide mammograms to women with possible burn pit or other toxin exposure. Thomas left active duty in 2008 and went on to earn a Doctorate degree in Health Education and Promotion. She wrote several books examining veterans' mental health and the unique experiences of women in the military. Captain Katherine Hendricks Thomas is remembered for her dedication to bettering the lives of veterans and active-duty military. Friends and family recall that she was positive and brave up until the very end. She is survived by her husband and son.

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.

VA | Family member



As a service member's spouse, child, or parent, you share in that service member's service and sacrifice. So after your loved one leaves the service, you may qualify for certain VA benefits. And if your family member died or was seriously injured in the line of duty or as a result of a service-related injury or disease, you may receive additional assistance.

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Explore VA benefits for spouses, dependents, and survivors, including eligibility rules and how to apply, at **VA.gov/family-member-benefits**.

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Paddle Together or Go Nowhere

To all dads out there: it takes a partnership with your spouse. You have to talk about the feelings part which is probably the hardest thing for me.

Editor's Note: In place of Shelly Huhtanen's monthly column in this issue, EP Magazine is publishing a conversation her husband Mark recorded with David Hirsch and the Special Fathers Network on their Dad to Dad Podcast (#176 aired on Nov. 18, 2021).

FAMILY UNIT: Colonel Huhtanene with wife Shelly and sons Hayden and Broden *(center).* "You can have a successful career in the military with a special needs child and still take care of them. Being enrolled in the EFMP program ensures that I can only get assigned places where Broden can get taken care of."

Colonel Mark Huhtanen of Columbia, SC, is a 25-year combat veteran of the US ARMY. He has served four active-duty tours, and is the father of two sons. Mark and his wife are the proud parents of Hayden (17) and Broden (15) who is non-verbal and has Autism. Serving in the military and raising a family presents unique challenges. Raising a child with special needs while serving in the military requires an extra level of dedication and additional resources, such a s those that are offered through the military's Exceptional Family Member Program, also known as EFMP. His wife, Shelly, is a mom raising two boys as well as a military spouse, which has entailed several moves. Shelly has authored a book and writes a monthly column for the Military Section of *Exceptional Parent Magazine*.

David Hirsch: Let's start with some background. Tell me about your family.

Mark Huhtanen: I grew up in Montana. We ended up in the small town of Hamilton, Montana. My parents retired and reside there. My dad did 28 years in the education system. After my mother went out of teaching, she worked for the National Institute of Health where she did 20 years and retired.

DH: Your dad was a Vietnam veteran.

MH: Yes. It was four years that he served. He served a tour in Vietnam, came back, married my mother, and asked to go to Germany. The army said, "We're going to send you back to Vietnam." My father politely declined, and started his education career.

DH: Did he talk about his experience in the military when you were growing up?

MH: The older I got, the more I learned about his time. Right before I came into the military, he shared his story with me.

DH: How would you describe your relationship with your father?

MH: He was always fair and firm. I got my work ethic from him. As a child, we had chores. You didn't play until your chores were done. He modeled that and made sure all of his stuff was done before he would sit down and watch a ball game, or relax. As I hit my teenage years, some friction started, as I came into my own. He was always very supportive.

PHOTOS PROVIDED BY SHELLY HUHTANEN

DH: Was there a lesson your dad modeled that you've incorporated into your own parenting?

MH: Integrity was very important to him and I try to pass that on to Hayden.

DH: You did four tours. What was that like?

MH: My first was probably the most defining tour for who I am now and our family. I deployed on my first combat tour in 2005. Hayden, our oldest, was one year old, and Shelly had just found out she was pregnant with Broden. Back in those times, for the 12-month deployments, you would get a two week leave. My commander came to all of us that had wives expecting and said, "We're going to do the best we can to get you back around the delivery dates, if there's not an emergency." I didn't make it quite on time. I was there right after Broden was born.

> "Somebody evaluated Broden and said 'He has autism.' You get hit with shock, depression, and 'I can't believe this is happening. What's the treatment?' 'Well, here's some pamphlets.'"

DH: Is there anything that you or Shelly learned as a result, that you might be able to share with other families, because that's the real world. Our expectations and reality are sometimes not in sync.

MH: In some ways, that probably started to prepare us, a little bit, for Broden's diagnosis, that happened a year and a half later. I think it definitely taught us as an army family, that plans change, and you're really not home until you're home.

DH: It's a matter of managing expectations. Certain things are within your control, and certain things are outside of your control. Maybe, it's a reminder to do the best with the facts that you have, and just move forward. Before Broden's diagnosis, did you or Shelly have any exposure or experience with the special needs community?

MH: I had a cousin that had Down Syndrome, so growing up I was aware of it, but neither one of us was immersed in it.

DH: How did the autism diagnosis come about, and what was your first reaction?

MH: I was at school in Kansas when we began to notice that Broden wouldn't react to certain things. He had a physician's assistant assigned through the military that was checking up on him. We thought he might be deaf. In Kansas you get amazing thunderstorms and when the thunder would go off, the dog would bark, we'd all scream and Broden would just sit there. We knew the visual cues were there, because he was very interested in visualization and cartoons, and visual stimulus. We went through a series of hearing tests. The Army actually paid us to go to Omaha, Nebraska, to do an extensive auditory test where they hooked a bunch of electrodes to him. They put him in a quiet room and they monitored him. It was a shock when we got done, and the doctor says, "Your son can hear fine." "What's wrong then?" "I can't really tell you. I just can tell you it's not his hearing." We walked out of the hospital and back to the hotel. We were bewildered. Shelly hopped on our laptop and started calling. She got hold of, somebody with the early intervention services in Kansas. They said, "You've got to get him into an interdisciplinary team. I don't want to tell you what I think it is, but if it's not a physical disability, then it might be something else. An interdisciplinary team will look at all different things." We went back to his doctor, told her everything, and ended up getting on a wait list. In our world, there are all these wait lists. Shelly would call every day to see if there was an opening. Finally, one day there was an opening, so we went to KU Med. They interviewed Shelly and me. We felt like it was an interrogation. I'm sure many parents have gone through that. "What did he eat? How did he sleep? What did you do?..." Then somebody was evaluating Broden, and when they got done said, "He has autism." You get hit with: shock, depression, and "I can't believe this is happening." Looking back, Shelly and I would both say, "This is the way ahead. What's the treatment?" I think what floored us was that there wasn't any treatment. There was, "Well, here's some pamphlets. There's this Defeat Autism Now program, and there's this thing called applied behavioral analysis therapy." We walked out of there stunned. Shelly ran to the restroom. I didn't know at the time what was going on, but she says in her book, she was dry heaving, from the stress and everything. That night she starts looking for BCBAs. Wait list. Finally, we found this BCBA, "Okay, I can take a look at him in a couple weeks." That was when we saw a little bit of a light at the end of the tunnel.

DH: Were there some fears that you remember experiencing early on, or maybe as things transpired?

MH: My first fear was "Shelly is outrunning me right now, because she's a mom, this is her baby, and she is trying to find ways to fix it." I'm still processing everything. Later, we would find out that I was fighting PTSD. I'd just come back from that first tour. My fear was, "I'm not going to be able to do enough as a dad. I'm not going to be able to pull my weight. I'm not going to be able to keep up with Shelly". After about the first month, I looked at Shelly, "You can't do this all by yourself. How can I help?" We figured out, since I was still in the military, I was going to navigate the military systems. Our healthcare was provided by TRICARE, so I was going to navigate how to get Broden's referrals. We have a program in the military called the Exceptional Family Member Program, and I would enroll us in that. EFMP ensures that I can only get assigned places where Broden can get taken care of. I began to advocate on that side, and Shelly began to be the go-between, between therapists and doctors. She researched who she needed to get a referral to. I'd figure out how to make that happen. It allowed us to share the weight.

MAKING THE DREAM WORK: The Huhtanen family; "It takes a partnership with your spouse. It takes a lot of patience, communication, talking through: feelings, responsibilities, jobs, who's doing what. If you don't know what your partner's going through, and you don't know what your partner's taking care of, then you're not complementing each other."

DH: Was there any meaningful advice, that you can look back and say, "I'm really glad this person told us this,"?

MH: We got to meet a family that are still friends. She actually went on to be a BCBA and was Broden's BCBA. He's a general officer now. Andy and Nikki Helms were ahead of us on the journey.

> "It is okay to fight for Broden, and it was okay to buck the Army system. I think sometimes we don't want to buck the system, but it's okay to buck the system to take care of your child."

I think the one thing they both told us is, that it is okay to fight for Broden, and it was okay to buck the Army system. I think sometimes we don't want to buck the system, but it's okay to buck the system to take care of your child. They showed us that you could still have a successful career with a special needs child, and as I've gone through my career, that was some great advice.

I haven't been in the civilian world for 25 years, but I think I get a persona sometimes. I'm a leader in the army, and I'm supposed to be on this pedestal, and I'm not supposed to have all these flaws. I've gotten to mentor many younger families in the military. We have some great stories where Broden just brings us right back to reality. It's great, because it allows us to stay humble, and to connect with those around us. I got my first battalion command, and we were doing a big event at our house. Broden likes to wear his favorite pair of pajama pants. When he's done with school, those pajama pants are going on. We were so busy getting ready to host all these people at our house, that we didn't think about the fact that Broden's pajama pants were in the laundry in the basement. Here comes Broden with no pants on. Broden's on a mission to go downstairs to get his pajama pants. It's "Here's Broden." I think it was just great, because as embarrassing as it was at the time, it was also a great lesson of humility. After that, people were not afraid to bring issues to us and talk to us. It was exactly what the organization needed at the time and Broden did it.

DH: What are some of the bigger challenges for you and Shelly, or for Broden?

MH: There's a couple challenges, I don't think are unique to the military. The first challenge is, I had three more combat deployments after Broden's diagnosis. Shelly and I always have to be very deliberate about what roles and responsibilities people would do. I'm out the door. Shelly takes over everything. She's running kids to therapy. We've got our older son Hayden, who's typical, so he is going to school, sports, etc. She takes on the role of mom and dad. Then all of a sudden, after six or nine months, I'm back in. I'm looking around, "What do you need me to do"? "Nothing." I feel we had some delicate negotiations there. It's life, you get going and focused on things. I see the immense progress he makes, because I've been gone for six months. Shelly's in the knife fight, and sometimes she'd be so frustrated. "I can't believe he's not doing this, and we've been working on this for months." I'm like, "Look at all this stuff he can do." It brings some perspective for our family. That's a good side of it. The other side of it is figuring out those roles and responsibilities. It's always a challenge, because I feel guilty. But technology has been great. I have done IEP meetings and counseling sessions thousands of miles away. When we first were diagnosed, we couldn't have done that. Now it's a matter of making time for it. The other challenge is not to forget you have other challenges. We're raising another child who is going through different things. Right when Broden's diagnosis was going on, I was battling PTSD from my first deployment. Between autism and that, it took us a lot longer to get everything under control and back in balance. Those are some of the downsides, but there are silver linings.

> "When Broden's diagnosis was going on, I was battling PTSD from my first deployment. Between autism and that, it took us a lot longer to get everything back in balance."

DH: What impact has Broden's situation had on his older brother, your marriage, or the extended family?

MH: I'll start with the extended family. Both my parents and Shelly's parents feel challenged because we move around. We were lucky in Texas. We got to spend the last three or four years there, and we were about an hour apart. That meant they got to see quite a bit of Broden and Hayden growing up. Once we were out to Georgia, now in Columbia, and then with the pandemic… we're going to see my parents next week for the first time in two years. They're going to be floored at the progress. We can zoom and see it, but it's not the same as being able to spend every holiday together. The blessings are that both have done a phenomenal job of finding different ways to help Broden. My father was a grant writer, so he's big into finances. He did lots of research for all his grandkids, but especially with Broden, he helped with things like a special needs trust. We did the legwork with the lawyers, but then my dad helped figure out how to set up some future stuff for Broden, that you wouldn't think about. For a typical kid, you do your college fund, and then you kind of hope they're out of the nest and going. For our special needs kids, you have to have longer term planning. Shelly's parents have planned trips around times when we need somebody to watch Broden, even if it means flying halfway across the country. I remember her mom flying in because I had a bunch of training to do. At one point she also flew in, so Shelly could go to an advocate conference in Washington, DC. Within our immediate family, watching Hayden, at times he does feel like he is an only child. He can't do normal sibling things, because Broden can't go with him. Hayden played basketball for many years, and he has had to suffer through just one parent being at the events, because it was too loud for Broden. We finally got Broden hearing protection, so he could come. I think the good thing is, I don't think there's anybody who knows Broden better than Hayden. Hayden will step up to the plate and watch Broden at a moment's notice, if we've got to do something. He knows how to take care of him, knows how to handle outbursts, knows what his diet is. He's kind of a walking encyclopedia on what Broden needs, and is in tune with him. He can anticipate, as fast as Shelly and I can, when something's going to upset him or something's off balance. As we've had the struggles, it has shaped Hayden a lot. In Columbia, we've got a camp called Camp Cole, for special needs kids. Hayden's going to go be a counselor there for some volunteer hours. It was fun listening to the interview, because they like throwing situations at him, and Hayden's like, "Oh, I take care of that all the time with my brother." I think he was a shoe-in for the job.

DH: You mentioned the Exceptional Family Member Program. That's not just for families who have a child with autism, but for a lot of different diagnoses. Is that correct?

MH: Absolutely. In the Army and Air Force, we have two EFMP programs. One is tied to our medical system, and once you're enrolled in that, it will ensure that you're only assigned where your family member gets care. The second, is a community service organization that connects you with support groups and activities. The Navy and the Marine Corps combine theirs, so they're just a little different between the services. I think it's more efficient seeing what the Navy and Marine

Corps do. We'll see if the Army gets there. But coming back to medical needs, it's for any family member. I've had friends who have had family members with cancer that they've taken on as a dependent. That soldier can enroll in that program. Whatever need is designated as a medical necessity, the Army can only assign them where they can get that care.

DH: Shelly writes a column for *Exceptional Parent Magazine,* Where did the motivation come from with as much as she has on her plate?

MH: I think for Shelly, writing started as kind of a way to process the diagnosis and everything that she was going through. She's a communications teacher by trade. I think writing was her way of voicing it. She kind of fell into *Exceptional Parent Magazine,* because it had some articles that were handed to us, early on with Broden. I think she read a couple of the articles, and she thought, "I need to share our story." Then they kept asking her to write about different things, and pretty soon they made a column for her. It was part of her process to be able to talk about and think about what she's been through, and synthesize everything.

DH: Are there important takeaways that you might share, A) for a military family, and B) just for dads at large?

MH: For military families, number one is you can have a successful career in the military with a special needs child or special needs family member and still take care of them. You have to be enrolled in the EFMP program, because then the military knows, and they won't assign you somewhere else. To all dads out there: it takes a partnership with your spouse. It takes a lot of patience, communication, talking through: feelings, responsibilities, jobs, who's doing what. You have to talk about the feelings part which is probably the hardest thing for me. If you don't know what your partner's going through, and you don't know what your partner's taking care of, then you're not complementing each other. We like to joke that navigating this is like being in a canoe. You've got to paddle together, or you're not going to go anywhere, or you're going to go in circles.

DH:. Why is it that you've agreed to be a mentor father as part of the Special Fathers Network?

MH: I've been doing it already in the military, so if it helps a broader audience, then great. I had a friend of mine tell me, "Mark, I've got this young major who works for me, and they just found out their son has autism. Can you take a few minutes to talk to him?" I didn't have that when I went through it. I literally stumbled through it with Shelly. I needed to know that there was somebody who had gone ahead of me and had been through a few more doors than I had. Someone who could look back and say, "Okay, this is what's coming up next," So I think that's the biggest reason.

DH: We're thrilled to have you. Thank you for being involved. In fact, I would say that a very, very large majority of the 500 plus dads in the network have said, "I wish there had been something like this when I was a younger dad."

MH: There's some male pride that sometimes gets in our way. You just have to be willing to make the phone call. Us old guys, we'll tell stories all day long. If you just have the phone call and listen, it might get you something.

DH: Let's give a special shout out to your lovely wife, Shelly, and our mutual friends at *Exceptional Parent Magazine* for helping connect us.

MH: Absolutely.

DH: Is there anything else you'd like to say before we wrap up?

MH: Hopefully somebody out there was helped just by listening to me.

DH: Mark, thank you for your time and your many insights. As a reminder, Mark is just one of the dads who is part of the Special Fathers Network, a mentoring program for fathers raising a child with special needs. If you're a dad looking for help or would like to offer help, we would be honored to have you join our closed Facebook group. Please go to facebook.com/groups and search Dad to Dad. Also, please be sure to register for the Special Fathers Network biweekly Zoom calls held on the first and third Tuesdays of every month.

SFN Mentor Fathers share their experiences with younger dads closer to the beginning of their journey raising a child with the same or similar special needs. The SFN Mentor Fathers do NOT offer legal or medical advice – that is what lawyers and doctors do. They simply share their experiences and how they have made the most of challenging situations. •

To listen to this entire podcast or other interesting and informative podcasts (including the interview with our Editor In Chief, Faye Simon) go to: Dad to Dad Podcast at https://podcasts.apple.com/us/podcast/dad-to-dad-podcast/id1373738974

RESOURCES FOR FATHERS

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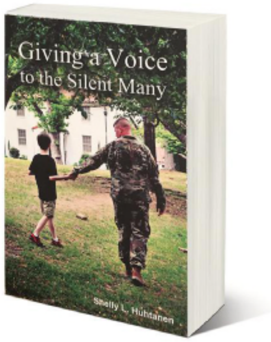

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OUR JOURNEY IN CAMO

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

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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.

Talk with your children about what to do if they are faced with a decision about alcohol and other drugs, such as texting a code word to a family member. Practice the exit plan in a safe environment. For tips on how—and when—to begin the conversation, visit:

www.underagedrinking.samhsa.gov

SAMHSA
Substance Abuse and Mental Health Services Administration