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THE KEY TO A HEALTHIER LIFE

Cortical Visual Impairment
MAKING THE DIFFERENCE

CONVERSATIONS ABOUT DIAGNOSES

2025 EP GUIDE
NAVIGATING SPECIAL NEEDS RESOURCES

SKATING FORWARD TOGETHER: PAUL'S JOURNEY

Adapting to Autism:
THE UNSEEN JOURNEY

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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. A special thank you to Blank Rome LLP for sponsoring this special issue.

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DEPARTMENTS

MILITARY SECTION

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Bright and Early

The topics of early intervention and genetic testing lead off the year in our 2025 EP Guide: Navigating Special Needs Resources.

We hope that your new year has gotten off to a good start! We feel that our first issue of 2025, the annual EP Guide: Navigating Special Needs Resources, is a good fit for the topics of early intervention and genetic testing. The importance of early intervention is discussed in the article by Larry Prensky and Mike Pattrick,"Why Early Detection Is the Key to a Healthier Life." Intervention at the earliest stage can greatly improve outcomes for children with cortical visual impairment, according to Francesca Crozier-Fitzgerald. Her article "Making the Difference: CVI-Specific Early Intervention," can help inform parents who are striving to obtain early intervention services for a condition that is often missed or misdiagnosed.

> The 2025 EP Guide contains a number of candid and inspiring personal stories of struggles and strength.

Authors Cindy Weber and Tara Szymanek each have both professional and personal experience with genetic testing and genetic-based diagnosis. In their article "Genetic Resources," they clarify how best to discuss the processes with your provider and present a wide variety of resources on the subject.

The 2025 EP Guide also contains a number of candid and inspiring personal stories of struggles and strength. JJ McLeod sheds light on adapting to autism's ever-evolving realities in her article "The Unseen Journey." In "Heartbeats and Lifelines," Tracey Lynne Scheuers describes her profound shock, and her ultimate gratitude, that she felt during the short life of her son Sammy Jo who was born with Spina Bifida.

Also in this issue, you will meet Jeff Lowry, born with developmental disabilities, and Paul Smagula, who lives with Asperger's syndrome. Both Jeff and Paul have overcome earlier struggles to lead rich lives that include helping others.

We appreciate the comments, suggestions, and questions about *EP Magazine*. Your feedback, helps us maintain the relevance of our magazine.

I personally want to express my appreciation for all of you who share about the magazine and EP for Free, on social media, websites, through newsletters and word of mouth! Follow us on **facebook.com/exceptionalparentmag**, Instagram **@epmzine** and **x.com/epmzine** and share our posts. It's easy to subscribe and get "EP for Free" – just visit www.epmagazine.com and click EP for Free Sign Up!

Faye Simon

Editor In Chief

THE EDITOR IN CHIEF'S DESK

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

Information and Support for the Special Needs Community

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WHAT'S HAPPENING

ENDING THE 14(C) PROGRAM: PHASING OUT PAY INEQUITY FOR WORKERS WITH DISABILITIES

BY TARYN M. WILLIAMS
AND KRISTIN GARCÍA

In 1938, Congress enacted the Fair Labor Standards Act (FLSA), which included a provision, now referred to as section 14(c), that grants the Secretary of Labor authority to certify employers to pay workers with disabilities below the federal minimum wage.

A FAIR DAY'S PAY: The DOL has announced a proposed rule to phase out use of current section 14(c) certificates over a 3-year period.

Today, many workers with disabilities whose employers pay subminimum wages are paid less than half the minimum wage with some being paid just pennies an hour for their work.

In the past 86 years, civil rights and economic opportunities for workers with disabilities have evolved due to profound legal and policy developments, the disability rights movement, and changes in societal and cultural expectations. Legislation, judicial precedent and regulatory initiatives have fundamentally and profoundly altered the rights, protections, access and opportunities available to individuals with disabilities. Additionally, these evolving changes to the employment landscape have dramatically altered access to employment opportunities and available supports for workers with disabilities.

Today, numerous states and localities have prohibited or limited the payment of subminimum wages to workers with disabilities within their jurisdiction. In addition, an increasing number of employers are voluntarily opting out of seeking certifications that allow them to pay subminimum wages to workers with disabilities.

Section 14(c) of the FLSA authorizes the Secretary of Labor to issue certificates allowing employers to pay subminimum wages to workers with disabilities only if such certificates are necessary to prevent the curtailment of opportunities for employment. On Dec. 3, the department announced a notice of proposed rulemaking to end the issuance of new section 14(c) certificates to pay subminimum wages to workers with disabilities and phase out use of current section 14(c) certificates over a 3-year period. The department proposes that subminimum wages are no longer necessary for job opportunities for workers with disabilities.

If finalized, the proposed rule would not require workers with disabilities to leave their current places of employment and would not require current section 14(c) certificate holders to amend the employment setting or type of services they provide. Based on reviews of data and information from states that have already eliminated subminimum wage payments for workers with disabilities, the department expects that many workers with disabilities currently paid subminimum wages would be able to transition to full-wage employment, leading to benefits for workers and society.

The cornerstone of our promise to workers has always been a fair day's pay for a hard day's work. But for too long, individuals with disabilities have been left out of that promise. Today's proposal is an important step toward addressing that.

We encourage the public to provide feedback about this proposed rule during the comment period. All comments must be received by 11:59 p.m. ET on Jan. 17, 2025, for consideration in this rulemaking. Comments received after the comment period closes will not be considered. Learn more about how to comment on a notice of proposed rulemaking.

ABOUT THE US DEPARTMENT OF LABOR:

The mission of the Department of Labor is to foster, promote, and develop the welfare of the wage earners, job seekers, and retirees of the United States; improve working conditions; advance opportunities for profitable employment; and assure work-related benefits and rights. For more information, visit **www.dol.gov**

ABOUT THE AUTHORS:

Taryn M. Williams is the assistant secretary of labor for disability employment policy; Kristin García is the deputy administrator in the Wage and Hour Division.

ten

Things You Need To Know About Birth Defects

1. Did you know that birth defects are common?

Fact: Birth defects affect 1 in 33 babies every year and cause 1 in 5 infant deaths. For many babies born with a birth defect, there is no family history of the condition.

2. Did you know that a woman should take folic acid during her teens and throughout her life?

Fact: Because half of all pregnancies in the United States are not planned, all women who can become pregnant should take a vitamin with folic acid every day. Folic acid helps a baby's brain and spine develop very early in the first month of pregnancy when a woman might not know she is pregnant.

3. Did you know that many birth defects are diagnosed after a baby leaves the hospital?

Fact: Many birth defects are not found immediately at birth. A birth defect can affect how the body looks, how it works, or both. Some birth defects like cleft lip or spina bifida are easy to see. Others, like heart defects, are not.

4. Did you know that some birth defects can be diagnosed before birth?

Fact: Tests like an ultrasound and amniocentesis can detect birth defects such as spina bifida, heart defects, or Down syndrome before a baby is born. Prenatal care and screening are important because early diagnosis allows families to make decisions and plan for the future.

5. Did you know that birth defects can greatly affect the finances not only of the families involved, but of everyone?

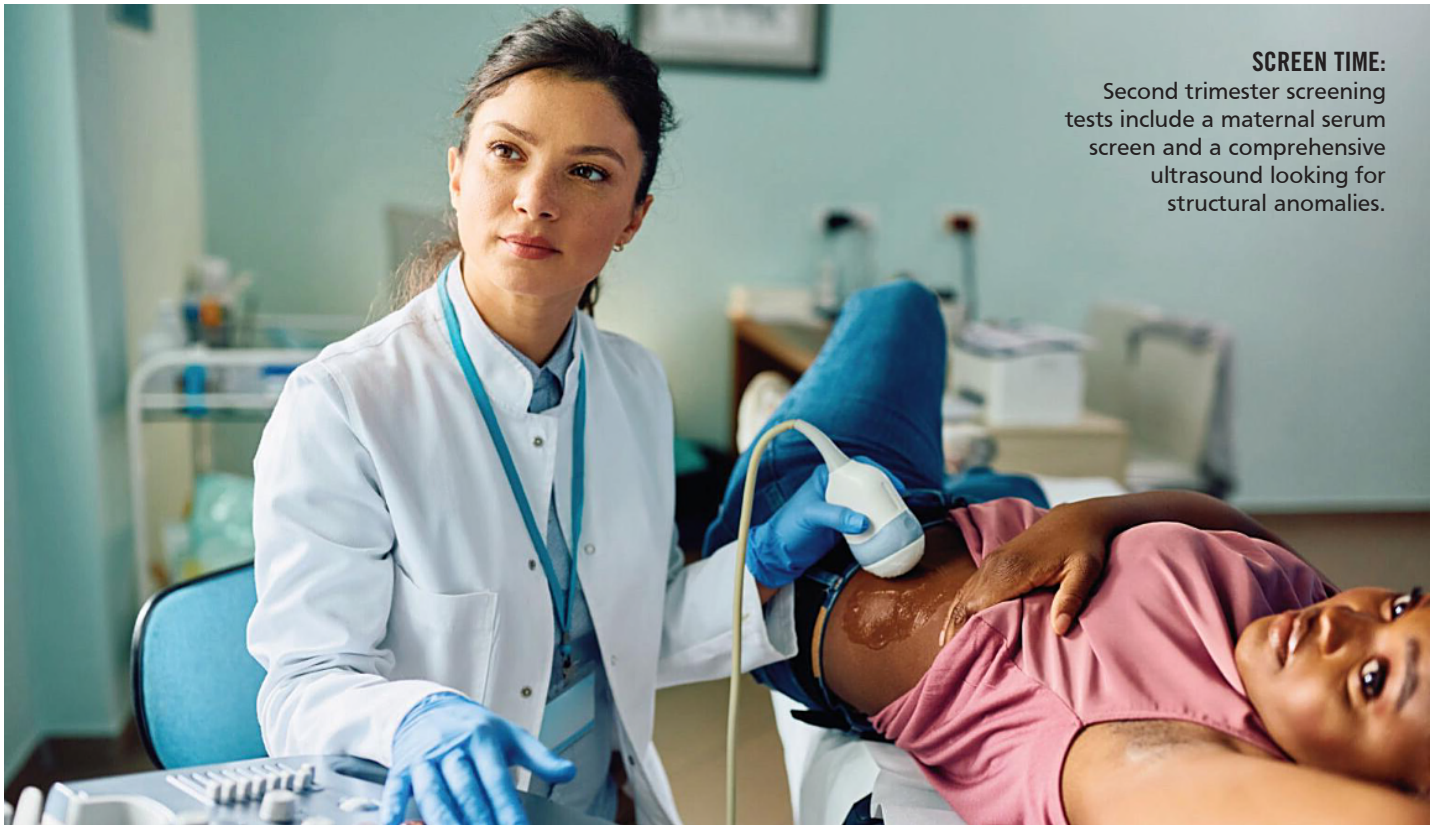
Fact: In the United States, birth defects have accounted for over 139,000 hospital stays during a single year, resulting in $2.6 billion in hospital costs alone. Families and the government share the burden of these costs. Additional costs due to lost wages or occupational limitations can affect families as well.

DEPARTMENT OF HEALTH & HUMAN SERVICES · USA

CDC
CENTERS FOR DISEASE CONTROL AND PREVENTION

WHAT'S HAPPENING

EVERY JOURNEY MATTERS: JANUARY MARKS NATIONAL BIRTH DEFECTS AWARENESS MONTH



SCREEN TIME: Second trimester screening tests include a maternal serum screen and a comprehensive ultrasound looking for structural anomalies.

Every 4.5 minutes a baby is born with a condition that affects the structure or function of their body. Collectively, these conditions are referred to as birth defects.

They can vary widely in how and where they affect the body and include things from cleft lip to heart problems. While medical advancements have greatly improved health and survival, many of these conditions are lifelong and require lifelong care.

Achieving the best possible health will look different for different people. No two people living with these conditions are exactly alike. Everyone's journey is unique, shaped by their specific condition, individual strengths, and the support system in place. However, a community of support can help people with these conditions no matter what health experiences they are navigating.

Parents should consider joining with the CDC to raise awareness about birth defects at **www.cdc.gov/birth-defects/php/communication-resources/index.html.** For parents or caregivers of children born with one of these conditions, CDC will discuss actionable tips that may help you to:

- *Seek out and advocate for coordinated care if you can.*
- *Help your child build skills toward independence as they grow.*
- *Connect to your local community.*
- *Coordinating care*

Many children living with conditions such as spina bifida or gastroschisis require care from a variety of specialists and support services. Children and their parents can benefit from the medical home approach to care. This personalized approach allows healthcare providers and families to work together to make sure medical and nonmedical needs are met. Coordinated care can lead to an improved patient and family experience, more consistent care, and reduced healthcare costs.

Knowledge empowers parents to make the best choices for their child's future. Understanding the child's condition is essential to making informed decisions about their health and well-being. Early identification and early intervention also can help a child receive the right care and resources they need to thrive.

LANGUAGE MATTERS : SENSITIVITY AND ACCURACY

While "birth defect" is a medical term, it doesn't mean that an individual is "defective." It refers to health conditions that develop in a baby before birth. In an attempt to be accurate and sensitive, we try to use the specific name of the condition present at birth when possible.

PHOTOS COURTESY CDC.GOV/BIRTH-DEFECTS

SCREENING BEFORE BIRTH

Some birth defects require special medical care after birth. Screening tests can help you and your providers prepare for any additional care you or your baby may need. Talk to your provider about any concerns you have about screening tests or other testing during pregnancy (prenatal tests).

First trimester screening (11–13 weeks pregnant): A combination of tests are offered in the first trimester to look for certain heart birth defects or chromosomal disorders. This includes a maternal blood test and an ultrasound.

The maternal blood screen is a simple blood test. It measures the levels of two proteins, human chorionic gonadotropin (hCG) and pregnancy associated plasma protein A (PAPP-A). If either protein level is abnormally high or low, there could be a chromosomal disorder in the baby.

An ultrasound creates pictures of the baby. The ultrasound for the first trimester screen looks for extra fluid behind the baby's neck. This could indicate a chromosomal disorder or heart defect in the baby.

Second trimester screening (15–20 weeks pregnant): Second trimester screening tests include a maternal serum screen and a comprehensive ultrasound looking for structural anomalies. The second trimester ultrasound is usually completed around 18–20 weeks of pregnancy.

The maternal serum screen is a blood test used to identify increased risk for certain birth defects. It is known as a "triple screen" or "quad screen" depending on the number of proteins measured in the mother's blood. For example, a quad screen tests the levels of 4 proteins - AFP (alpha-fetoprotein), hCG, estriol, and inhibin-A.

During the second trimester ultrasound, providers check all the major structures of the baby's body. Providers also do a fetal echocardiogram. This test uses sound waves to check the baby's heart and can provide a more detailed image.

SCREENING RESULTS

A screening test can sometimes give an abnormal result even when there is nothing wrong with the mother or her baby. Less often, a screening test result can be normal and miss a problem that does exist. If you receive an abnormal screening test result, your provider will discuss diagnostic test options.

BUILDING INDEPENDENCE

Adolescents and young adults living with birth defects may face unique challenges as they grow older. Navigating the shift from pediatric to adult health care may feel challenging, but early planning and support can empower teens.

For young adults considering independence, making a plan to move from pediatric to adult care is a key step. This plan can be made together with caregiving family members and healthcare providers. Young adults can also start taking charge of other pieces of their care. This may include keeping track of medical records or learning to manage their insurance.

Together, families can ensure that individuals with birth defects receive the care and services they need to be as healthy, active, and independent as they can be.

CREATING COMMUNITY

Community plays an integral role in the lives of individuals and families affected by birth defects. For families navigating this journey, connecting with others who share similar experiences can be a helpful source of support and understanding. This connection may be in person or through internet groups hosted by condition-specific organizations.

Additionally, a community-wide focus on inclusion encourages an environment of acceptance that benefits everyone. Disability inclusion means understanding the relationship between the way people function and how they can participate in society. Everybody deserves the same opportunities to participate in every aspect of life to the best of their abilities and desires. Every community member can make a difference and play a part to help create a place where everyone knows they belong.

STEPS TO HEALTHY PREGNANCY

It is important to understand that birth defects can happen for many reasons, and not all of them can be prevented. However, you can take steps to help you and your baby be as healthy as you can be.

- Get *400 micrograms (mcg) of folic acid every day.*
- *Try to prevent infections.*
- *Manage health conditions such as diabetes or high blood pressure.*
- *See a healthcare professional regularly.*
- *Get recommended vaccines.*
- *Avoid alcohol, smoking, and other recreational drugs.*
- *Talk to a healthcare professional about any medications you take.*

If you are pregnant, your partner, family, and friends can support you in a variety of ways. Pregnancy is an exciting time. But it can also be stressful. Knowing you are doing your best during pregnancy, including staying healthy, can give you and your baby a great start.

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WHAT'S HAPPENING

OVER 988,000 NEW CONSUMERS OBTAIN AFFORDABLE HEALTH COVERAGE IN ACA MARKETPLACE SO FAR

The Centers for Medicare & Medicaid Services (CMS) reports that nearly 988,000 consumers who do not currently have health care coverage through the individual market Marketplace have signed up for plan year 2025 coverage.

The CMS is committed to creating a robust Marketplace Open Enrollment process for consumers so they can effortlessly purchase high-quality, affordable health care coverage. During last year's record-setting Open Enrollment Period, 21.4 million people signed up for coverage, driving the uninsured rate to a historic low, where it remains today. Consumers who have Marketplace coverage now will generally see their coverage renewed for 2025 if they take no action during the current Open Enrollment Period. At the same time, existing consumers are encouraged to return to the Marketplace and actively renew their coverage. Nearly 4.4 million existing consumers have already returned to the Marketplace to select a plan for 2025. Building on the historic success of last year, we are on track for a record high number of plan selections for this year's Open Enrollment.

OPEN MARKET: Those needing affordable, quality health insurance are encouraged to visit HealthCare.gov and sign up, where four out of five people can find coverage at $10 or less after subsidies

"Through the Marketplace millions of Americans seeking health coverage continue to find a high-quality plan at a low cost," said Health and Human Services (HHS) Secretary Xavier Becerra. "With many people shopping online for holiday gifts, you'll find the best deal in town at **HealthCare.gov**. Sign up for a health plan that meets your needs — and gives you peace of mind."

"ACA Marketplace open enrollment continues with more than 5.3 million people signing up for coverage since the beginning of the open enrollment period," said CMS Administrator Chiquita Brooks-LaSure. "These numbers reflect the strong and ongoing demand that individuals and families have for affordable, high-quality health care coverage and we expect this year will set another plan selection record."

For 2025, consumers continue to have greater plan choices, and, thanks to the Biden-Harris Administration and the Inflation Reduction Act of 2022, many people who were previously ineligible for financial assistance now have access to lower premiums after tax credits. Four out of five HealthCare.gov consumers can find a plan for $10 or less per month through expanded financial assistance. Consumers are reminded that this additional financial assistance will remain available through 2025. For more information on the range of updates CMS has implemented to improve the Health Insurance Marketplace for 2025 — including web and navigation enhancements and more — consult the "What's New for 2025 Open Enrollment" fact sheet at **www.cms.gov/newsroom/fact-sheets/marketplace-2025-open-enrollment-fact-sheet**

Marketplace Open Enrollment on **HealthCare.gov** runs from November 1 to January 15. Consumers who enroll by midnight December 15 (5 a.m. EST on December 16) can get full-year coverage that starts January 1, 2025.

Individuals can enroll or re-enroll in health insurance coverage for 2025 by visiting **HealthCare.gov** (or **CuidadoDeSalud.gov**), or by calling 1-800-318-2596 to fill out an application. Individuals who want assistance signing up for coverage may go to "Find Local Help" on HealthCare.gov to find a Navigator, Certified Application Counselor, or agent or broker. Additionally, if someone learns they are no longer eligible for Medicaid or Children's Health Insurance Program (CHIP) coverage, they can visit HealthCare.gov to see if they are eligible to enroll in a low-cost, quality health plan. They can also contact the Marketplace Call Center for support in finding a plan that fits their needs.

ABOUT THE HEALTH INSURANCE MARKETPLACE:

HealthCare.gov

The Health Insurance Marketplace is a service that helps people shop for and enroll in health insurance. The federal government operates the Health Insurance Marketplace, available at **HealthCare.gov**, for most states. Some states run their own Marketplaces. The Health Insurance Marketplace (also known as the "Marketplace" or "exchange") provides health plan shopping and enrollment services through websites, call centers, and in-person help. Small businesses can use the Small Business Health Options Program (SHOP) Marketplace to provide health insurance for their employees. When you apply for individual and family coverage, you'll provide income and household information. You'll find out if you qualify for premium tax credits and other savings that make insurance more affordable and/or coverage through the Medicaid and Children's Health Insurance Program (CHIP) in your state. Visit **HealthCare.gov** for more information.

WHAT'S HAPPENING

ASSOCIATION OF UNIVERSITY CENTERS ON DISABILITIES APPLAUDS CONGRESS PASSAGE OF AUTISM CARES ACT

The Association of University Centers on Disabilities (AUCD) applauds the Senate for passage of the Autism CARES Act of 2024. This bipartisan, bicameral bill is crucial to maintaining and improving the monitoring, training, and research programs throughout the U.S. Department of Health and Human Services focused on children and adults with autism, people with other neurodevelopmental disabilities, and their families.

CARE PACKAGE: The Autism CARES Act is the primary source of federal funding for autism research, services, training, and monitoring.

According to the Centers for Disease Control and Prevention Autism and Developmental Disabilities Monitoring (ADDM) Network, autism now affects one in every 36 children.

The reauthorized CARES Act will expand research, increase public awareness and surveillance, and improve the capacity of the interdisciplinary health professional training programs that support individuals with autism and other neurodevelopmental disabilities and their families.

The CARES Act was unanimously passed in the Senate by voice vote. The CARES Act is sponsored in the Senate by Senators Ben Ray Luján (D-NM) and Susan Collins (R-ME). In the House of Representatives, the bill is sponsored by the co-chairs of the Autism Caucus, Representative Chris Smith (R-NJ) and Representative Henry Cuellar (D-TX).

"AUCD commends Congress on its unwavering commitment to improving the lives of people with autism and their families. We are grateful to Senator Luján, Senator Collins, Representative Smith, and Representative Cuellar for their leadership to get the CARES Act reauthorized this Congress. AUCD also thanks the AUCD Network, self-advocates, family members, and other leaders in the disability community for their efforts to educate Members of Congress to understand the importance of this bill, the work it supports, and the needs of people with autism in each state and territory," said AUCD Public Policy Director Cindy Smith. "We look forward to continuing to work with leaders in Congress and the community to continue to make a positive impact in the lives of people with autism and their families."

The membership of AUCD includes a national Network–serving every state and territory–of 68 University Centers for Excellence in Developmental Disabilities (UCEDDs), 60 Leadership Education in Neurodevelopmental and Related Disabilities (LENDs) Programs, and 15 Intellectual and Developmental Disabilities Research Centers (IDDRCs). Together, these Centers and Programs provide a direct national impact through direct services, the development of new professionals, and the use of new knowledge generated from our research.

AUCD is available for contact. Please contact Cindy Smith, Director of Public Policy, at **csmith@aucd.org**.

ABOUT THE AUCD:

AUCD
ASSOCIATION OF UNIVERSITY CENTERS ON DISABILITIES
RESEARCH. EDUCATION. SERVICE

The Association of University Centers on Disabilities' (AUCD) mission is to amplify and advance the work of the AUCD Network to promote community inclusion and quality of life for people with developmental and other disabilities and their families. AUCD envisions a future where people with developmental and other disabilities live the lives they want in fully inclusive and accessible communities. Visit **www.aucd.org**

WHAT'S HAPPENING

DISABILITY RIGHTS ACTIVIST PUSHES GOVERNMENT TO LET HIM PARTICIPATE IN SOCIETY

BY TONY LEYS

Garret Frey refuses to be sidelined.

Frey has been paralyzed from the neck down for more than 37 of his 42 years. He has spent decades rejecting the government's excuses when he and others with disabilities are denied the support they need to live in their own homes and to participate in society.

The Iowan won a landmark case (www.washingtonpost.com/wp-srv/national/longterm/supcourt/stories/court030499.htm) before the U.S. Supreme Court in 1999, after his school district refused to pay for the care he needed to continue attending high school classes in Cedar Rapids. He recently scored another victory when a complaint he lodged with federal officials pressured Iowa to agree to increase Medicaid payments for caregivers to stay overnight with Frey so he won't need to move into a nursing home.

"These are civil rights issues," he said. "They are human rights issues."

FLEXIBLE BUT FIRM: Activist Garret Frey confers with Nancy Baker Curtis, president of The Arc of Iowa, in July 2024 during a state board meeting of the disability-rights group in Cedar Rapids, Iowa.

Frey makes his points a handful of words at a time. The cadence of his speech follows the rhythm of a mechanical ventilator, which pushes air into his lungs every few seconds through a tube in his throat. His voice is soft, but he makes sure it's heard.

Frey was paralyzed in an accident at age 4. He uses sip-and-puff controls to drive his wheelchair into courtrooms and through the halls of the Iowa Statehouse and the U.S. Capitol, where he demands policies that allow people with disabilities to live full lives.

"We'll get there. It takes time, but I'm not going to just let things go or let things slide," he said in an interview on the sunny patio of his Cedar Rapids home.

A color film photograph from 1999 shows a young boy in a wheelchair beside then-Vice President Al Gore.

Frey emphasizes that anyone could find themselves needing assistance if they suffer an accident or illness that hampers their ability to care for themselves. He encourages other people with disabilities to cite his victories when seeking services they're entitled to under federal law.

He has served on numerous local, state, and national boards and committees focused on protecting disability rights. He composes emails and updates his website using voice commands and a sticker on his chin that can interact with his computer's camera.

His activism has drawn admirers nationwide.

"People like Garret are critically important, because they are the trailblazers," said Melanie Fontes Rainer, director of the Office for Civil Rights at the U.S. Department of Health and Human Services.

In June of last year, Fontes Rainer's office announced an agreement with the state of Iowa to settle Frey's complaint that Medicaid pay rates were insufficient for him to hire and retain overnight caregivers at his home.

Frey said he filed his federal complaint after being rebuffed by state officials. The resulting agreement increased his workers' pay from about $15.50 to $22 an hour, the federal agency said. It also made other changes designed to allow Frey to continue living in the home he shares with his mother and brother.

Fontes Rainer said state officials cooperated with her office in settling Frey's complaint. She said she hopes other people will take notice of the result and report problems they have in obtaining services that help them remain in their communities.

The federal administrator said she gets emotional when she sees how hard Frey and others fight for their rights. "You shouldn't have to advocate for health care," she said. "When I think about all that he's been through, and that he continues to use his voice, I think it is so powerful."

The Iowa Department of Health and Human Services declined to comment on Frey's case. But spokesperson Alex Murphy said the department is "committed to ensuring access to high-quality behavioral health, disability, and aging services for all Iowans in their communities."

Last summer, Frey and his mother visited Washington, D.C., where they participated in a 25th anniversary celebration of the Supreme Court decision *Olmstead v. L.C.* (https://archive.ada.gov/olmstead/olmstead_about.htm) In that landmark case, the justices declared that people with disabilities have a right to live in their own communities, instead of in an institution, if their needs can be reasonably accommodated.

PHOTO COURTESY TONY LEYS/KFF HEALTH NEWS

Frey was reminded during the ceremony that others are still buoyed by his own Supreme Court case, Cedar Rapids Community School District v. Garret F (https://caselaw.findlaw.com/court/us-supreme-court/526/66.html).

The 1999 case focused on the Frey family's contention that the school district should pay for help Garret needed to safely use his ventilator so he could continue to attend classes. School district leaders said they shouldn't have to pay for such assistance because it was health care.

The court, in a 7-2 decision, described Frey as "a friendly, creative, and intelligent young man" who had a right to services enabling him to attend school with his peers.

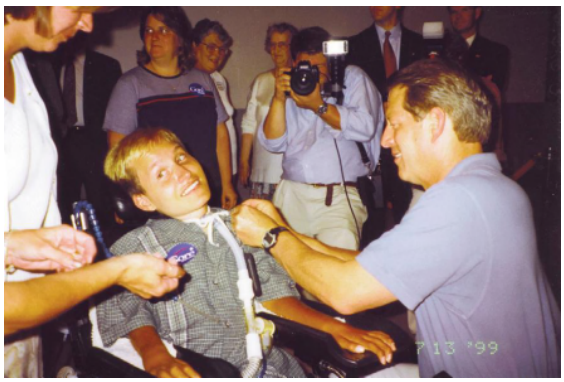
At the recent Washington ceremony, a California teenager approached Frey. "He said, 'You're Garret F? Thank you. Without you, I'd never have been able to go to school,'" recalled Frey's mother, Charlene Frey.

The 13-year-old fan was James McLelland (https://littlelobbyists.org/blog/2024/6/22/25-years-of-olmstead-rights-james-amp-jenny-mclellands-story), who breathes through a tube in his throat because of a genetic issue that impedes his windpipe. His breathing apparatus needs constant monitoring and frequent cleaning by a nurse.

His mother, Jenny McLelland, said she shows printed copies of the Garret F. court decision to school officials when she requests that James be provided with a nurse so he can attend regular classes instead of being sent to a separate school.

Because of the Supreme Court precedent, "we didn't have to litigate, we just had to educate," she said in an interview.

James, who is entering eighth grade this school year, is thriving in classes and loves playing percussion in band, his mother said. "James has had the life that people like Garret had to fight to get," she said. "These are the kinds of rights that are built brick by brick."



READY TO RUMBLE: *(Left)* In 1999, Garret Frey won his Supreme Court case; that same year, the teenager was greeted at a Cedar Rapids event by Vice President Al Gore. *(Right)* Disability rights activist Garret Frey is checked by Kelly Kirkpatrick, a registered nurse, outside Frey's home in Cedar Rapids in July.

"The 1999 case focused on the Frey family's contention that the school district should pay for help Garret needed to safely use his ventilator so he could continue to attend classes."

Frey said he found inspiration from earlier advocates, including Katie Beckett (www.nytimes.com/2012/05/23/us/katie-beckett-who-inspired-health-reform-dies-at-34.html), a fellow Cedar Rapids resident who, four decades ago, drew national attention to the plight of children with disabilities who were forced to live away from their families. Beckett, who was partly paralyzed by encephalitis as an infant, was kept in a hospital for about three years. At the time, federal rules prevented payment for Beckett to receive care in her home, even though it would have been much less expensive than hospital care.

In 1981, President Ronald Reagan denounced the situation as absurd and told administrators to find a way to let the young Iowan go home. The Republican president's stance led to the creation of what are still known as Katie Beckett waivers (https://ciswh.org/wp-content/uploads/2023/06/Catalyst-Center-Workbook_Chapter-5.pdf), which make it easier for families to get Medicaid coverage for in-home care for children with disabilities.

Frey knew Beckett and her mother, Julie Beckett (www.thegazette.com/health-care-medicine/julie-beckett-who-fought-for-change-in-medicaid-system-dies), and admired how their outspokenness prompted reforms. He also drew inspiration from meeting Tom Harkin, the longtime U.S. senator from Iowa who was the lead author of the 1990 Americans with Disabilities Act (www.ada.gov/topics/intro-to-ada).

Harkin, a Democrat, is retired from the Senate but keeps tabs on disability issues. In an interview, he said he was glad to hear that Frey continues to push for the right to participate in society.

Harkin said he is disappointed when he sees government officials and business leaders fail to follow requirements under the Americans with Disabilities Act. To maintain the law's power, people should speak up when they're denied services or accommodations, he said. "It's important to have warriors like Garret and his mother and their supporters."

Iowa's agreement to increase Medicaid pay for Frey's caregivers has helped him hire more overnight workers, but he still goes some nights without one. When no outside help is available, his mother handles his care. Although she can be paid, she no longer wants to play that role. "She should be able to just be my mom," he said.

At a recent board meeting of The Arc of Iowa, a disability rights group, Frey told his friends he's thinking about applying for a civil rights job with the federal government or running for public office.

"I'm ready to rumble," he 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 Massachusetts Institute of Technology.

PHOTOS COURTESY FREY FAMILY; TONY LEYS/KFF HEALTH NEWS

WHAT'S NEW

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INCLUSIVE INC.
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AUTISM PRODUCTS
www.autism-products.com

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The Irene & Eric Simon (IES) Brain Research Foundation is a volunteer-run nonprofit whose mission is to help advance research toward treatments and cures for brain diseases and conditions. The Irene & Eric Simon (IES) Brain Research Foundation Summer Fellowship Program in Neuroscience attracts bright, motivated students to neuroscience.
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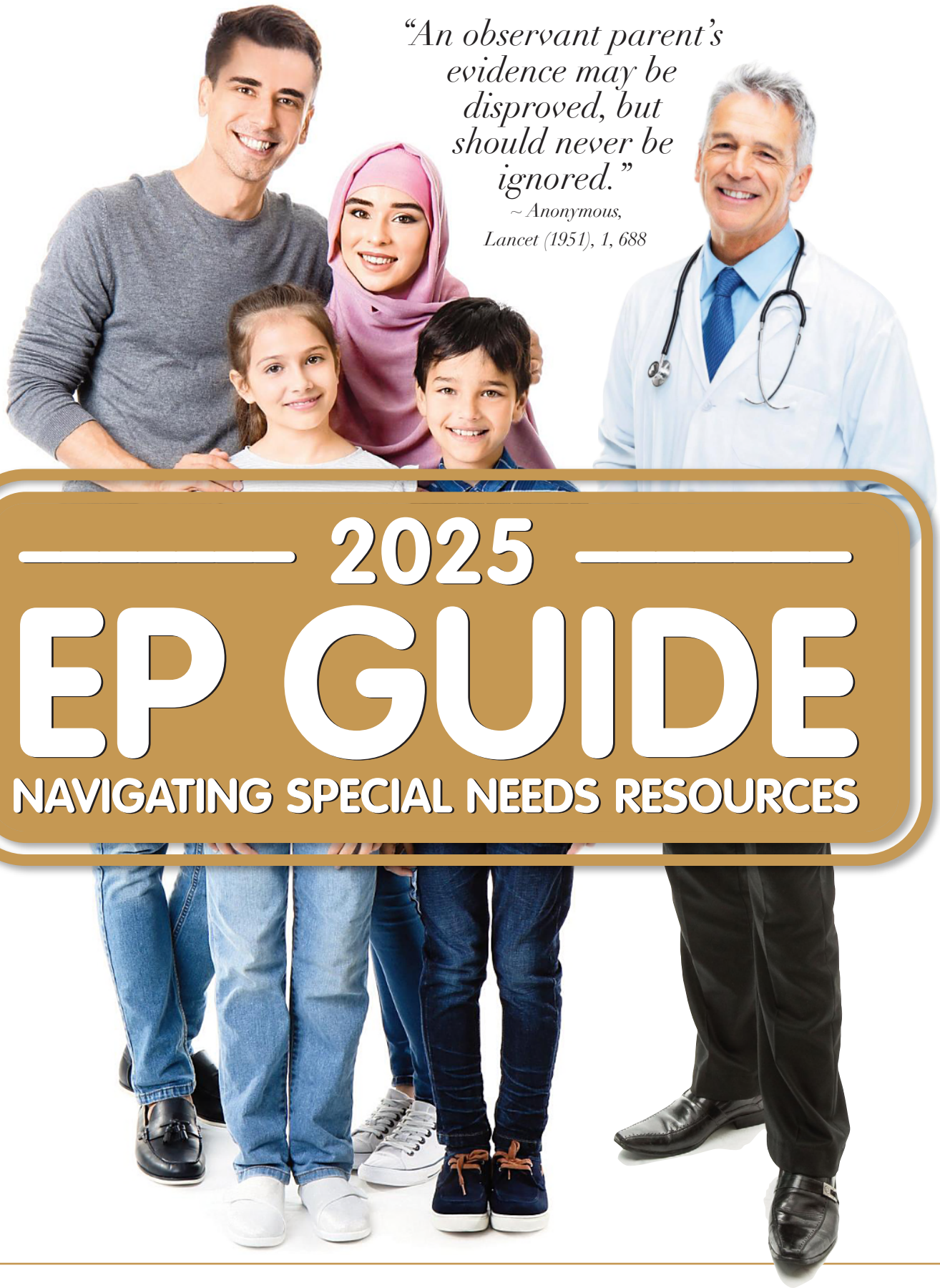
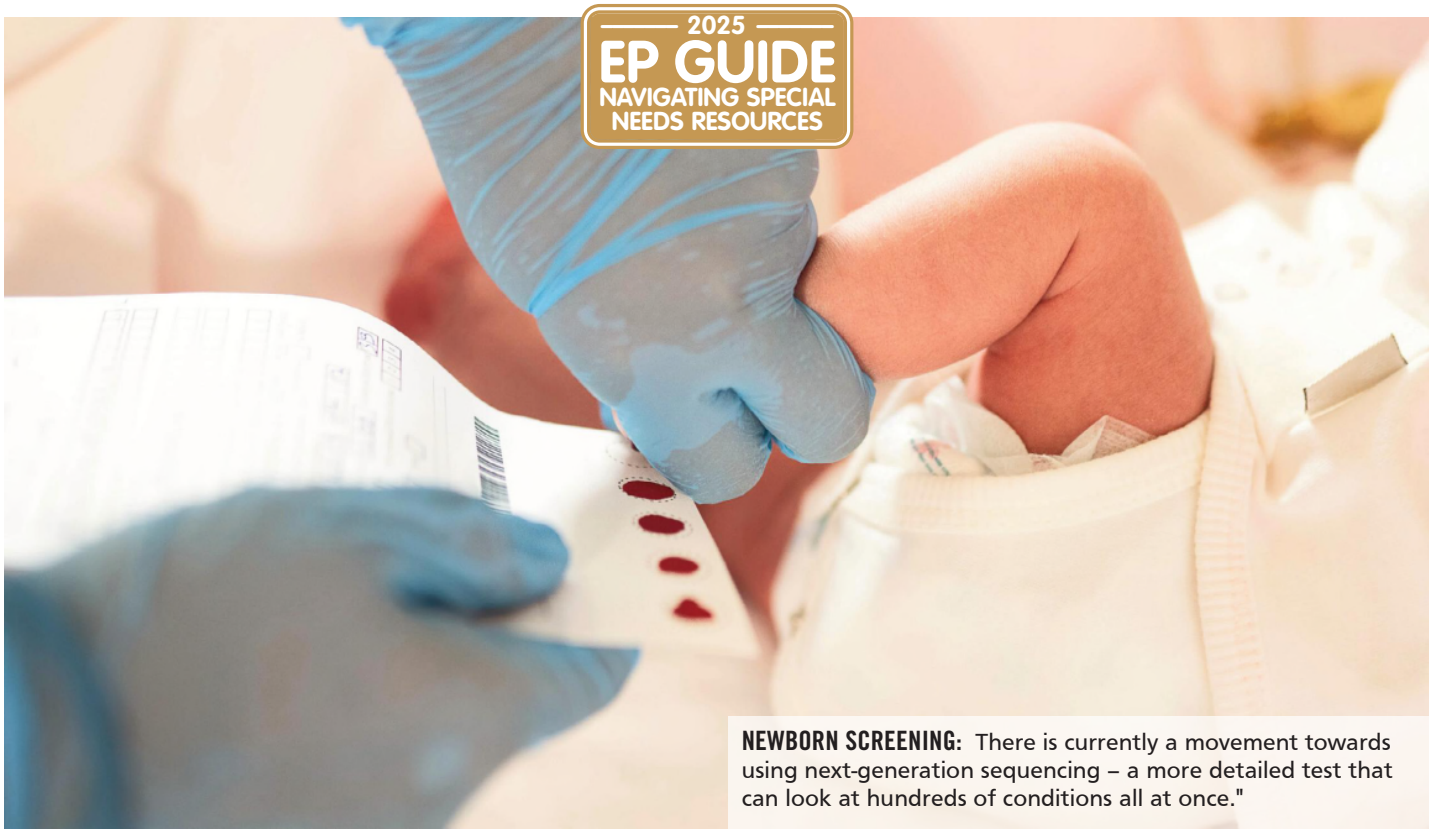


"An observant parent's evidence may be disproved, but should never be ignored."

~ Anonymous, Lancet (1951), 1, 688

2025 EP GUIDE

NAVIGATING SPECIAL NEEDS RESOURCES



NEWBORN SCREENING: There is currently a movement towards using next-generation sequencing – a more detailed test that can look at hundreds of conditions all at once."

SAMANTHA AND LOUIS'S JOURNEY: WHY EARLY DETECTION IS THE KEY TO A HEALTHIER LIFE

BY LARRY PRENSKY AND MIKE PATTRICK

Samantha was a couple of years old when her parents started to worry. A beautiful, happy child, Samantha started having trouble reaching her developmental milestones as quickly as her friends did.

She did not speak and only started walking at 18 months. Samantha didn't look any different from the other children she played with, but her parents could tell that she was slowly falling behind and that something was wrong. Her doctors felt that she may be autistic, but they couldn't explain her symptoms.

When Samantha turned five, she started having seizures. After seeing multiple specialists over those five years to try to figure out what was happening to their little girl, the Wallis family was fortunate enough to finally get a diagnosis. Samantha's testing results showed that she was born with a rare genetic condition called GAMT deficiency.[1]

GAMT stands for guanidinoacetate methyltransferase. This is a chemical that is made in our livers. GAMT partners with another chemical called AGAT to make creatine. This creatine is used throughout our entire bodies to make the energy our bodies need to work. People who can't make GAMT (like Samantha) have two problems going on in their bodies. First, they can't make creatine.

Without creatine, the body, and especially the brain, don't have the energy they need to work properly. Secondly, the AGAT chemical has nothing to partner with, so it just keeps building up in the body. Unfortunately, a buildup of AGAT damages organs, especially the brain. Together, these issues lead to developmental delays, intellectual disability, epilepsy, and sometimes movement disorders.

Luckily, if a diagnosis of GAMT deficiency is made early in life, it is likely these problems can be avoided. By providing the child with creatine and reducing the AGAT chemical in the body, the issues that Samantha has lived with could be prevented. The key issue though, is that you need to start treatment early, especially before the AGAT has damaged the brain.[2]

"Advances in newborn screening and the availability of government screening programs mean millions of babies can get a healthier start in life."

In Samantha's case, her diagnosis explained her symptoms and provided the Wallis family with an explanation and an avenue for improving her condition. Simply by changing her diet and adding a supplement, Samantha was able to stop the deterioration of her condition. Although much of the damage has already been done, Samantha is now able to speak a little and ride a bike with help. The fact that she said her first sentence at the age of nine was something her parents never thought they'd experience.

Since GAMT is a hereditary genetic disease, the Wallis family knew that there was a 25% chance of having another child with this condition. Fortunately, because of the known family history, they were able to have genetic testing performed on their babies at birth to look for this condition. One of their children, Louis, was tested and diagnosed with GAMT after his birth. Louis was lucky to get this early diagnosis because it meant that he could start treatment right away, before any of the problems associated with this disease started. Today, Louis is a healthy, happy, active boy who plays hockey, baseball, and video games. He does well in school and is expected to live a normal, healthy life.

The biggest worry about many of the hereditary disorders such as GAMT is that parents often do not know that their child has the condition until it is too late to prevent the long term damage. Fortunately, advances in newborn screening (NBS) and the availability of government screening programs mean millions of babies can get a healthier start in life.

In many countries around the world when a child is born, hospitals perform a routine prick on their heel and takes a few drops of blood. This blood will then be sent to a laboratory where they will perform a series of tests to look for a number of genetic diseases. In some regions this will include GAMT.

The goal behind this testing is to find babies who have one of the conditions they are looking for so that they can start managing it early. Early diagnoses of these conditions can lead to better outcomes for these children through medications, changes in diet and/or lifestyles, and/or early therapies. These early blood tests have been a part of the medical community's toolbox to save children since the 1960s.[3]

Samantha's brother Louis is a perfect example of why early detection, and therefore the benefit of NBS, is so important. Since Louis was diagnosed so early in life, he could start taking medication and make some simple changes to his diet, and thereby prevent any of the health concerns that his big sister Samantha struggled with.

Without NBS, children like Louis would have had to go on a diagnostic journey like Samantha, and might not have been diagnosed for many years, when the treatment would have been too late and their health would have suffered.

Over 13,000 newborns are diagnosed with medical disorders every year in the U.S. Luckily, NBS is able to help diagnose some of these conditions and prevent or lessen the irreversible damage they can cause.[4] Depending upon where you live, NBS looks for 2–75 different conditions, with more being added every year. There is currently a movement towards considering using more detailed tests that could look at hundreds of conditions all at once. Called next-generation sequencing, this test has the capability of being faster, more accurate, and more comprehensive than the current technologies. Although there may still be some hurdles before this technology is used as a first-line test in the screening of newborns, such as cost and complexity, it holds the promise of helping more babies like Louis live a longer and healthier life.

Unfortunately, of the 134 million babies born in the world each year, only about one third of them receive screening of any type, and many babies are only screened for one or two conditions.[3] As technologies get better, and politicians are convinced to devote more money and attention to the health of children, the hope is that more newborns like Louis will be saved, and more families like the Wallis' can be helped.

To learn what they screen for in your state go to: Newborn Screening in Your State at **newbornscreening.hrsa.gov** •

Revvity does not endorse or make recommendations with respect to research, medication, or treatments. All information presented is for informational purposes only and is not intended as medical advice. For country specific recommendations please consult your local health care professionals.

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ABOUT THE AUTHORS:

Larry Prensky is the Senior Medical Affairs and Medical Education Manager at Revvity. He is a licensed genetic counselor and is a diplomate of the American Board of Genetic Counseling and the Canadian Association of Genetic Counsellors. Prior to working with Revvity, Larry was a clinical prenatal genetic counselor for over 20 years.

Mike Pattrick is the Reproductive Health Marketing Leader at Revvity, focused on maternal, fetal, and newborn health. He has worked within the healthcare industry for over 20 years in various roles, including: administration, sales and marketing. His experience has been gained through a variety of companies, from small venture set ups to large global corporations.

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NAVIGATING SPECIAL NEEDS RESOURCES

GENETICS RESOURCES

BY CINDY WEBER AND TARA SZYMANEK

It is universally important for all patients and caregivers to understand their health and medical history. When we consider that statement with regard to a genetic-based diagnosis, it takes on additional significance. It is helpful for patients to understand their genetics in order to fully consider appropriate options for care.

ILLUSTRATION BY LUZ EUGENIA VELASQUEZ

It is the shared lived and professional experience of both authors that patients rarely leave a genetics appointment with a clear understanding of their diagnosis for treatment of their unique needs and effective planning for the future. Looking back, neither author felt as though they had enough information about their diagnosis to make informed choices about their care, let alone the care of their children or any potential future children. Knowing the information about your genetics diagnosis including treatment options, specialty care clinics, access to research, related disorders and future treatment or complications can have long-reaching and long-lasting effects on health, wellness, family relationships and overall family stability.

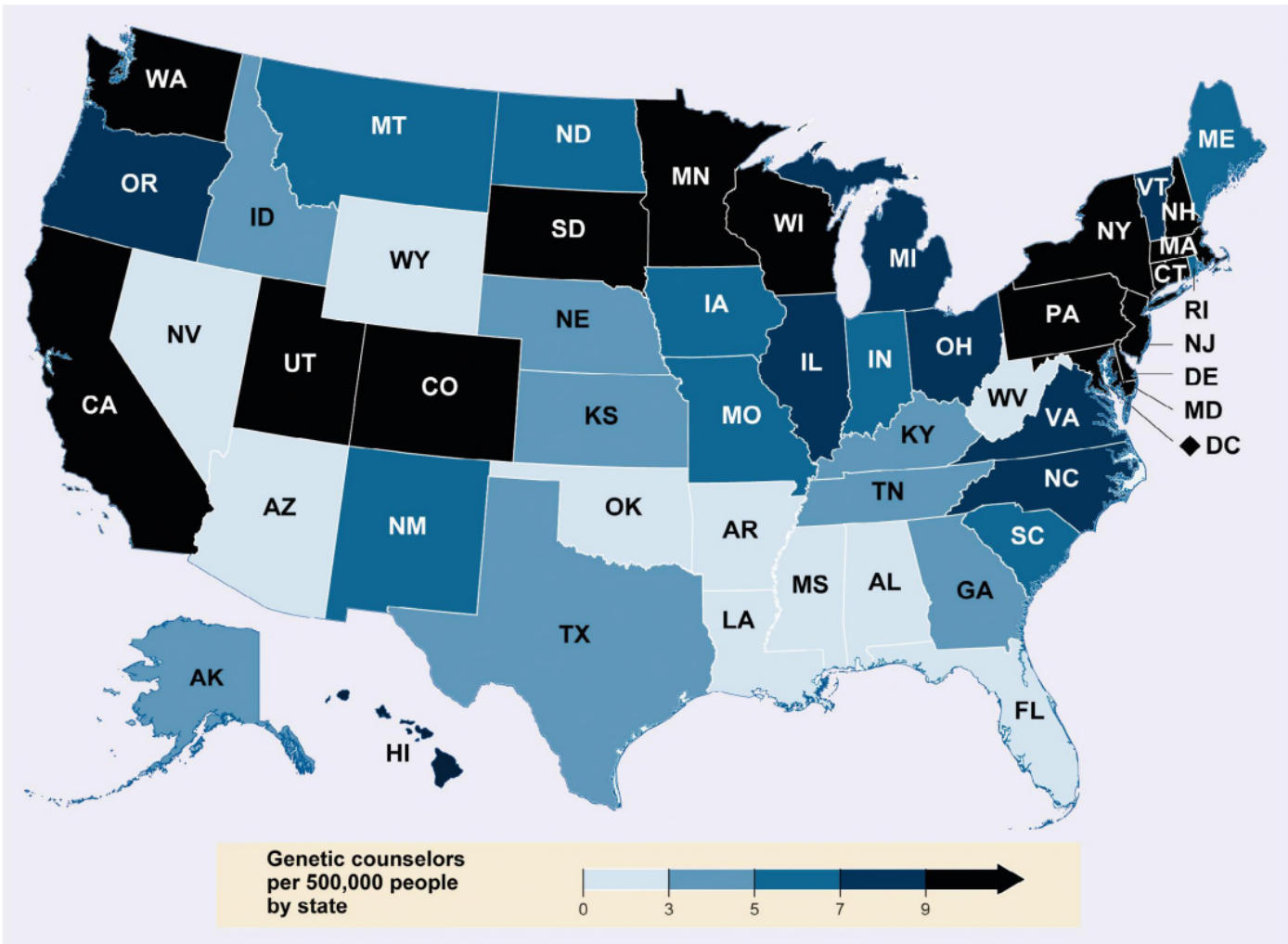
As most people who have completed genetics testing will tell you, genetics as a specialty doesn't have the same patient follow up that other medical specialties do. When you leave that office you may not see that provider ever again despite genetic breakthroughs happening on a continuous basis. Advances are made all the time, but no one is sharing that with patients already diagnosed. The diagnosis and follow up need to be digested over time with additional follow up and support. This can leave the patient and their families with crushing grief, frustration and a sense of being overwhelmed. Navigating the medical system as a professional can be quite challenging. It is even more challenging for the patient who has no medical training or experience and is now tasked with being their own best advocate, in addition to advocating for their child(ren). It is critical for therapy and support options to be utilized early and with a high degree of compliance, posing an additional problem for patients and caregivers who lack understanding or experience with genetic conditions.

It doesn't seem as though families are being set up for success.

The authors are aware of the very limited number of specialists in the field of genetics (*see GAO graphic below*) and so we understand why this happens. However, when we look to other complex care subspecialties, we see utilization of a larger team of staff functioning in a supportive role as care navigators.

A genetics navigator is a role that exists in some states. The genetics navigator is tasked with assisting patients and their families to bridge the knowledge gap and gain access to genetic services such as: complex genetic testing processes, diagnoses, and treatment pathways. Also included may be help with how to start the conversation with your provider, red flags that may help you see the value in testing, and resources that explain genetics and how they may impact your health.

GENETIC PROFESSIONALS SCARCITY : DISTRIBUTION OF GENETIC COUNSELORS PER 500,000 PEOPLE BY STATE, 2019



GRAPHIC SOURCE: GAO ANALYSIS OF DATA FROM THE AMERICAN BOARD OF GENETIC COUNSELING AND CENSUS BUREAU

Following a diagnosis, it can be common to enter a grieving process and feel unable to seek help. It is the shared experience of both authors that grief and guilt are common responses to genetic diagnosis.

"When we finally got a name for why my son was not walking or talking, I felt relieved. We had somewhere to start. When I later learned the cause came from me, I felt like someone kicked me in the gut. As a parent, you want to protect your child and help them learn and grow. The pain I felt learning that I passed on the gene that caused so much in him, while I was much better off, made me want to switch places. It was my fault. It was not until many years later when I would be able to better process the grief and guilt, that I would be able to truly understand that I had no control over any of this, any more than choosing his hair color, eye color or height," says Cindy Weber.

Reflecting on these experiences and a deep desire to help others not sit in grief for so long is what caused both authors to participate in a multi-year committee at New York Mid Atlantic Caribbean Regional Genetics Network (NYMAC). The committee was tasked with how to increase family participation in genetics. Having been through the genetics process ourselves, we agreed families needed meaningful access to genetics resources, not just a flyer with a contact number. Through vigorous group discussion, we decided the best way forward was to use the established community and parent leaders to empower and educate families new to genetics, by training community health workers (https://www.njchw.org/) on how to approach working with and supporting families that are navigating a genetic diagnosis.

We already know through countless families' testimony, including our own, what happens when there is a lack of access to resources digestible for an everyday family. The National Family Center compiled a video of Family Leaders and their experiences navigating the genetic system federally (https://youtu.be/bI0X09SGtIc?feature=shared).

"Sitting in the genetics counseling office with my twin 5 year olds and a 2-year-old, trying to pay attention to the conversation the genetics counselor was having with me regarding the results of the twins' genetic testing results and the new diagnosis, I was so shocked and overwhelmed and I honestly heard her words, but didn't have the capacity to take it all in. At home later that night, I was distressed because I felt like I left the appointment learning nothing and with more questions than when I started the genetics journey. I needed access to relevant genetics resources and I was not sure where to start. The genetics counselor had provided me with some trifolds and talked to me about local resources, but I needed tangible help," says Tara Syzmanek

PROMOTING AND STRENGTHENING FAMILY ENGAGEMENT : GENETIC RESOURCES AND INFORMATION

NEW YORK MID-ATLANTIC CARIBBEAN GENETICS NETWORK

Now closed, but their website remains a wealth of knowledge for families navigating genetics.

https://nymacgenetics.org/patients-and-families

https://nymacgenetics.org/wp-content/uploads/2023/02/Infographics-Genetic-Recipe.pdf

NATIONAL GENETICS EDUCATION AND FAMILY SUPPORT CENTER (NGEFSC)

Now closed, but their website remains a wealth of knowledge for families navigating genetics.

https://nationalfamilycenter.org

Family Leaders: Forging Pathways for Systems Change

https://youtu.be/bI0X09SGtIc?feature=shared

NATIONAL ORGANIZATION FOR RARE DISORDERS

A valuable resource for families who are looking for information on patient centered advocacy groups.

https://rarediseases.org

NATIONAL SOCIETY OF GENETICS COUNSELORS

A helpful resource for families to locate tangible support.

www.aboutgeneticcounselors.com/Resources-to-Help-You

NATIONAL HUMAN GENOME RESEARCH INSTITUTE

www.genome.gov

SPAN PARENT ADVOCACY NETWORK

https://spanadvocacy.org/programs/f2f/

HRSA MATERNAL AND CHILD HEALTH BLOCK GRANT APPLICATION - NATIONAL SCHS CMU

https://mchb.tvisdata.hrsa.gov/Narratives/Overview/793fcbd4-8ac8-4c50-9229-4ee30a519824

PARENT2PARENT USA

A peer to peer matching service where parents can be matched to those experiencing a similar journey.

www.p2pusa.org

PARENT TRAINING AND INFORMATION CENTER

A valuable place to start when you are looking for health advocacy information.

www.parentcenterhub.org/find-your-center/

The impact of a genetic diagnosis is not limited to those who test positive. We see increased anxiety, frustration, anger and often isolation throughout the family. An increase in anxiety may lead to a family"s internal struggles and difficulty accepting a diagnosis, or lead to family members experiencing helplessness. If providers do not address patient and family feelings following diagnosis, it may lead to misplaced blame or resentment towards the providers or frustration with the process and system. They may begin to feel unsupported by the healthcare system, causing potential trust issues, reluctance to seek further assistance, and as a result, worse health outcomes.

A lack of access to genetic resources could lead to missed opportunities or a lack of direction. Families might overlook or completely miss opportunities due to a lack of knowledge or understanding. Families could miss important networking opportunities, increasing feelings of isolation, helplessness, and as a result deepened depression.

Once there is a trust issue with the system, conflict is inevitable. Conflict between a provider and the patient/family as well as internally within the family, can put a lot of strain on relationships. This is especially true when we consider families with multiple children impacted by a genetic-based disability like ours.

When we created the collection of resources we are sharing today, we considered advocacy and patient empowerment to be of utmost importance. Families who lack information may miss chances to advocate for themselves or the patient they are supporting. This is why the resources are multilingual, utilize pictures over words, and are designed to remove blame and shame from the diagnosis. These tools were created to support parents in the understanding of their diagnosis, as well as the diagnosis of their children. They are also designed to support starting the conversation with extended families, as that can be quite challenging too.

If you are going on your first appointment to see a genetic counselor, or you have been recently diagnosed with a genetic disorder, below you will find resources and information to support you in the next part of your journey as a parent, regardless of the outcome. •

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ABOUT THE AUTHORS:

Cindy Weber is the Detection, Connection and Intervention Project Coordinator and an Early Childhood Training and TA Specialist for the New Jersey Inclusive Child Care Project, both of which are projects that are part of SPAN, New Jersey's Parent Training and Information Center (PTI). In addition, Cindy is the Board President of the Cumberland Gloucester and Salem Family Support Organization. Cindy and both of her children share a diagnosis of PTEN Hamartoma Tumor Syndrome. Through their diagnostic journey and beyond, Cindy learned to adapt to a parenting journey full of unexpected specialists and last minute changes. Cindy is a member of various committees serving New Jersey families as well as serving families of children with disabilities nationally through her volunteer work with the Rare Disease Legislative Advocates and (NYMAC) New York Mid-Atlantic Caribbean Regional Genetics Network before it sunset in May of 2024.

Tara Szymanek works as a Family Engagement Specialist for the New Jersey Family Engagement Hub which is a project of SPAN New Jersey's Parent Training and Information Center (PTI) Tara is a premutation carrier and her twin twelve-year-old children share a diagnosis of Fragile X Syndrome. Tara is a military family member with parenting experiences in military programs, special education, and health advocacy systems. Tara is a graduate of Partners in Policy Making through the Boggs Center of New Jersey and is a member of various committees serving New Jersey families as well as serving families of children with disabilities nationally through her volunteer work with the Rare Disease Legislative Advocates, (NYMAC) New York Mid-Atlantic Caribbean Regional Genetics Network before it sunset in May of 2024, and the National Fragile X Foundation.


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DIFFERENCE MAKER: An individual with CVI participates in a CVI Intensive Assessment; "It's what is done during early intervention in: the classroom, home therapies, medical exam rooms, the community, and during IEP meetings, when service time and critical goals are determined, that make the difference."

MAKING THE DIFFERENCE: CVI-SPECIFIC EARLY INTERVENTION

BY FRANCESCA CROZIER-FITZGERALD

"We all had the same problem; early intervention and private therapy providers who were not trained to work with our kids," says Kathyrne Hart, a dedicated parent advocate and policy reform pioneer. When she says "our kids" she is referring to the large community of children with cortical visual impairment (CVI), the leading cause of pediatric visual impairment in both developed and developing nations.

PHOTOS PROVIDED BY FRANCESCA CROZIER-FITZGERALD

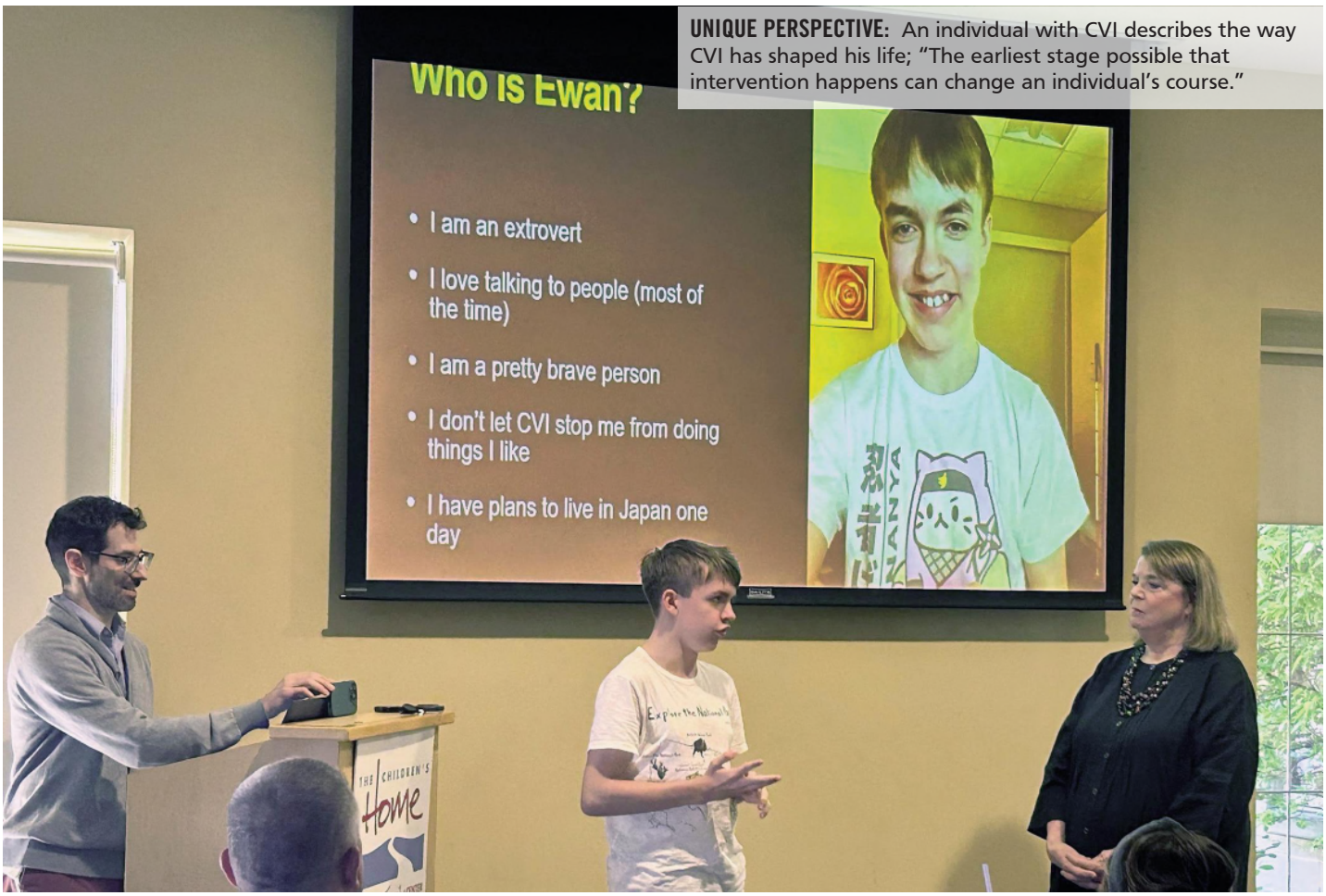
Despite its prevalence, CVI remains widely misdiagnosed and misunderstood worldwide. Often invisible or masked behind other co-existing conditions, this brain-based visual impairment does not affect the function of the eyes, but that of the brain. It causes damage to the brain's visual processing pathways, making it difficult for the individual to interpret what they see. For these reasons, CVI is considered a **disability of access,** in which children with CVI are often unable to make sense of the visual world around them.

The working definition of CVI from the National Eye Institute (NEI) and National Institutes of Health (NIH)[1] refers to five key elements of CVI, including the presence of an underlying neurologic insult or injury affecting the visual processing pathways in the brain, functional vision that cannot be explained by co-existing ocular conditions (the individual's eyes are often healthy), and the presence of characteristic visual behaviors (*such as those in Table 1*). The definition also recognizes common comorbidities such as cerebral palsy (CP), as up to 83% of individuals with CP also have CVI, and other neurodevelopmental disorders, such as autism and dyslexia. Critical next steps in the NEI's strategic plan is to determine the reliability and validity of **functional vision assessments.**[2]

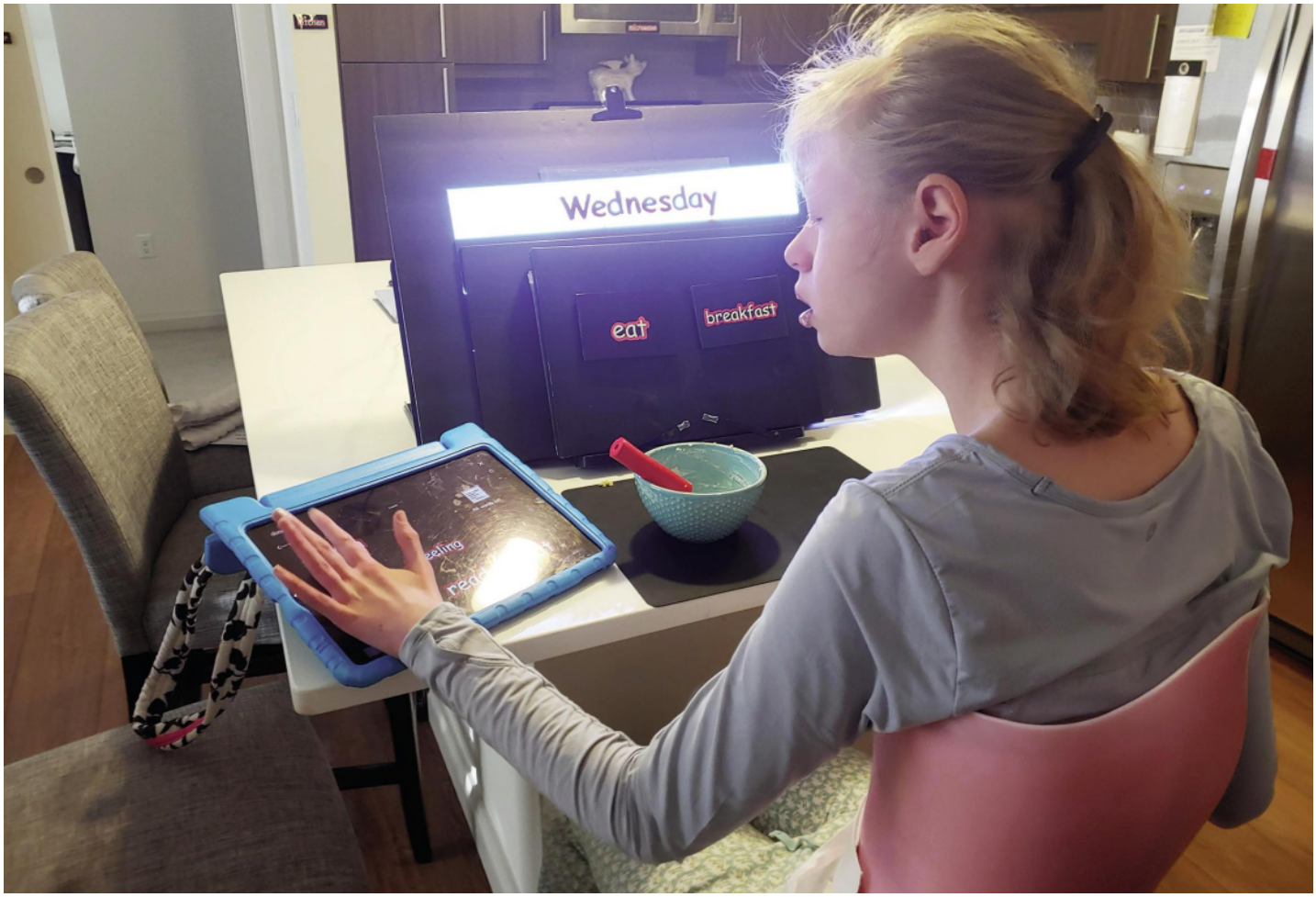
Pediatric VIEW, founded in 1999 and now housed by The Children's Home of Pittsburgh and Lemieux Family Center, was developed in response to an overwhelming request from families searching for CVI-specific assessment and direction for intervention. The practice, serving individuals birth to 23, their families, and teams, has continued to grow beyond Pittsburgh, PA. The primary mission is that the needs of individuals with CVI and the priorities of their families come first. Families and children are met every day at different stages of their educational journey. Parents and caregivers witness, firsthand, how their child's vision can be unreliable – a mesh of ambiguous form and color – especially when environments and materials are visually complex. Families report the ways that their child struggles to access learning inside and outside of the classroom or therapy center. The struggles can include recognizing classmates, engaging in opportunities for interactive play and social development, feeling safe and secure in their environment, recognizing objects and activities around them, interpreting materials in their curricula, and building independence in daily routines. Families are searching for specific, effective intervention and sup-

TABLE 1 : THE 10 CHARACTERISTICS OF CVI[4]

- *Need for or attention to light*
- *Need for or attention to color*
- *Need for or attention to movement or objects with reflective properties*
- *Difficulty with visual complexity (objects, array, sensory environment, faces)*
- *Difficulty visually interpreting novelty (people, environments, objects)*
- *Visual latency*
- *Visual field preferences*
- *Difficulty with distance viewing*
- *Difficulty with visually guided reach (visual-motor)*
- *Abnormal responses to visual threat and touch*



UNIQUE PERSPECTIVE: An individual with CVI describes the way CVI has shaped his life; "The earliest stage possible that intervention happens can change an individual's course."



LESSONS LEARNED: An individual with CVI uses her CVI-adapted AAC System in an adapted learning space; "For functional vision to improve in individuals with CVI, the primary responsibility rests on timely and appropriate early intervention."

port from educators, early interventionists, therapists, and advocates. It's important to bring sense to this otherwise senseless visual world.

With research breakthroughs in visual neuroplasticity and the expectation for functional vision to improve in individuals with CVI, the primary responsibility rests on **timely and appropriate early intervention (EI).** Dealing with age-dependent neuroplasticity, "the assessment and management of children with CVI require a multidisciplinary approach to facilitate access to appropriate services and accommodations throughout childhood and beyond."[3] It is inherently challenging to provide appropriate EI services for a condition that is often missed or misdiagnosed. EI service provision will vary from state to state. Children with CVI and their families often find themselves on a long and difficult search for adequate and appropriate services that can address their unique visual needs. Some may never find it.

"In my family's experience," shares Mara LaViola, an advocate and CVI parent, "the greatest hurdles include lack of awareness, dismissal from medical professionals, systemic neglect and misdiagnosis (often related to autism), a lack of appropriately trained professionals, and a failure to act proactively." To further complicate matters, even when families are promptly aligned with services, "many children are met with professionals who lack the training necessary to recognize and address brain-based visual impairments. This gap leads to missed opportunities for timely intervention and hinders the child's overall progress."

As Mara describes, without CVI-specific EI, children with CVI fall behind on critical opportunities for functional vision development. EI team members may not have received CVI-specific training, or the team does not include a vision professional to lead CVI-specific intervention. Whatever the reason, by age 3, when many states transition children out of EI services and into school-aged services, children with CVI are already playing catch-up. Instead of interven-

TABLE 2 : COMMON CAUSES OF CVI[2]

If your child has experienced any of the below, they should be screened for CVI.

- *hydrocephalus*
- *intraventricular hemorrhage (IVH)*
- *periventricular leukomalacia (white matter damage) in prematurity*
- *hypoxic-ischemic encephalopathy*
- *metabolic and genetic disorders*
- *infections such as meningoencephalitis*
- *seizures and infantile spasms*
- *drug exposure*
- *non-accidental head trauma, near-drowning incidents*
- *rare genetic conditions*
- *central nervous system malformations*

SPECIALIZED SPACE: Carter, a student with CVI, uses adapted materials that incorporate his need for light, color, reduced visual complexity, movement, visual field preferences, and reduced distance to learning surfaces, among others.

ing in a way that sets these individuals up for success – the core purpose of this federally mandated program – the very opposite may be done unintentionally.

In 2017, before her son was 9 months old, Kathryne Hart discovered Dr. Roman-Lantzy's research, identifying the 10 Characteristics of CVI. When she discussed her observations and concerns with her son's ophthalmologist, he was diagnosed with CVI, and immediately scheduled to receive a functional vision assessment for CVI, the CVI Range Assessment©. With clear assessment results describing her son's functional vision, Kathryne had a plan she could bring to his team. "I ended up having to train our early interventionists myself, and yet, I'd still consider myself one of the lucky ones. I had the education and resources to not settle for what I was given." EI, when driven by an individual who considers the unique manifestations of CVI, can change an individual's course to access for the rest of their educational career.

"We need a systemic shift in how CVI is identified and addressed, starting with better education for professionals and parents. Increased training for personnel across all disciplines, and a commitment to early and proactive intervention is needed," notes Mara. "Collaboration and specialization should become the standard to ensure children like my son receive the care and support they deserve."

STRUCTURED COLLABORATION AND BEST PRACTICES

Certainly, no one team member can tackle this multi-pronged condition alone. Teams will look different, depending on the needs of the individual. A team may require specialists in AAC (Augmentative and Alternative Communication), orientation and mobility (COMS), or assistive technology (CATIS), while others may have different priorities.

Early identification through infant/NICU screening: The earlier individuals at-risk for CVI can be identified, the sooner they can be referred for further examination by neurology, ophthalmology, optometry and ultimately, initiate EI services in their state.

CVI-specific functional vision assessment: The CVI Range is an activities-based behavioral assessment of functional vision administered by certified examiners, typically teachers for the visually impaired. Through parent interview, observation, and direct assessment, the examiner scores the child's performance regarding the 10 characteristics of CVI (*Table 1*), determining if a child is in Phase I, II, or III.2 While there are a variety of CVI inventories and questionnaires available to clinical and educational teams, the CVI Range Assessment provides a critical element, a quantitative measure of the impact of CVI on a child's functional vision. The score, when determined by a skilled assessor, offers families and teams a baseline from which to measure the progress and effectiveness of interventions, over time. It is used to guide accommodations and CVI-specific instructional methods, and directly inform the development of an Individualized Family Service Plan (IFSP) and Individualized Educational Plan (IEP) goals, supporting the team through strategic and data-based early intervention, and beyond.[4]

Collaboration in CVI-specific EI services: Once an individual has been identified as having CVI, they should receive a referral to the state department, providing EI services and a functional vision assessment that can determine the degree of impact on their functional vision. Services beyond that point should include a plan, routed in CVI principles, that address the individual's visual needs. It can be used to initiate an ongoing and collaborative partnership between the EI team and individuals who specialize in CVI services.

Strategic educational planning for individuals with CVI, beyond EI: Once a child turns 3 or 5 years old (depending on the state) and transitions out of EI services, that intervention should not end. On the contrary, as an individual continues to build functional vision and utilize vision as a reliable learning channel, IFSP and IEP-mandated services may need to increase to meet the growing demands of curricula and daily routines. "Children with CVI have a range of challenges that require long-term intervention and monitoring. Improved public health policies and education are important to optimally support children with CVI, their families, and those who provide care for them."[3]

Routine evaluation of progress to inform ongoing team collaboration: As functional vision is expected to improve with strategic and thoughtful approaches to intervention, it's critical to conduct annual assessment and progress monitoring. IFSP and IEP teams often meet once a year. Consistent, routine collaboration amongst team members can directly impact the effectiveness of service time.

Ongoing professional development for those working with individuals with CVI: Professionals can be better prepared across all disciplines if robust coursework on CVI is integrated into graduate level and medical school curricula. Before they enter their respective fields, and meet children with CVI in the exam room, classroom, or therapy center, professionals should be familiar with the heterogeneity of the condition, recognize red flags for diagnosis, and understand their state's policies on next steps for referral and intervention. This can create more supportive networks and direct, hassle-free paths toward appropriate services.

Continually evolving to meet the unique needs of children with CVI: Currently, CVI-specific programs with skilled professionals can be found across the US, but the number of service providers remains gravely disproportionate to the number of children requiring services. To meet this overwhelming demand, new and existing programs must be willing to dig in and do the hard work. In return, they will see immeasurable rewards in their student or client's progress.

It's what is done during early intervention in the classroom, home therapies, medical exam rooms, the community, at times of transition, in professional development coursework, during IEP meetings, when service time and critical goals are determined, that make the difference. The earliest stage possible that intervention happens can change an individual's course. •

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Francesca Crozier-Fitzgerald, MS, MEd, is a Certified Teacher of Students with Visual Impairment and a Practitioner at Pediatric VIEW of The Children's Home of Pittsburgh and Lemieux Family Center. She has devoted her career to providing assessment, instruction and support to individuals with CVI, their families and their teams. Francesca is a Co-President of the Board of Pediatric Cortical Visual Impairment Society.

A WIDER VIEW : CVI RESOURCES

Resources serving individuals with CVI, their families, and teams around the US include:

PEDIATRIC VIEW PROGRAM
CHILDREN'S HOME OF PITTSBURGH
www.childrenshomepgh.org/our-services/pediatric-view-program

PEDIATRIC CORTICAL VISUAL IMPAIRMENT SOCIETY
https://pcvis.vision

THE BRIDGE SCHOOL
https://cvi.bridgeschool.org

CONNECTIONS BEYOND SIGHT AND SOUND
https://marylanddb.org

PATHS TO LITERACY
www.pathstoliteracy.org/learning-center/cvi

PERKINS SCHOOL FOR THE BLIND
www.perkins.org/our-work/cvi

TEXAS SCHOOL FOR THE BLIND AND VISUALLY IMPAIRED
www.tsbvi.edu

WEST VIRGINIA DEPARTMENT OF EDUCATION
wvde.us/special-education/resources-sp-page/low-incidence-disabilities/cvi-special-topics

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DYSLEXIA INTERVENTION FOR TEENAGERS AND ADULTS: EMPOWERING LIFELONG LEARNERS

BY JESS CORINNE

For many, dyslexia is often seen as a challenge that primarily affects young children learning to read. However, the reality is that reading difficulties can impact individuals throughout their lives, from high school students struggling with coursework to adults facing professional demands.

This article explores practical and effective strategies tailored for teenagers and adults, focusing on how to use a strengths-based, interest-driven, and age-appropriate approach to help individuals thrive in their learning journeys.

CHALLENGES FACED BY TEENAGERS AND ADULTS WITH READING DIFFICULTIES

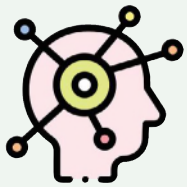
For many teenagers and adults, challenges with reading may go undiagnosed or misunderstood as laziness, leading to frustration and low self-esteem. Those who have never received a formal diagnosis such as dyslexia often feel isolated and misunderstood in school or work settings.

Without early help, these individuals may develop coping mechanisms that hide their struggles, but do not fix the underlying issues. As a result, tasks like reading school assignments, job-related documents, or even everyday activities like reading menus or filling out forms can become major obstacles.

It's never too late to get help. With the right support, individuals can build skills, gain confidence, and turn reading from a source of stress into something more manageable.

A SENSE OF OWNERSHIP : EFFECTIVE INTERVENTIONS AND STRATEGIES FOR READING DIFFICULTIES

While reading difficulties may look different at various stages of life, effective interventions should be rooted in the principles of personalized, engaging, and multisensory instruction. For teenagers and adults with reading challenges, the key is not just remediation, but fostering a sense of ownership over their learning journey. Incorporating interests, using strength-based approaches, and offering instruction in a way that is respectful and age-appropriate can lead to long-term success.



1. MULTISENSORY APPROACHES

These approaches tap into multiple senses: sight, sound, touch, and movement to reinforce learning and ensure information sticks. For older learners, adapting these strategies to match their current level and learning style can enhance effectiveness.

2. TECHNOLOGY TOOLS

In today's digital age, technology offers a wealth of resources. Audiobooks, text-to-speech software, and apps that highlight text while it's read aloud can provide crucial support, allowing individuals to access material at their own pace and with greater ease. Tools like speech-to-text programs also help with writing, reducing the stress often felt when asked to produce written content.

3. EXECUTIVE FUNCTIONING SUPPORT

Many individuals with reading difficulties also experience challenges with organization, time management, and focus, which are key elements of executive functioning. Introducing strategies such as using visual schedules, breaking tasks into manageable chunks, and using tools like planners or digital reminders can help learners stay on track and feel more in control of their work.

4. STRENGTH-BASED, INTEREST-DRIVEN LEARNING

Focusing on strengths and interests is important for motivating learners. Instead of solely focusing on reading deficits, educators and therapists can incorporate reading materials that align with the learner's hobbies, career aspirations, or personal passions. Whether it's science fiction for an aspiring scientist, or business articles for an entrepreneur, these materials can make reading feel more relevant and exciting.

5. RESPECTFUL, AGE-APPROPRIATE INSTRUCTION

Treating teenagers and adults with dignity and respect is paramount. Learning is a personal process, and individuals should feel empowered, not belittled. Instruction should reflect the learner's age. Interventions designed for younger students might need to be adapted to feel less juvenile. Incorporating real-world contexts, like workplace or college assignments ensures the material remains applicable to their current stage of life.

By implementing these strategies, learners can build not only reading proficiency but also confidence in their ability to succeed academically and professionally.

SUCCESS STORIES OR EXAMPLES

Real-life success stories can be incredibly motivating for teenagers and adults struggling with reading difficulties. These examples serve as reminders that progress is possible, no matter the age.

1. **Case Study: Sarah, a College Student with Late Diagnosis:** Sarah, a 20-year-old college student, had always struggled with reading, but it wasn't until her sophomore year that she received a formal dyslexia diagnosis. Throughout high school, Sarah's reading challenges were misunderstood, and she was often labeled as "lazy" or "unmotivated." With her diagnosis, Sarah worked with a tutor who used a multisensory, strength-based approach tailored to her interests. By reading articles and books about marine biology, a subject she was passionate about, Sarah became more engaged in her studies. With consistent support, her reading skills improved, and she graduated with honors!
2. **Case Study: John, an Adult Professional:** John,a man in his mid-thirties, had always struggled with reading, but had never sought help due to fear of stigma in the workplace. His challenges became more apparent when he began pursuing a managerial position. After a thorough assessment, John was diagnosed with dyslexia. He began using text-to-speech software at work to help with emails and reports. He started receiving coaching to strengthen his executive functioning skills. Today, John excels in his role and feels empowered to ask for accommodations when needed, helping him overcome barriers that once felt insurmountable.

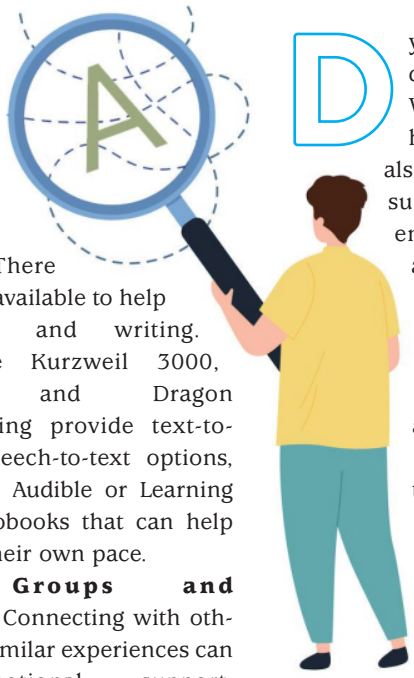
These stories illustrate the power of intervention at any stage of life. With the right support, teenagers and adults with reading challenges can transform their experiences and achieve their goals.

RESOURCES FOR SUPPORT

For people with reading challenges, finding the right resources can make all the difference. Whether you're a teenager facing schoolwork or an adult managing a career, these tools and organizations can help you succeed.

- **Educational Therapy Services:** Working with a trained educational therapist can offer personalized strategies to meet each learner's unique needs. Therapists trained in programs like Orton-Gillingham and the Wilson Reading System can create customized plans that address reading difficulties and support long-term success.
- **Assistive Technology:** There are many tools available to help with reading and writing. Programs like Kurzweil 3000, Read&Write, and Dragon NaturallySpeaking provide text-to-speech and speech-to-text options, while apps like Audible or Learning Ally offer audiobooks that can help learners go at their own pace.
- **Support Groups and Communities:** Connecting with others who share similar experiences can provide emotional support. Organizations like the International Dyslexia Association (IDA) and Learning Disabilities Association of America (LDA) offer resources and connect individuals with support groups. These communities help learners feel less alone, and provide guidance as they work through challenges.
- **Local and Online Tutoring Services:** Many tutoring services focus on helping individuals with reading difficulties. Online platforms can help learners find tutors who specialize in dyslexia and other learning challenges. These tutors offer one-on-one support tailored to the learner's needs, making reading instruction more personalized.
- **Self-Help Books and Online Resources:** Books like *Overcoming Dyslexia* by Sally Shaywitz and The *Dyslexic Advantage* by Brock and Fernette Eide provide helpful insights into dyslexia, and practical strategies for improvement. Websites like Understood.org offer free articles, videos, and tools that are accessible to families and learners looking for support.

These resources offer a wealth of support, from technological tools to personal guidance, helping teenagers and adults build skills, improve confidence, and succeed in their academic and professional pursuits.



Dyslexia and reading challenges do not have an expiration date. Whether diagnosed in childhood or later in life, individuals can benefit from continued support and intervention. By embracing strength-based approaches, incorporating personal interests, and using age-appropriate methods, we can help teenagers and adults overcome barriers to reading and learning.

It's important to remember that with the right tools, strategies, and mindset, reading difficulties are not a life sentence. They are challenges that can be addressed, allowing learners to reach their full potential. Don't hesitate to seek help, no matter your age. The journey to better reading, greater confidence, and lifelong learning is always worth it. •

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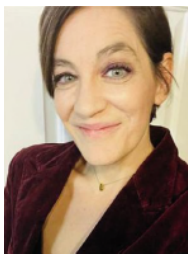


Jess Corinne is a structured literacy specialist and executive functioning coach for children, teenagers, and adults. With over 20 years of experience in multisensory, evidence-based instruction, she has a deep understanding of neurodiversity and a passion for helping individuals overcome learning challenges. Her practice integrates evidence-based approaches like Orton-Gillingham, Lindamood-Bell™, Social Thinking and ADHD/executive function coaching to support lifelong learning. From California and based in Georgia with four children of her own, she is dedicated to empowering clients to build confidence and achieve their full potential at any age. For more information, visit **www.corinnelearningsolutions.com**

A FAMILY PERSPECTIVE

HONEST CONVERSATIONS ABOUT A DIAGNOSIS

BY PAMELA AASEN, CARLITO MORROBEL, ETHAN MORROBEL AND GAVIN MORROBEL

As the parents of two young adult sons with Usher syndrome, my husband and I have embarked on a unique journey filled with both challenges and triumphs. One of the most significant decisions we faced was when and how to tell our sons they had Usher syndrome after they were diagnosed in 2009, at seven and five years old.

TIES THAT BIND: "As a family, we will overcome these obstacles and help Ethan and Gavin live fulfilling lives."

PHOTOS PROVIDED BY PAMELA AASEN

*In this article, each of us will share our perspective on how we have navigated discussions about Usher syndrome over the past 15 years. We hope to offer insights into our decision-making process and illustrate the importance of open family conversations, about a lifelong condition that impacts three major senses in the body: vision, hearing, and balance (**www.usher-syndrome.org/resources**).*

Talking to our children about their diagnosis and having a disability was a process that required candid and straightforward communication. We needed to be direct and honest, while at the same time considering their age and level of understanding. We approached the topic using simple and clear language. It was our hope that by fostering a supportive and accepting environment, we could help them develop a positive self-image, embrace their unique abilities, and feel comfortable sharing their struggles and concerns.

PAM'S PERSPECTIVE

In "Advocating as a Family in the Community," my first article for *EP Magazine* in December 2019 (**https://reader.mediawiremobile.com/epmagazine/issues/206890/viewer?page=26**), I emphasized the importance of open communication, early intervention, and a positive mindset. By empowering our children to advocate for themselves and providing them with the appropriate information and necessary support, my husband and I aspired to help them reach their full potential. Now that they are in university and I reflect on the journey, I believe we have laid a strong foundation. However, there were a lot of difficult conversations along the way.

Ethan and Gavin were born deaf and received their first cochlear implants at 13 months and 8 months respectively, They have been speaking openly about their hearing loss from a very young age, making it a natural part of their identity. However, the diagnosis of Usher syndrome introduced a new layer of complexity to their understanding. They now faced additional challenges related to vision loss and balance problems. As difficult as the diagnosis was, we also had a clearer explanation for the challenges they had been facing, such as clumsiness, difficulty riding a bike, and seeing at night.

PEAK PERFORMANCE: The family on their first ski trip; "We encouraged them to take risks and challenge themselves."

Of course, my husband and I needed time to digest the news and process our grief, but we knew that we needed to address it directly and soon. We also knew we wanted them to be a part of meetings at school to discuss their added services. When we were ready, we explained that just as their ears were different, their eyes were too, and that Usher syndrome was the name for this combination of challenges, including their poor balance. They were so young at this point, and since it did not particularly change anything significantly at that moment, they accepted it rather matter-of-factly, and asked if they could go play. The hardest part was not breaking the news about Usher Syndrome, but rather anticipating future conversations about its implications on their lives, such as sports, driving, and career choices.

Beginning these conversations early, and maintaining an open dialogue throughout their lives made these discussions less daunting. By actively engaging them in opportunities like speech contests and school presentations, we not only helped them learn more about their condition, but also fostered a sense of comfort and confidence in discussing Usher syndrome openly. Our family's involvement in advocacy and awareness efforts, first in Fighting Blindness Canada, and later with Ava's Voice in New Jersey, has fostered a sense of purpose and resilience in them. In addition, with sharing their story with the Usher Syndrome Society and the SPAN Parent Advocacy Network, our sons have learned to embrace their challenges and turn them into opportunities for growth.

CARLITO'S PERSPECTIVE

Growing up in the Dominican Republic, I was exposed to a culture that often marginalized individuals with disabilities. People with disabilities were frequently hidden from society, seen as a source of shame or a burden. When my son Ethan was born in the Dominican Republic and first diagnosed as deaf, it ignited a desire in me to challenge these dated notions that still prevailed in the 2000s. After moving to Canada, where Gavin was born and diagnosed as deaf, I was determined to break the cycle of stigma. I used our annual trips back to the Dominican Republic as an opportunity to challenge these outdated norms. I wanted to show my pride in my sons, and prove that there was nothing to be ashamed of. I would organize a big party for my friends and family, showcasing their abilities and potential. Through these gatherings, I hoped to shift perceptions and demonstrate that individuals with disabilities could lead fulfilling lives.

These parties were more than just celebrations. They were opportunities for my sons to share their experiences with having a disability, and to inspire others. They spoke openly about their challenges and successes, demonstrating that they were not ashamed of who they were. Additionally, these visits challenged the assumptions I had made about their limitations. Despite their balance issues, they were determined to try new activities, including surfing and horseback riding. By witnessing their courage and perseverance, I realized that the only true limitations were the ones we impose on ourselves.

CATCH A WAVE: Ethan and Gavin surfing with their dad; "Despite the boys' balance issues, they were determined to try new activities, including surfing and horseback riding."

As their father, I felt a deep responsibility to protect my sons from a cruel world. However, I realized that I could not shield them from the realities of their disability. The monthly calls with the Usher Syndrome Coalition were instrumental in helping me understand Usher Syndrome, and connect with other families who were navigating similar challenges. This empowered me to reevaluate my own dreams and expectations for them, and to face the future with optimism. While some of my original aspirations had to be adjusted, new, more inclusive dreams emerged. We were always open with our sons about their limitations, but we also encouraged them to take risks and challenge themselves. Above all, I wanted to provide them with as many visual experiences as possible, and give them opportunities to explore the world and live life to the fullest.

ETHAN'S PERSPECTIVE

Being deaf has always been a part of my life. It is not something I have ever struggled with, because it is all I have ever known. I have also always been a bit clumsy, and have been going to physical therapy since I was a baby. Obviously, there was a reason for it. When I was diagnosed with Usher syndrome, it finally put a name to the extra challenges in vision and balance that required extra effort on my part. Despite this, I was determined to lead an active life and I participated in various sports, eventually transitioning to adaptive sports and Paralympic events.

Learning about my diagnosis at an early age, was not necessarily a difficult conversation. My parents fostered an open and honest environment where I could ask questions and learn about my condition. In fact, this openness became the cornerstone of my approach to life.

One of the most impactful experiences during my childhood was the opportunity to give speeches about Usher syndrome to my classmates and teachers. This lead to speaking and presenting about Usher syndrome at workshops, schools/universities, teacher trainings, parent to parent meetings, fundraisers, retreats, and Deafblind family activities.

I am incredibly grateful to my parents for encouraging me to share my story. These presentations not only helped to educate others, but also boosted my confidence and public speaking skills. In fact, I even entered a speech contest with a speech about Usher syndrome. While I did not win that year, I was determined to improve. The following year, I delivered a speech about my experiences with public speaking, and took home the first-place prize. These experiences, combined with my role as an Advocacy Ambassador for Ava's Voice, and my involvement in the creation of the first USHthis camp, has further solidified my commitment to advocating for individuals with Usher Syndrome. As an USH Mentor (pronounced *"ush"*) at camps in the US and the UK, I have had the opportunity to share my experiences and provide support to younger individuals with Usher Syndrome, making a positive impact on the lives of others.

All of these experiences led to the publication of my own story, An Uncomfortable Life: Getting Comfortable with Being Uncomfortable," in the April 2024 issue of *EP Magazine* (**https://reader.mediawiremobile.com/epmagazine/issues/208904/viewer?page=39**). This article allowed me to share my

SOUND EFFECTS: Gavin *(left)* and Ethan show their cochlear implants; "Usher syndrome is a lifelong condition that impacts three major senses in the body: vision, hearing, and balance."

personal journey with Usher syndrome with a wider audience, and inspire others to embrace their own challenges. As I now navigate university and future career aspirations, the conversations surrounding my disability are becoming more serious. While I am still comfortable talking about it, the practical implications are becoming more real.

With my upcoming co-op in aerospace engineering, I have to balance my professional goals with the realities of my disability. Despite these challenges, I am confident that my family's support and positive attitude has prepared me to handle whatever comes my way.

GAVIN'S PERSPECTIVE

Much of my perspective is like Ethan's, although I do not really remember being told about my diagnosis. It has always been part of who I am. I just remember always being included in conversations about the different therapies and accommodations that I needed. I know that this helped me develop advocacy skills and the confidence to speak up for myself. Public speaking about these experiences gave me even more confidence, and eventually became a way to raise awareness about Usher syndrome. Not to be outdone by my brother, his article inspired me to write about my experiences advocating for myself. My article, "Speaking Up" was published in the July 2024 issue of *EP Magazine* (https://reader.mediawiremobile.com/epmagazine/issues/209001/viewer?page=34).

Growing up with an older brother who also had Usher syndrome provided invaluable insights and support. We share a unique bond, understanding each other's challenges and triumphs in a way few others could. His experiences helped me anticipate and adapt to the challenges I would face. He offered practical advice and emotional support. Together, we learned to navigate the world, advocate for our needs, and embrace the opportunities that came our way. This bond further inspired us when we met Ava, and joined forces with Ava's Voice. We wanted to empower others by fostering connections and creating opportunities for support and shared experiences, like at the USHthis camp and at the USH Connections Conference hosted by the Usher Syndrome Coalition.

Our openness about our challenges encouraged our parents to find innovative solutions. When we moved to a new country, they recognized the added stress, and we got a service dog to provide companionship and support. Our parents' supportive approach empowered us to redefine what a full-time class schedule meant for deafblind individuals. They made sure we had a level playing field, ensuring we had the resources to succeed without compromising our well-being. Additionally, they have employed a bit of humor, using bribery to make appointments an adventure when we were young, or to encourage us to use our white canes as we got older. Their unwavering support and creative problem-solving have equipped us with the confidence to navigate challenges and advocate for ourselves in any setting.

THE FUTURE

As brothers, Ethan and Gavin have always been there for each other, offering support and encouragement. They have learned to rely on each other's strengths and weaknesses and have grown

LEAN ON ME: Ethan *(left)* and Gavin in a recent photo; "As brothers, Ethan and Gavin have always been there for each other, offering support and encouragement."

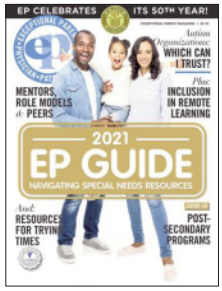
together through shared experiences. As they embark on their adult lives, we are confident that their bond will continue to be a source of strength. We hope that they will have open and honest discussions about their diagnosis, struggles, and hopes for the future. While the future may still hold uncertainties, we know that their resilience, determination, and unwavering support for one another will help guide them towards a bright future.

As a family, we have always been open about our sons' diagnosis of Usher Syndrome and the challenges they may face. We have had countless conversations about their condition, offering support, encouragement, and honest information. This open dialogue has fostered a sense of understanding and acceptance, allowing our sons to embrace their unique experiences. However, the challenges are far from over. As they navigate adulthood and independence, we continue to have difficult conversations about the future. The world is not designed with accessibility in mind, and we must confront the reality of potential limitations. Yet, through open communication, unwavering support, and a focus on their strengths, we remain hopeful that, as a family, we will overcome these obstacles and help them live fulfilling lives.•

ABOUT THE AUTHORS:

The Morrobel Family are active members of several Usher Syndrome organizations, dedicating their time and energy to raising funds, promoting education, and increasing awareness about Usher syndrome. Pamela (Aaen), Ethan, and Gavin have previously written for Exceptional Parent Magazine. This article marks Carlito's debut as a writer. Ethan and Gavin are brothers living with Usher Syndrome.

FURTHER CONTEXT : USHER SYNDROME RESOURCES



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EMOTIONAL REGULATION STRATEGIES TO PRACTICE AT HOME AND BUILD YOUR CHILD'S CONFIDENCE

BY THERESA MELITO-CONNERS, PHD

In the most intense moments, we can access skills to bring ourselves and others back to a balanced state. Emotional regulation, a skill of recognizing, managing, and expressing our emotions, can feel challenging for students navigating the world with ASD, ADHD, or other neurodiverse needs.

Amid overstimulation and stress, neurodivergent students can find emotions amplified and difficult to control. Some children may exhibit withdrawal symptoms or deep sadness, while others may act out.

As special educators, we work to guide students in building and expanding their abilities to identify, channel, and modulate their emotions. Parents and caregivers play a critical role in this journey. Research from Maughan and Cicchetti in the National Library of Medicine identified 4-6 years old children as having the ability to mirror their parents' emotional reactions.[1] When caregivers bring strategies from school to model at home, they can provide predictability and reduce potential stressors. This collaboration yields benefits in strengthening executive functioning, self-identity, academic engagement, and social relationships. A 2022 German study published in *Current Psychology*[2] found that children whose parents exhibit a warm, supportive approach to emotional regulation tend to develop more positive adaptive behaviors over time.

Practicing healthy emotional regulation techniques with children allows caregivers to reflect on their emotional health. Do

HOME STRETCH: Movement therapy, even in short spurts, remains one of the most effective emotional regulation tools. Try yoga or tai chi poses, which spur kids to tune into motion and link it to their breath.

you react with blame or tend to internalize stress? These strategies, whether employed on the verge or during emotional dysregulation, can equip caregivers and their children to be more mindful and resilient.

BEGINNING WITH THE BREATH

Babies naturally breathe through their diaphragm, a dome-like muscle at the bottom of the lungs. Stress causes the body to unconsciously shift into shallower chest breathing in a "fight or flight" scenario. Returning to this diaphragmatic, or "belly" breathing can help children relax their bodies and minds.

Belly breathing works by tightening and engaging the diaphragm downward while raising the abdomen, allowing the lungs to fully expand. This deeper breathing can reduce heart rate and blood pressure, which can surge when a child experiences triggering stimuli.

For younger children, practice diaphragmatic breathing by raising and lowering your arms together. Inhale as you raise your arms and exhale as you lower, keeping the shoulders steady. Strive to make your exhale longer than the inhale. Consider pairing this gentle breathing with visualization, such as asking a child to imagine blowing out the candles on a birthday cake. Older children can understand the mechanics, feeling their abdomens rise as they breathe in through the nose and exhale through the mouth.

Prioritizing the breath helps students become more aware of their emotions, thoughts, and bodily sensations. When a student becomes dysregulated, they may experience an "out of body" sensation, feeling disconnected from their physiological and emotional response, which can manifest as impulsivity, anger, or withdrawal. In these moments, a child's heart can often race, invoking frustration and panic. Taking a moment of mindfulness can encourage students to tune out external distractions and focus on how their bodies feel.

FRESH AIR: Stabilizing the breath – bringing breathing back to a regular rhythm – facilitates emotional regulation and demonstrates how the mind and body work to change behavior.

Stabilizing the breath facilitates emotional regulation, noting how the mind and body work to change behavior. Bringing breathing back to a regular rhythm provides an opportunity for a child to regain control and reset."

DIGGING INTO GROUNDING TECHNIQUES

When kids experience emotional dysregulation, they may have anxious or ruminating thoughts, which makes it tough to focus on a task or interact with others. Grounding exercises interrupt this cycle by redirecting attention to the present and fostering stillness and awareness.

Cognitive grounding techniques, like recalling familiar thoughts, offer structure in a chaotic moment. For example, some neurodiverse children may find loud sounds or bright lights distressing. Encourage them to recite the lyrics of a song or list their favorite colors or foods. Experiment with different lists that they can repeat aloud or quietly, in their mind. Repetition reinforces a soothing, recognizable thought pattern.

> "TALKING ABOUT A TOPIC OF INTEREST OR FAMILIARITY HELPS CUE STUDENTS THAT THEY CAN SUCCESSFULLY SHIFT THEIR MOOD."

Sensory grounding exercises, such as asking a child to make observations among their five senses, can also redirect a return to their environment. Spend a minute or two asking about physical sensations when they begin to feel worried, restless, or upset, and in the heart of the emotion: "Do you feel yourself getting warmer? Do your muscles tighten?" Grounding techniques also involve guiding a child on what ease and calm look like in their body, which may not be as noticeable. You might ask, "Can you do something to make yourself 1% more comfortable?" This can remind a child that they can address their discomfort.

Up-regulation grounding can energize young children showing fatigue or depressive symptoms. When a student feels down, we might talk about their favorite book or sport, or go through their morning routine. These conversations refer students back to what is comfortable, which promotes feelings of competency. Talking about a topic of interest or familiarity helps cue students that they can successfully shift their mood. By understanding their emotional patterns in action, they can access ways to make themselves feel better with fewer supports.

THE POWER OF MOVEMENT

In my early days as a guidance counselor at a therapeutic high school, we encouraged students to self-identify when they needed a break. They had a list of options to choose from. Yet time and again, most selected a five-minute walk outside to reset before heading back to class.

Movement therapy, even in short spurts, remains one of the most effective emotional regulation tools. Physical activity releases built-up energy from overstimulation, making it easier for a child to make decisions and focus. It's a key reason why intentional movement serves as a constructive outlet for children with more hyperactive aspects of ADHD.

Walks are great but aren't always a possibility. At home, you might start with slow music and dance, gradually speeding up the music. Try yoga or tai chi poses, which spur kids to tune into motion and link it to their breath. Drumming or strumming a guitar incorporates physicality and tactile engagement. In smaller spaces, like waiting in a line, try muscle relaxation, such as pushing and releasing against a wall. One favorite among young grade-schoolers is "curl and release." Imagine a football center, crouched, ready for a play. On your "Hike!" signal, they can stretch up to catch an imaginary throw, slow-motion instant replay included. Encourage children to notice the contrast as their body tightens and releases. By integrating movement and emotions, children learn how to acknowledge and release built-up tension.

> "NEURODIVERSE CHILDREN OFTEN EXPERIENCE AN EXPANSIVE, RICHER RANGE OF EMOTIONS THAN THEIR PEERS."

Neurodiverse children often experience an expansive, richer range of emotions than their peers. As educators and caregivers, it's on us to guide them in normalizing and managing the day-to-day emotional ups and downs in positive, productive ways. These strategies require patience and persistence and, as necessary, individualization that accounts for your child's unique needs and abilities. By providing support in and outside of school, we can help our learners become confident and proud of the skills they need to face adversity and the unknown – no matter where life takes them. •

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ABOUT THE AUTHOR:

Dr. Theresa Melito-Conners is a special education district administrator in Massachusetts, working with 100+ families and supervising a team of teachers, paraprofessionals, and related service providers. She is the founder of Dr. MC's Self-Care Cabaret, where she creates theater-inspired professional development services on mental health and work-life balance for educators and other helping professionals.

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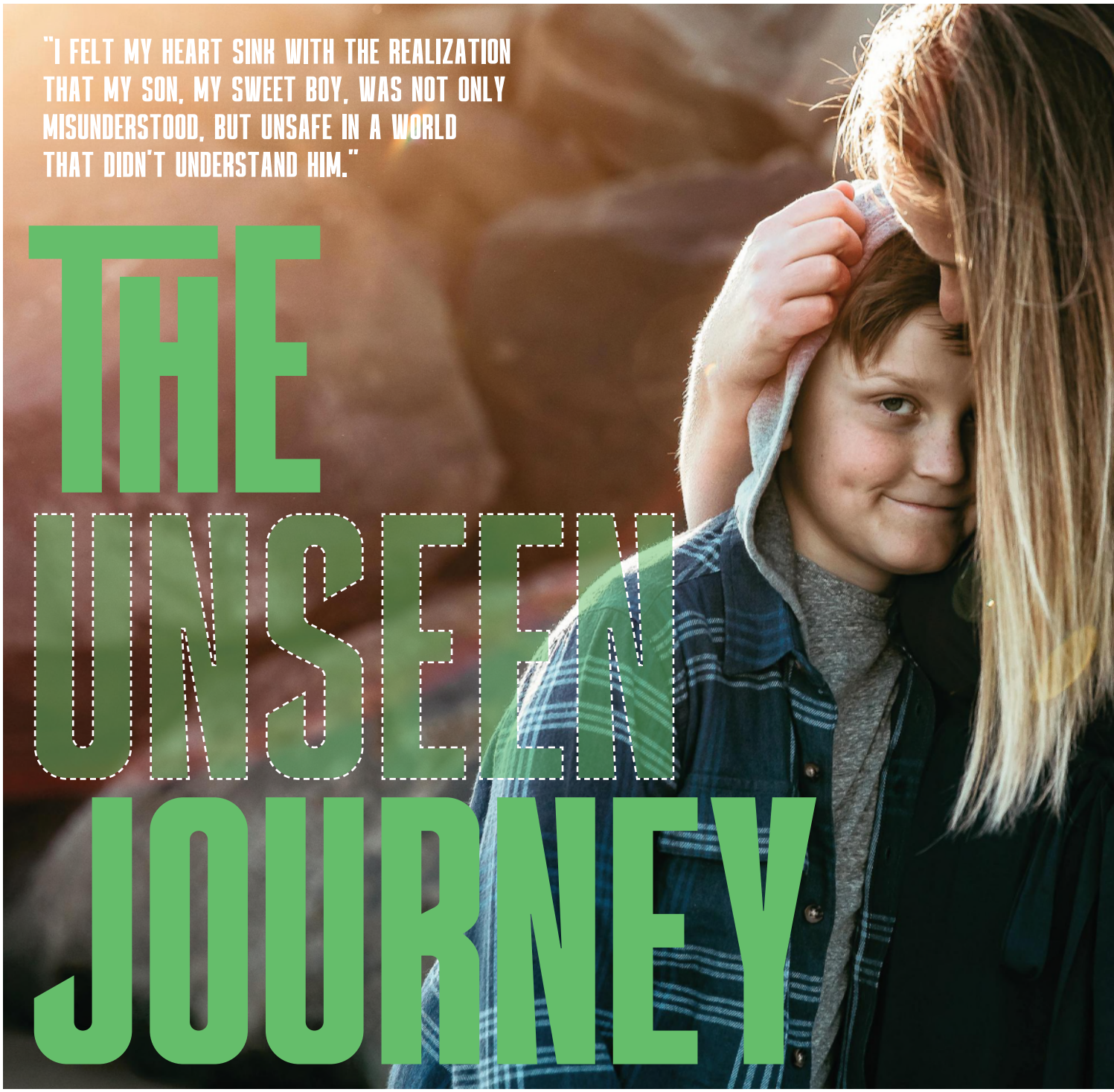

"I FELT MY HEART SINK WITH THE REALIZATION THAT MY SON, MY SWEET BOY, WAS NOT ONLY MISUNDERSTOOD, BUT UNSAFE IN A WORLD THAT DIDN'T UNDERSTAND HIM."

THE UNSEEN JOURNEY

ADAPTING TO AUTISM'S EVER-EVOLVING REALITIES

BY JJ MCLEOD

PHOTO PROVIDED BY JJ MCLEOD

SPARKING UNDERSTANDING:
The author enjoying a warm moment with her son; "There's an immense power in hearing someone say, 'Yes, I've been there, too. Here's what helped us.'"

A decade into autism motherhood, I thought I'd have it all figured out; that I'd understand more, that I'd get better at it. Somewhere along the way, I stopped hoping that autism would disappear, accepting it as part of who my son is.

Many of the things that once made me anxious faded, as I grew in my understanding and resilience. But new challenges appeared, ones I had never imagined. They were daunting, sometimes terrifying, and they changed my life in ways I hadn't prepared for.

This journey was never just about learning. It was about adapting to a reality that kept evolving.

At age 39, I felt the weight of that journey became even heavier. My son was having a hard morning; nothing unusual in our world. He was stimming more intensely than usual, a behavior that was familiar to us, but can sometimes look intense or even alarming to those who don't understand it. My husband and I decided he would stay home from school that day, as we had done on tough days before. My son liked to wrap things like a phone charger back and forth around his wrist, and on and off for pressure. I told the school that I was worried he would try and wrap other parts of his body, and I wanted to keep him home since he seemed overly anxious that morning. To us, it was a day like any other in our family's journey.

"THE BREAKTHROUGH CAME FROM REAL FAMILIES, SHARING REAL STORIES THAT WERE RAW, UNFILTERED EXPERIENCES, AND THAT MATCHED THE UPS AND DOWNS WE WERE NAVIGATING."

Then, our world shattered. Four police officers in bulletproof vests appeared at our door and entered our home. The school had called in a report, labeling my son as "emotionally disturbed" and "unstable." They hadn't mentioned autism, not even once. The officers weren't there for a child having a hard morning. They were there for someone they believed to be a threat. In that moment, I felt my heart sink with the realization that my son, my sweet boy, was not only misunderstood, but unsafe in a world that didn't understand him.

Sitting there, waves of grief, anger, and disbelief crashed over me. I had heard stories like this before about other families of autistic children, parents like me, but now it was our story. After years of advocating, equipping his school team, his caseworkers, and our community with tools and knowledge to support him, I thought he was safe. But as my son grew, the stakes grew too. No longer seen as a child, the world saw him as a risk, a problem. I realized then that advocacy had never been just about building support, it was about protecting his very right to exist peacefully in a world unprepared for him.

The breakthrough for me didn't come in a classroom or a counselor's office. It came from "some of us" reaching out to "all of us." A community of people who truly understood. Real families, sharing real stories that were raw, unfiltered experiences, and that matched the ups and downs we were navigating. In this community, we shared everything from daily struggles to the small victories, the tricks that worked, and often most importantly, what didn't.

This was the connection I had been missing, and it was the "special sauce" that made all the difference. These weren't just theoretical resources, they were lived experiences that felt tangible and real. Tips, strategies, and even practical day-to-day hacks poured in, ranging from therapies to finding a brand of shoes that didn't tie, but still looked "cool enough" for a growing child. It was in these spaces that I realized we weren't alone.

There's an immense power in hearing someone say, "Yes, I've been there, too. Here's what helped us." These connections empowered me to show up for my son in ways I hadn't even considered before. It reminded me that inclusion doesn't only happen in classrooms or workplaces. It thrives in the spaces where we feel truly heard and supported.

In these moments of sharing, we built solutions, perspectives, and solidarity. Each shared resource became a lifeline that helped us not just survive, but truly show up for our children with strength and resilience.

I share this story not to evoke pity, but to spark understanding. There is an urgent need for people to see beyond labels and behaviors, to understand the person and the family behind them. Every small action, every shared story, brings us closer to a world where children like my son can be safe, understood, and valued, not because they fit the mold but because they are inherently deserving of acceptance.

At the end of the day, that's what every parent wants; a world that truly sees their child. Until that world exists, we will continue to build it together; one resource, one conversation, and one powerful story at a time. •

ABOUT THE AUTHOR:

JJ McLeod, founder of Autism Embrace, is a dedicated autism advocate with over 15 years of experience creating inclusive programs, championing disability rights, and building vital resources that empower families with real support and impactful stories. Honored as one of Pacific Business Times' Top 40 Professionals in 2020, JJ brings both professional expertise and a unique, personal perspective—she's both an autism professional and a parent navigating this journey with her own child. As a certified Autism Specialist, Education Director, and PhD student, JJ proudly calls "mom of three" her most valued role. Her work is driven by a vision to empower communities and create lasting change. JJ's commitment is clear: to build a world where every family feels seen, supported, and ready to thrive. For JJ, inclusion is more than a mission; it's a commitment to making sure no one journeys alone. Learn more by visiting **https://autismembrace.com**

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SELF-ADVOCACY:
HOW TO GET THE SUPPORT YOU NEED

BY LARRY LANDAUER AND WAYED KABIR

Whether it's engaging with social service agencies, public school special education teams or medical providers, parents of children with special needs can sometimes feel they're at a disadvantage when seeking the support their child needs. The professionals likely know their systems and specialties well. They may or may not be well-versed in person-centered approaches that seek to identify the services an individual needs and wants, and to provide those services in ways that support the person in achieving what is for them a meaningful and satisfying life.

GETTING THE BEST SUPPORT FROM ORGANIZATIONS AND INDIVIDUALS : SELF ADVOCACY TIPS

Drawing on Larry's four decades of social service career experience and Wayed's personal experiences as a highly effective self-advocate, we have several tips to help parents get the best support from organizations and individuals.

LEAD WITH GRATITUDE

For busy parents who may feel their needs have historically been ignored, this could seem like too "soft" an approach. However, the parent or individual served who begins a conversation by expressing appreciation for what others do and have done for them can often be the instigator of a collaborative mindset that reinvigorates the relationship.

For example, Wayed, who has cerebral palsy, is in hospitals regularly in connection with his asthma. It's not a comfortable situation for him, but he uses his positive outlook to connect with the nurses and other practitioners on duty. Even those who may initially have been distant are almost always won over by his graciousness. When making requests or asking questions, he frames his statements in ways that express appreciation for the help at the same time he's asking for it. This almost invariably leads people to at least meet him halfway, and often inspires them to go above and beyond to ensure his needs are met.

BE HONEST ABOUT YOUR NEEDS

Parents often think they shouldn't need help, or that they're supposed to know all the answers when it comes to their children's special needs. But it's important to remember that if that were the case, there would not be the range of specialized service providers and systems available for providing help to families.

A person-centered social service organization will likely employ tools and techniques that encourage deep, productive conversations which help them discover and better understand a family's needs. For the process to deliver optimal results, it's important for parents to get out of their comfort zones enough, to be honest and forthright about their family circumstances and child's needs.

HAVE CONFIDENCE STANDING UP FOR YOURSELF

Embracing collaboration and focusing on gratitude can be hugely beneficial, but there likely will still be occasions when you believe you aren't being well-served. Many organizations, schools and social services agencies have an appeals process for when parents disagree with professionals about appropriate services for their child.

If you have a disagreement with your service team, it's important to express your concerns promptly, and to ask your contact person about the process for pursuing an appeal. With your child's IEP (Individualized Education Program), for example, you should not sign the IEP until your concerns have been resolved.

Wayed has CP and weighed 2 pounds 3 ounces at birth. He recalls his own experience in high school, with school staff who believed he could not succeed like his typical peers, with the traditional pathway to graduation. They insisted he instead follow the certificate of completion pathway that was then the norm for most students with developmental disabilities.

Wayed transformed that denial into motivation that spurred him to graduate from community college, and go on to earn both Bachelor's and Master's degrees. He encourages today's parents to stay strong and insist that their children not be subjected to unnecessary limitations that can impact their future career and social opportunities.

VIEW MISTAKES AS TEACHABLE MOMENTS

With businesses and organizations in the community, social media can be an effective tool for bringing concerns to light. For example, Wayed recalls a situation at a local gym when the manager made fun of his efforts to exercise, and continued to do so even after being called out for his insensitivity. Wayed shared the details of this experience on the business's social media page, which prompted higher management to issue an apology and to require the gym manager to also apologize. Wayed did not allow that negative experience to cause him to waiver in pursuing his fitness goals. Recognizing that people make mistakes, he sees these situations as opportunities to educate non-disabled people about inclusiveness, while still holding them accountable for their actions. •

ABOUT THE AUTHORS:

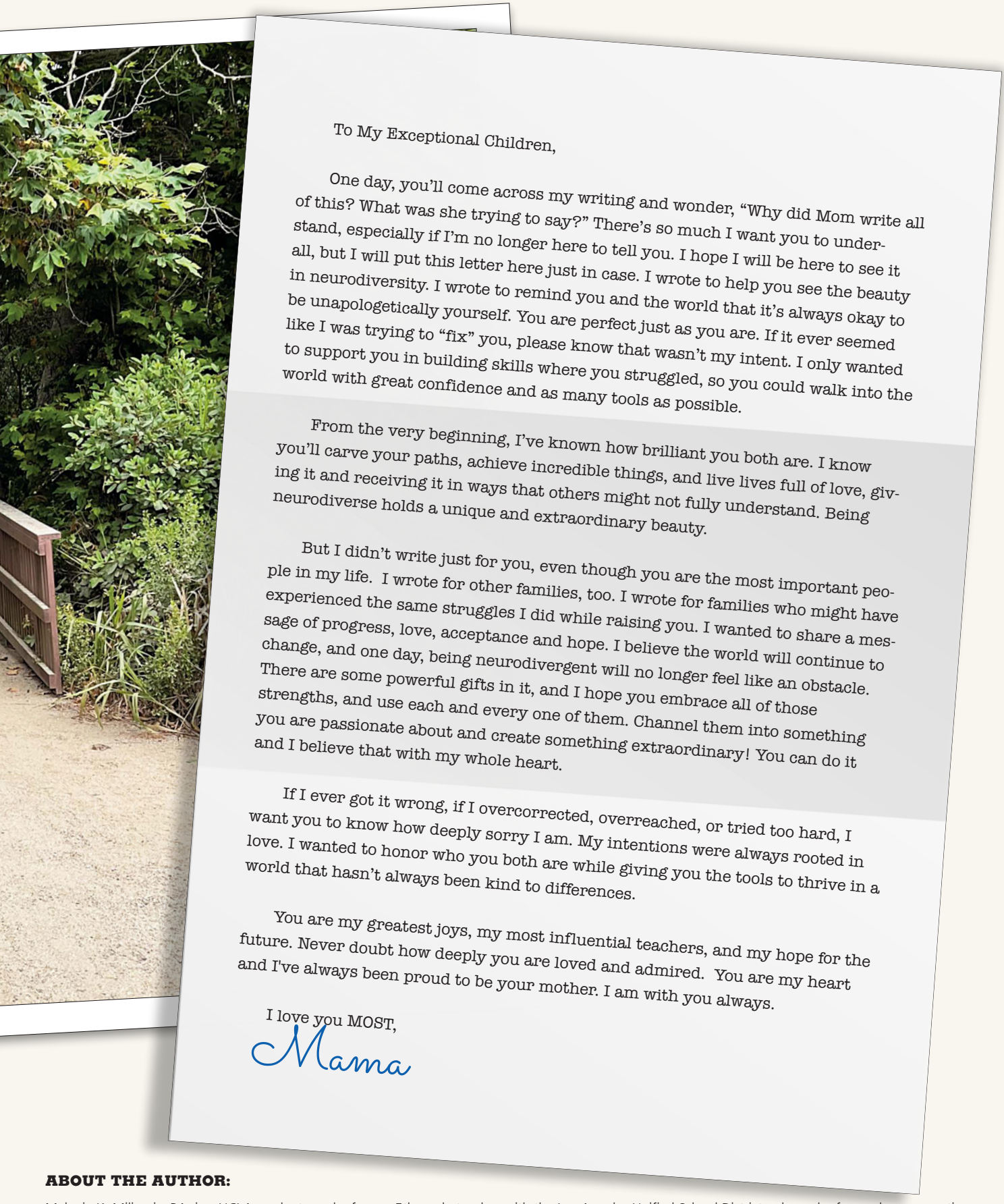
Larry Landauer is Executive Director for Regional Center of Orange County (RCOC), the private, nonprofit organization contracted by the State of California to coordinate lifelong services and supports for more than 27,000 Orange County residents with developmental disabilities and their families.

Wayed Kabir is a person served by RCOC, and also employed by RCOC, as a Peer Advocate, providing informal assistance to help resolve issues for other adults RCOC serves. In addition to providing information on issues related to self-advocacy and the rights of persons served, Wayed's responsibilities include sharing perspective, insights, and concerns of the person served, to those within RCOC. Wayed is a public speaker, high school basketball coach and founder of his own nonprofit organization, Ability on the Move.

A Mother's Letter to her Exceptional Children

BY MELANIE K. MILICEVIC, BA

PHOTOS PROVIDED BY MELANIE K. MILICEVIC



To My Exceptional Children,

One day, you'll come across my writing and wonder, "Why did Mom write all of this? What was she trying to say?" There's so much I want you to understand, especially if I'm no longer here to tell you. I hope I will be here to see it all, but I will put this letter here just in case. I wrote to help you see the beauty in neurodiversity. I wrote to remind you and the world that it's always okay to be unapologetically yourself. You are perfect just as you are. If it ever seemed like I was trying to "fix" you, please know that wasn't my intent. I only wanted to support you in building skills where you struggled, so you could walk into the world with great confidence and as many tools as possible.

From the very beginning, I've known how brilliant you both are. I know you'll carve your paths, achieve incredible things, and live lives full of love, giving it and receiving it in ways that others might not fully understand. Being neurodiverse holds a unique and extraordinary beauty.

But I didn't write just for you, even though you are the most important people in my life. I wrote for other families, too. I wrote for families who might have experienced the same struggles I did while raising you. I wanted to share a message of progress, love, acceptance and hope. I believe the world will continue to change, and one day, being neurodivergent will no longer feel like an obstacle. There are some powerful gifts in it, and I hope you embrace all of those strengths, and use each and every one of them. Channel them into something you are passionate about and create something extraordinary! You can do it and I believe that with my whole heart.

If I ever got it wrong, if I overcorrected, overreached, or tried too hard, I want you to know how deeply sorry I am. My intentions were always rooted in love. I wanted to honor who you both are while giving you the tools to thrive in a world that hasn't always been kind to differences.

You are my greatest joys, my most influential teachers, and my hope for the future. Never doubt how deeply you are loved and admired. You are my heart and I've always been proud to be your mother. I am with you always.

I love you MOST,

Mama

ABOUT THE AUTHOR:

Melanie K. Milicevic, BA, is a UCLA graduate and a former 5th-grade teacher with the Los Angeles Unified School District, where she focused on supporting second language learners and collaborated with special needs families to address diverse student needs. As a dedicated advocate for her own neurodiverse children, she continues to nurture her passion for writing, often typing ideas for future books on her iPhone. Her writing has been featured in publications such as *Autism Parenting Magazine, Exceptional Needs Today, Parenting Special Needs Magazine, the Special Needs Resource Foundation of San Diego*, and now *Exceptional Parent Magazine.* In August 2024, Melanie joined the Cajon Valley Union School District as a Learning Loss Intervention Teacher. She lives in San Diego with her husband and two children.

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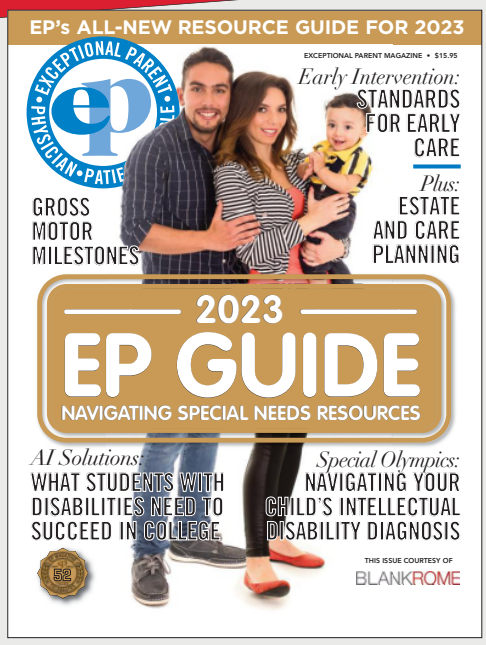

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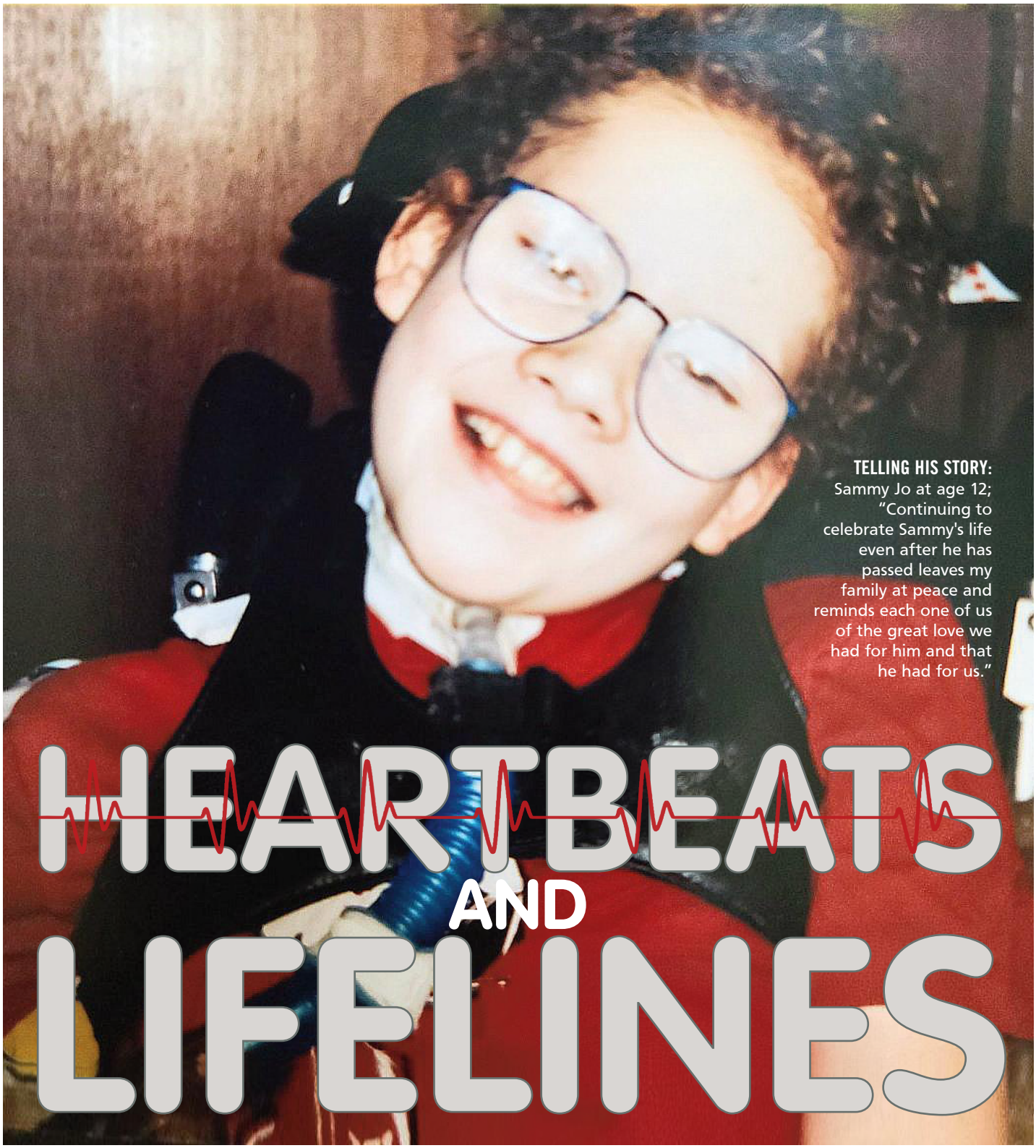


TELLING HIS STORY: Sammy Jo at age 12; "Continuing to celebrate Sammy's life even after he has passed leaves my family at peace and reminds each one of us of the great love we had for him and that he had for us."

HEARTBEATS AND LIFELINES

BY TRACEY LYNNE SCHEUERS

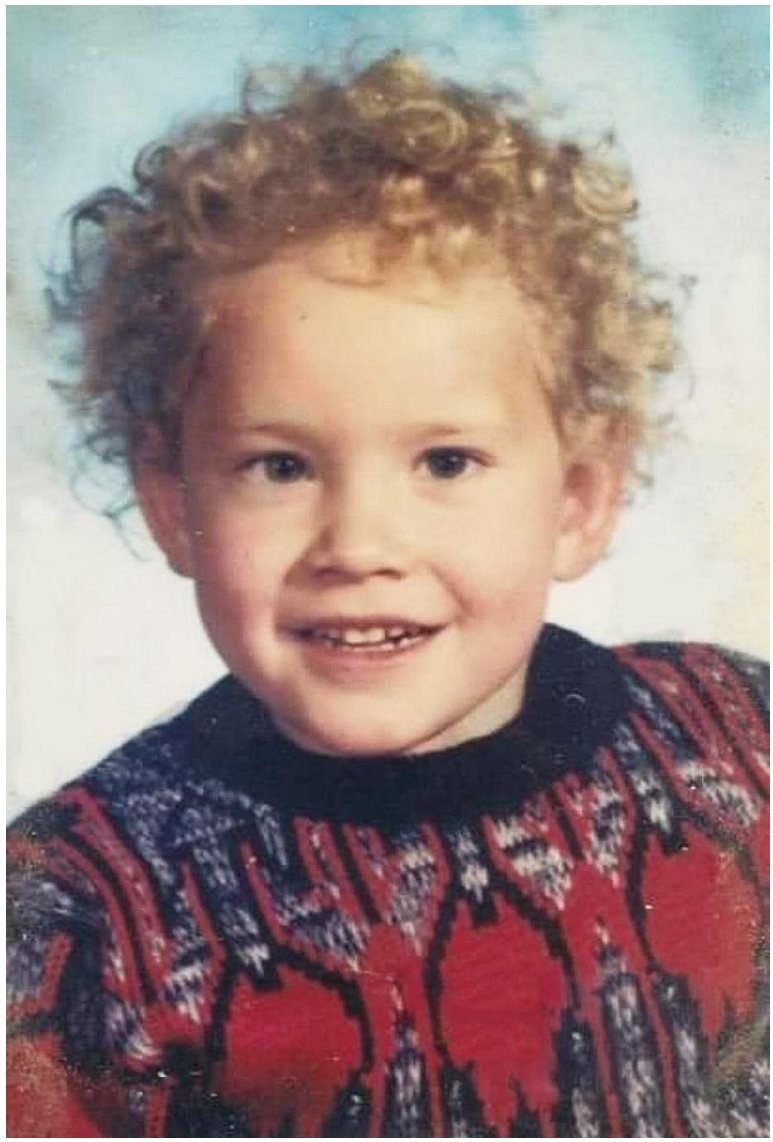
Life can change in one second. Those of us who parent or have parented a special needs child know the harsh truth of this statement. We suddenly find ourselves on the most bittersweet journey that life can offer.

Nothing prepares us for waves of extreme emotions that often are set aside to meet the physical needs of our children. Overwhelmed and stressed, often there is that lingering fear, wondering how long our child will live. Parental hazard includes failing to take care of our own physical and emotional health! As I look back at the bittersweet journey that I endured, I often wonder how I got through it. I sometimes think that with all I have been through, I could have

PHOTOS PROVIDED BY TRACEY LYNNE SCHEUERS

turned to smoking, drugs or alcohol. It is often tempting to rely on these vices to cope. However, making a conscious decision to choose a healthy coping mechanism is vital to our lifeline.

I recall people telling me how they thought that I would go off the deep end when my son passed because he had become my whole world. This was a legitimate concern, even for me. Life without my child was too scary to envision. I knew the day would come, but made a conscious decision to live in the present and enjoy every moment I had with my son. I knew he would not live a long life. Logically I thought, if I gave my son everything a parent could give of themselves, he would have the best quality of life possible. I told myself that when the day came and he would no longer be there to fill my day with love and smiles, I would have no regrets knowing that I gave him the best possible chance at life. When that day finally came in 2002, there was no rhyme or reason to anything, and I had to dig deep within myself to find the courage and strength to cope.

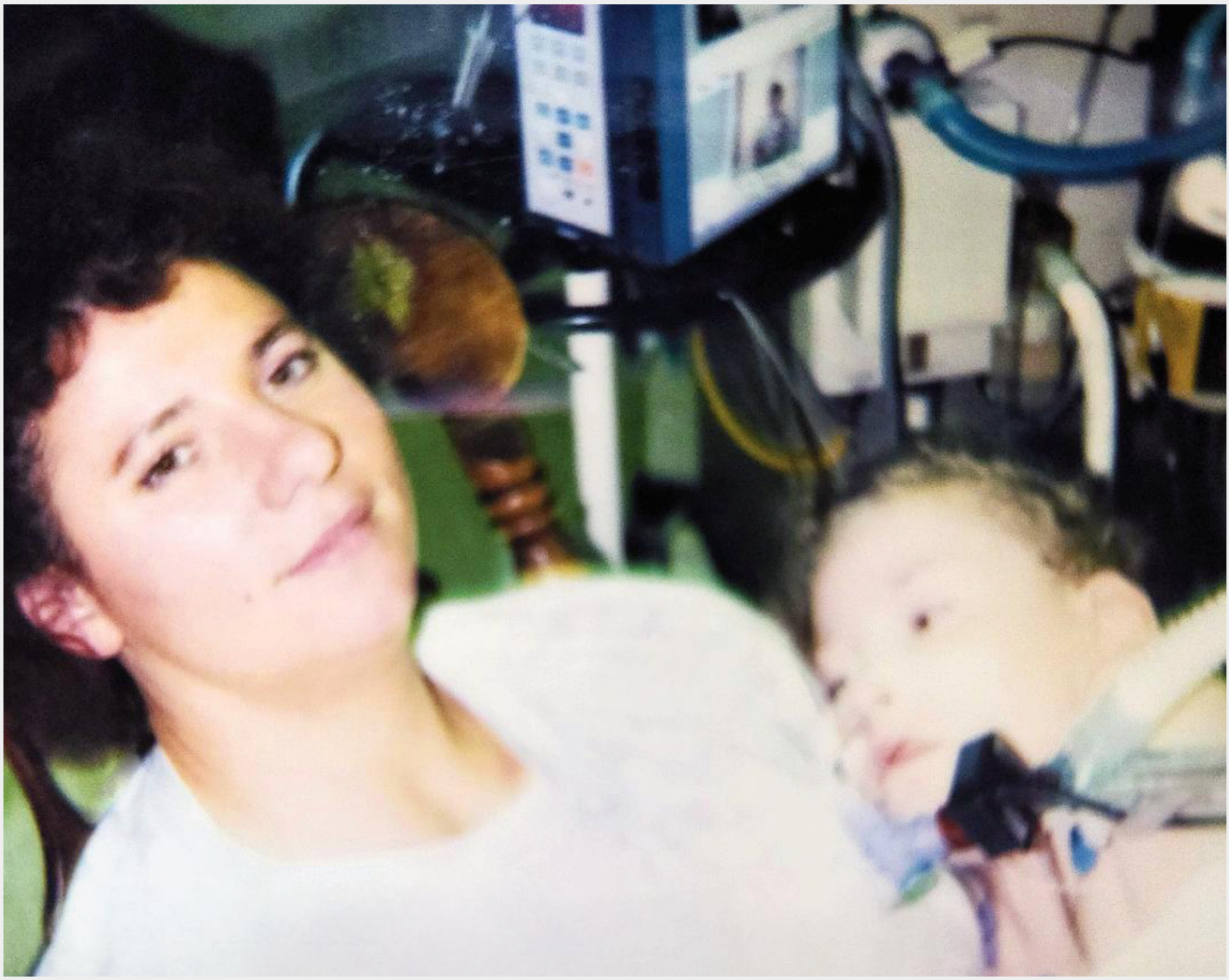


A ZEST TO LIVE: Sammy Jo at age 6; "Giving yourself the same empathy, compassion, and kindness that you gave to your child is key to emotional maturity and wellbeing."

I think back to lying on the hospital gurney, having just given birth to a son who had a significant neural (spinal) tube defect, and all I could feel was a stifled numbness. Even though I had three perfectly healthy children at home, I had no idea what whirlwind had just hit me. Feelings wanted to violently erupt, while reality quickly stopped the explosion, negating everything. The neurosurgeon was standing at my side, empathetically explaining how Spina Bifida was a condition where the vertebrae did not fuse completely, and the spinal cord protruded from the protection they offered causing paralysis. He told me that any dreams I had of owning a Ferrari I should just forget, because my son was going to be my Ferrari. He went on to explain that Samuel Joseph would need surgery within 24 hours to close the opening to prevent infection. A specialized team from Children's Hospital was already enroute with an incubator to transport him to Children's. I quickly realized that they were going to take my baby from me. In my mind, this could not happen! It was inconceivable to separate a newborn from the mother within moments of birth! While I struggled to accept what I had no say and no control over, the nurse brought my son to me, swaddled carefully in blankets. The very first time I said hello to my son, I also had to say goodbye. This defining moment is where I began the mourning of my healthy child. My child was paralyzed from the waist down, would spend his life in a wheelchair, and would be medically fragile. Six hours after giving birth, I was released from our community hospital and headed to Children's for my son's surgery.

"Life without my child was too scary to envision. I knew the day would come, but made a conscious decision to live in the present and enjoy every moment I had with my son."

In the beginning, the neurosurgeon had told my husband and me that Sammy Jo's life expectancy was around 3 years, and to enjoy every day we had with him. In 1988, at the age of 3, Sammy was admitted to Children's with failure to thrive. He was not eating and was admitted for a workup to find out why he wasn't doing well. After many tests and conclusions, there were no answers as to why he was failing. My son was literally drowning in his own secretions, because he could not swallow. He was dying. One morning, his neurosurgeon came into Sammy's hospital room to talk with us. He explained that Children's had just gotten its first stationary MRI (Magnetic Resonance Imaging) which uses magnets to do a type of scan that allows clearer images than that of a CAT scan. He stated they wanted to try out their new equipment and wanted permission to scan Sammy's brain, thinking we might just get lucky to find a potential cause for his failure to thrive. I realized we had nothing to lose, so agreed to the scan. The results of the MRI indicated Samuel had two water-filled cysts in his brainstem, called Syringobulbia. The cysts were putting pressure on the nerves that helped him swallow. I quickly had to research and become fluent in medical terminology and procedures to understand what was going on with my son's con-



A MOTHER'S LOVE: The author and her son Sammy Jo in the ICU in 1994; "Even after all he endured, he just wanted to play, just as a child should. I decided that I would honor Sammy Jo's great disposition by trying to be happy, for him.

dition. I visited the hospital's library and found a Merck Manual (the equivalent to medical terminology for dummies) and quickly deciphered conversations from the medical staff. Had the MRI not been introduced to Children's at that particular time, and my son had not been admitted on that particular day, he would have died at the age of three. He literally was born on the brink of technology!

Sammy had brainstem surgery to drain the cysts and relieve the pressure on the nerves that helped his swallowing mechanism. The MRI scans helped extend Sammy Jo's life expectancy, and he lived to be seventeen years old! He endured over 60 surgeries on his brain and spine. We spent countless days in the hospital's ICU while he was recovering from surgeries, fighting frequent infections, or needed seizure control. The physicians and clinical staff took the time to teach me all the skills of a registered nurse, so that I could care for my son along with his four other siblings, at home. Most children with Sammy's level of spinal defect never left the hospital. It was important to me to give him a regular family setting in hopes this would encourage his will to live.

"Had the MRI not been introduced to Children's at that particular time, he would have died at the age of three. He literally was born on the brink of technology!"

Money was super tight, as I had to miss many shifts as a Certified Nursing Assistant to meet Sammy Jo's medical needs. It was very fortunate that a Ronald McDonald house was right across the street from Children's Hospital. It allowed me to be at Sammy Jo's bedside for every single hospitalization. The atmosphere there was mostly of love and care, but the vibe was definitely heavy and tense. Each floor had its own kitchen and dining area that allowed parents to do something normal like cooking to divert their minds even for a short period. It was a place that allowed them to rest and refuel both physically and mentally. Surrounded by other parents in similar situations, there was an emotional

community developed of comradery and encouragement between parents. Sometimes the talk centered around whose child was worse off. Each child's condition was unique and could turn bleak at any given moment. I took away from my experience the importance of talking to others in similar situations, and drawing on them for emotional support and even inspiration to keep going. Talking about my situation with them and listening to their stories made me feel stronger and not so alone. Many times, when I was feeling sad and thinking about how tough things were going for my family, I realized there was always another family whose child was worse off. There was always a family who was closer to losing their child than I was. The families who had children going through bone marrow transplants always tugged at my heartstrings, because the outcomes were seldom good. The reality was that we were all in the same boat.

At the age of almost 9, Sammy had a severe medical crisis. It was Mother's Day, and I was getting ready for my shift as a Unit Clerk in the ICU when I was called to his bedside by his private duty nurse. I called the ambulance, called off my shift at the hospital, and for the umpteenth time accompanied my son to Children's, where he was admitted. This hospitalization resulted in Sammy being put into a medically induced coma and being placed on a ventilator. He spent the entire summer in the hospital. At one point during that hospitalization, I recall realizing I had been inside the hospital for over a week straight and never stepped outside of the building. Things were so unstable that the staff let me sleep in a room close to the ICU at night, so I didn't have to leave his side. This was a significant event and Sammy went from being paralyzed from the waist down, to being paralyzed from the neck down. He had a feeding tube to give him proper nutrition while his body healed. I was taught how to change his trach tube, operate his home ventilator, and manage his intense medication schedule. Miraculously, we were able to take Sammy home before his ninth birthday in August. Things were hard, but the hard things became normal. He was now in 24 hour skilled nursing care, so I utilized private duty nurses as much as possible. Whenever a nurse was not available, I would care for him myself. Finding ventilator certified nurses was challenging, and I often would have to care for my son for days at a time, with little to no relief. Somehow, we got through it all.

After years of repeated shunt revisions (mechanical failure of a tube that lies just underneath the skin and runs from the brain to the stomach and drains the excess fluid that causes pressure on the brain), repeated infections and seizures, Sammy eventually died of a shunt malfunction at the age of 17. He was at home with me and his siblings. One night, we said I love you to each other, and he drifted off to sleep. The next morning, he wouldn't wake up and it appeared that he was in a coma. Once at Children's, it was determined that he had suffered a brain death, and there was nothing more we could do. He was removed from the ventilator. This was the hardest day of my life.

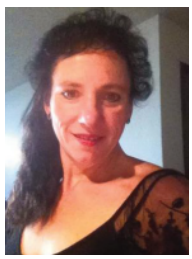
"I struggled with acceptance for a long time. During this last stage, I think the thing that resonated the most was my son's great disposition, even after all he endured."

The first days and weeks after his passing remain a blur. I know there was great support from well meaning friends and family. I quickly realized that there was nothing anyone could say. There were no words that could comfort me. On occasion, someone would try to say something to comfort me, but what they said irritated or angered me. I knew they meant well, but they could never understand because they had never been in my shoes. Ultimately, it was a personal journey for me to understand the purpose of his life and his death. I had to find a meaning that worked for me. I had to find my own way through the pain of losing something so precious.

I allowed myself to experience some of the stages of grief: the denial, the anger, the depression. I struggled with acceptance for a long time. During this last stage, I think the thing that resonated the most was my son's great disposition, even after all he endured. He just wanted to play, just as a child should. He also really hated to see me sad. I decided that I would honor that by trying to be happy, for him. I felt the need to adapt his coping mechanism and his wonderful disposition toward life. I knew that in his short life he had touched a lot of people with his zest to live and his ability to smile, even though things were tough. The greatest gift he gave to me and to anyone who knew him was the importance of unconditional love. Ultimately, I knew he had been given to me to teach me and others these valuable lessons. It took me a long time to get to this point and truly be able to move on and live my own life. Without a doubt, special needs children teach us all how to be better people.

They say that you know you have healed when you can tell your story without crying. I believe this to be true. I realized that death is a part of life, and that Sammy's purpose for existing did have a great impact on so many others, as well as myself. I've learned that each journey is a personal one. Allowing yourself to feel the emotions as you go through them and giving yourself the same empathy, compassion, and kindness that you gave to your child is key to emotional maturity and wellbeing. Continuing to celebrate Sammy's life even after he has passed leaves my family at peace and reminds each one of us of the great love we had for him and that he had for us. Remembering the good times and making a conscious decision to choose to be happy and enjoy what is left of my own life has helped me to survive emotionally.

ABOUT THE AUTHOR:



Tracey Lynne Scheuers was born in Fond du Lac, Wi. She has worked in healthcare for over 40 years and is now transitioning to being a freelance writer and an Author. She is currently working on her first novel about parenting a child with Spina Bifida. It is a passionate, raw story that centers around her bittersweet journey of parenting a medically fragile child who was born on the brink of technology, namely the MRI. Her other passions include her grandchildren, gardening and crafting.

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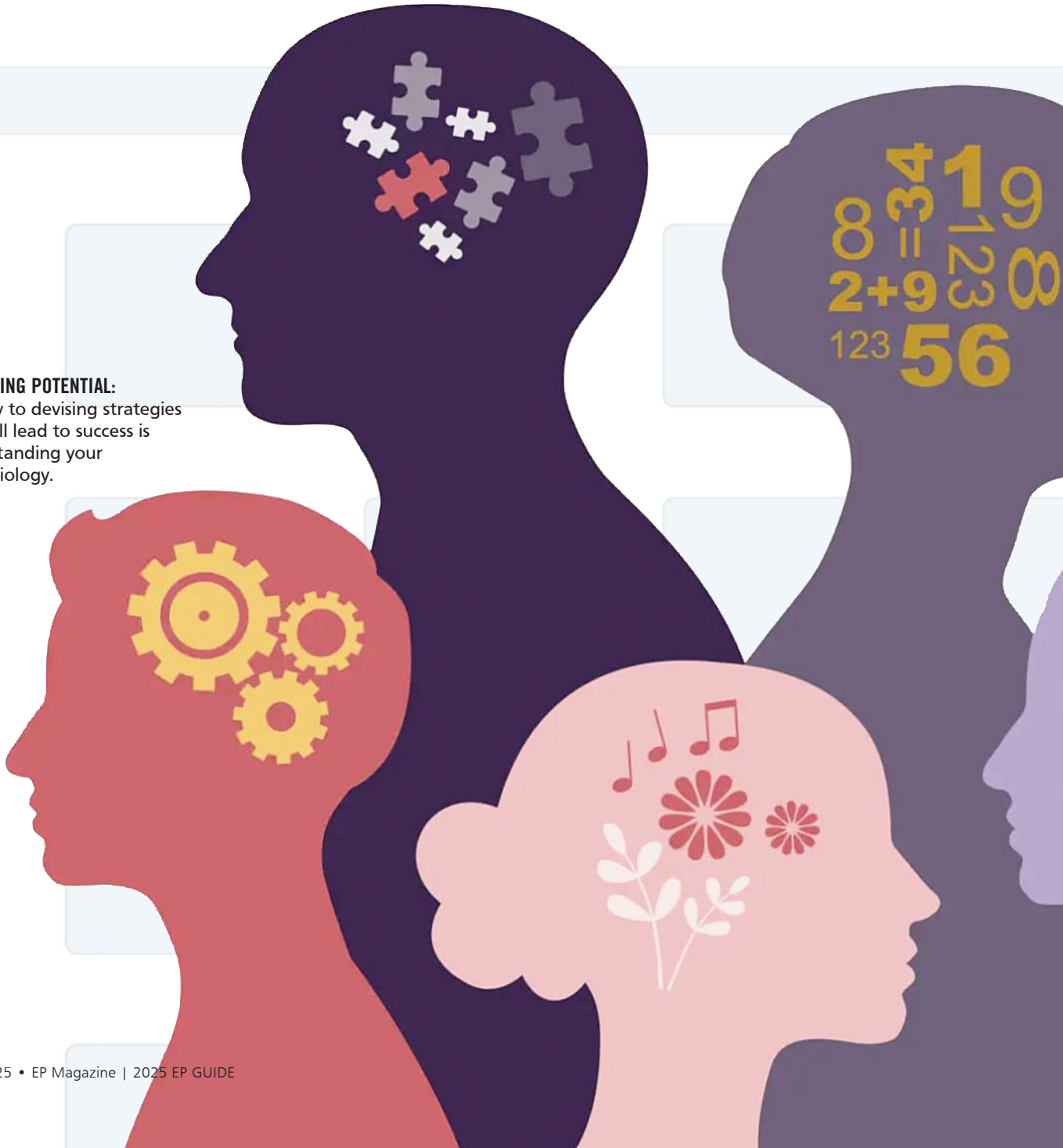
YOUR ADD TOOLKIT FOR CRUSHING NEW YEAR'S GOALS

BY NECHAMA SORSCHER, PHD

People with ADD often struggle to follow through on their resolutions despite their best intentions!



UNLOCKING POTENTIAL:
The key to devising strategies that will lead to success is understanding your neurobiology.

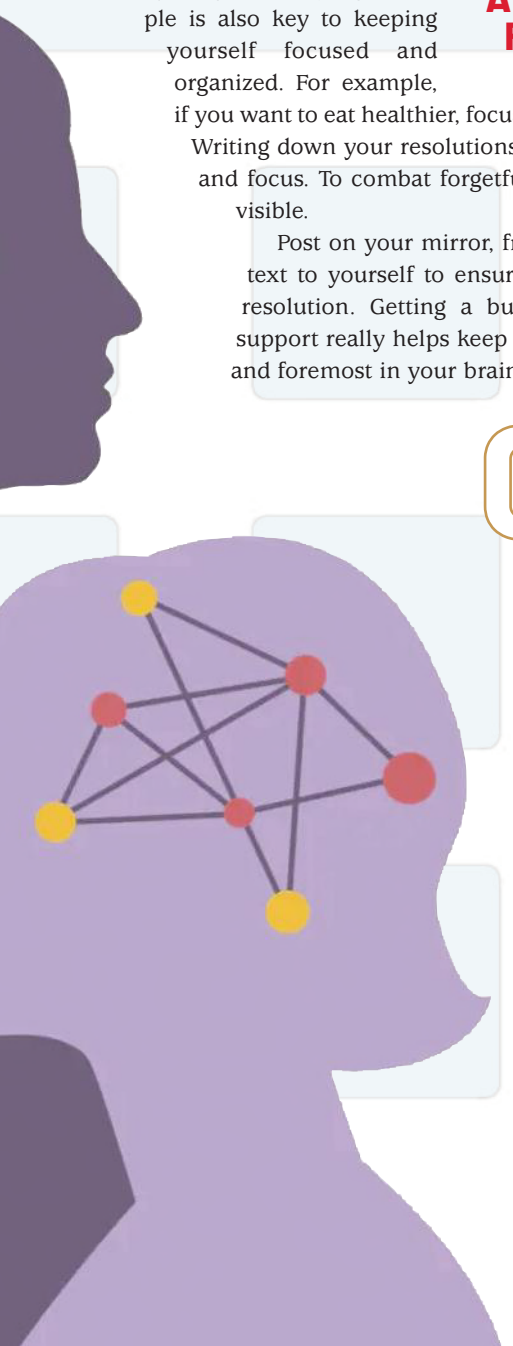
It may feel as if your brain gets hijacked, and you fall "off the wagon" as soon as you get on. That is because your frontal lobe, the part of the brain that is responsible for planning, organizing and producing [1], needs some help.

Understanding your neurobiology is key to devising strategies that will lead you to success. ADD often results in forgetfulness, procrastination and fatigue. These are ways that your brain responds to being overwhelmed by complexity. Scientists have documented that people with ADD often have an inordinate amount of sleep wave activity, even when they are awake.[2] You need to wake up your brain and keep it on track in order to have success.

Organize yourself for success by breaking down your goal into small steps. For example, if you want to run a 5K, start by walking for ten minutes, then running for ten minutes and slowly building on your goals. Keeping it simple is also key to keeping yourself focused and organized. For example, if you want to eat healthier, focus on eating more salads. Writing down your resolutions will help you organize and focus. To combat forgetfulness, keep your goals visible.

"PEOPLE WITH ADD HAVE TONS OF ENERGY, A MILLION IDEAS, CAPACITY FOR CREATIVITY AND EXCITEMENT, AND A PASSION FOR NOVELTY."

Post on your mirror, fridge door, or in a daily text to yourself to ensure commitment to your resolution. Getting a buddy for accountability support really helps keep your daily practice first and foremost in your brain.



One of the biggest challenges is how to respond when you don't meet your goals. People with ADD often think in "all or nothing" terms. Once they "fail" they throw in the towel because they become very discouraged. Create resilience and persistence. Do not set yourself up with unrealistic goals. Build in rest days or cheat days, and remember to be kind to yourself. Celebrate each small step in self-care.

ADD AND THE NEW YEAR : STRATEGIES FOR SUCCESS

Wake up your brain! Pair the activity with a favorite song, podcast or audible book to keep it exciting and motivating.

Keep it simple! Remember, less is more, don't overload your brain.

Keep it up! It takes three weeks to form a habit.

Get a buddy! We are social creatures and are wired to respond to social support.

Use technology for help! There are so many apps that help organize your goals.

Harness your super powers. People with ADD have tons of energy, a million ideas, capacity for creativity and excitement, and a passion for novelty. Change up your routine, spice up your salads and use your boundless energy to keep on going. •

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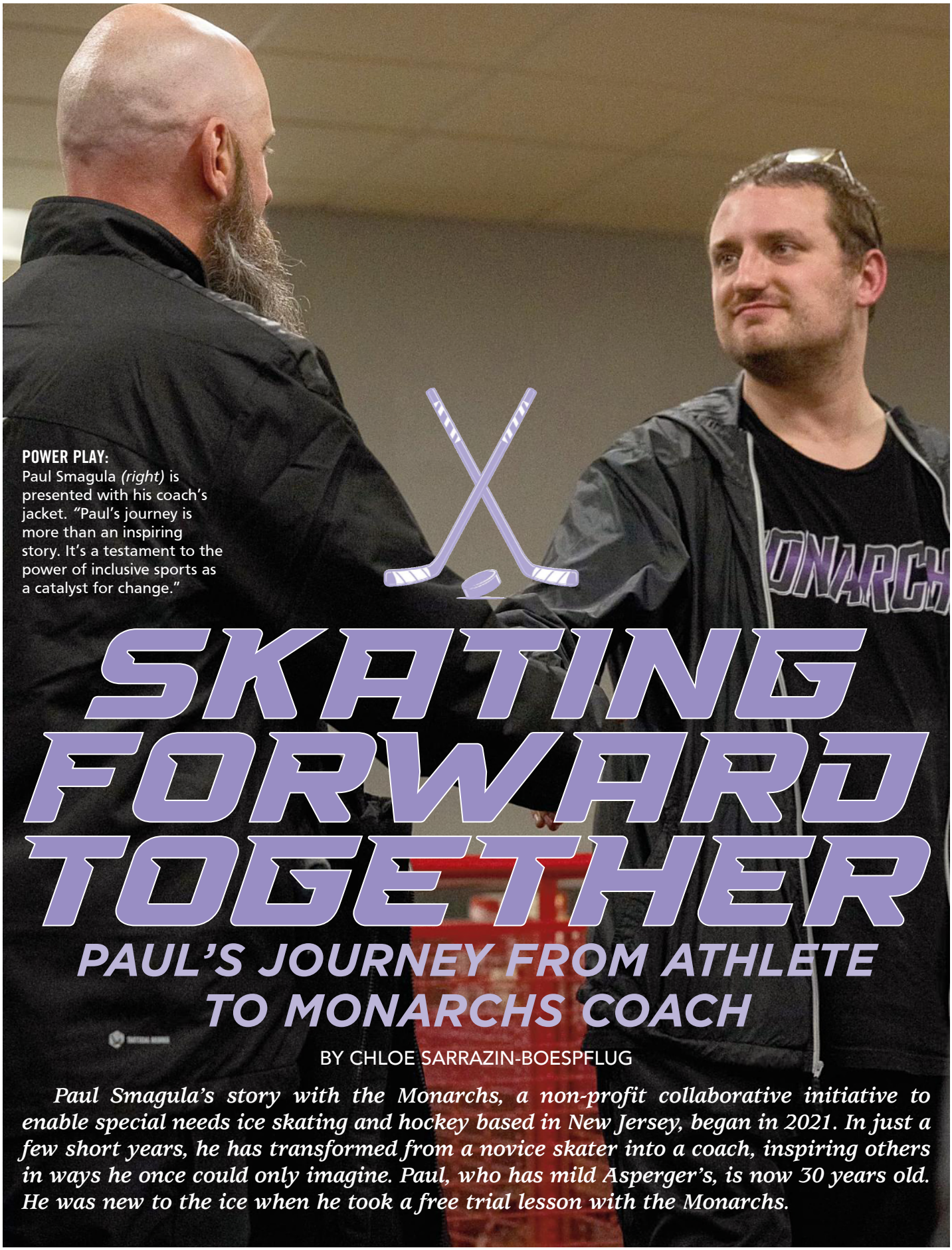
ABOUT THE AUTHOR:

Dr. Sorscher has over three decades of experience working with patients with neurocognitive challenges, both as an evaluator and a psychodynamic therapist. As a leading specialist in New York City, she combines a sophisticated understanding of the neurobiological makeup of these individuals with a nuanced appreciation for the emotional sequelae that come with each diagnosis. Dr. Sorscher obtained her PhD in clinical psychology from Adelphi University in 1992 and a certificate in psychoanalysis and psychotherapy from NYU's Postdoctoral Program of Psychotherapy and Psychoanalysis in 2016. She has published many articles in academic journals on neurocognitive challenges, trauma, and working with neurodiverse children and adolescents. Dr. Sorscher has two new books including *Assessment and Intervention with Children, Adolescents, and Adults with Neurocognitive Challenges: A Psychodynamic Perspective* and *Your Neurodiverse Child: How to Help Kids with Learning, Attention, and Neurocognitive Challenges Thrive. Visit* **amazon.com**



POWER PLAY: Paul Smagula *(right)* is presented with his coach's jacket. "Paul's journey is more than an inspiring story. It's a testament to the power of inclusive sports as a catalyst for change."

SKATING FORWARD TOGETHER

PAUL'S JOURNEY FROM ATHLETE TO MONARCHS COACH

BY CHLOE SARRAZIN-BOESPFLUG

Paul Smagula's story with the Monarchs, a non-profit collaborative initiative to enable special needs ice skating and hockey based in New Jersey, began in 2021. In just a few short years, he has transformed from a novice skater into a coach, inspiring others in ways he once could only imagine. Paul, who has mild Asperger's, is now 30 years old. He was new to the ice when he took a free trial lesson with the Monarchs.

PHOTO PROVIDED BY CHLOE SARRAZIN-BOESPFLUG

That trial session set off a spark. What started as curiosity, turned into a love for skating and ultimately a new passion for teaching. Paul's journey offers a powerful look at how inclusive sports can help individuals with different abilities build confidence, community, and joy.

STEPPING ONTO THE ICE

When Paul joined the Monarchs, he hadn't skated a single day in his life. Yet, as his mom Victoria recalls, that free lesson changed everything. "He had never skated before, and he fell in love with it." Paul initially started as a free skater working under the mentorship of Deana Sroka, an experienced coach who saw his potential. Deana encouraged him to push his boundaries and challenge his fears, especially the fear of falling or getting hurt – a daunting possibility that initially brought him to tears. However, Paul developed resilience through patience, practice, and his coach's support. He discovered a passion for the ice that went beyond skating itself.

Today, Paul plays a unique role within the Monarchs, bridging the gap between the young skaters and their coaches. He encourages young athletes to step out of their comfort zones just as he did, which allowed him to become not only an athlete, but a role model. In the words of his mom, "With your child, if they want to try something, say yes, no matter how scary. Never discourage them, and see where it takes them." For Paul, saying "yes" opened doors he had never expected.

COACHING WITH PURPOSE

As Paul transitioned into coaching, he found joy in fostering confidence in others. His coaching philosophy centers on patience, support, and fun. He also focuses on building life skills like balance, resilience, and teamwork. "Whatever you learn, it is never wasted," Paul reflected, emphasizing how his journey has taught him the value of patience and persistence. "Go for it. Every step you take is a step closer."

His words and actions encourage young skaters to believe in themselves, and his dedication demonstrates that the benefits of sports aren't just physical. They help build character, empathy, and a sense of belonging. Paul's unique perspective, having been a newcomer and now a coach, makes him an empathetic leader, who can reassure young skaters and guide them through the same challenges he once faced. His presence on the team has had a profound effect on other athletes. He has become a source of encouragement by having overcome the same challenges that many of the skaters have to face. His mom shared a heartwarming story of when she once asked Paul, "How do you like it?" He replied, "I ***love*** it." His journey has given him a sense of purpose that goes beyond the rink, a desire to make a difference in others' lives.

ABOUT THE MONARCHS

MONARCHS LEARN TO SKATE

The Monarchs are a non-profit collaborative initiative to enable participation in organized youth sports programs with a focus on teamwork, sportsmanship and fair play through scholarships, access to facilities and equipment, player and coaching development and mentoring. The Monarchs develop positive self-esteem and learn skills to help athletes lead healthy, successful lives. Visit **www.monarchs.us** for more information.

BUILDING COMMUNITY THROUGH SPORTS

The Monarchs offer a safe, supportive environment where skaters and their families find community and connection. Families get to see their children thrive, challenge themselves, make friends, and discover new passions. Programs like this are often hard to find. They are important for kids and young adults with special needs, helping them to feel a sense of inclusion.

In a recent charity game, while playing alongside retired NHL players including Travis Zajac, Ken Daneyko and Bruce Driver, Paul scored his first exhibition goal. It was a proud moment in which he demonstrated his progress and the joy he derives from the sport. Paul's mom explains that the Monarchs create a "safe space for individuals with special needs to socialize, build friendships, and enjoy family camaraderie." and that his journey is a powerful reminder of the importance of such organizations. Paul's progress speaks to the power of consistency and routine in building confidence. "Balance, consistency and forming a routine helps build your confidence and makes you proud," he shares. This sense of pride and belonging has transformed Paul's life, allowing him to grow in ways he never anticipated.

"PAUL'S STORY SHOWS THE REMARKABLE DIFFERENCE THAT INCLUSIVE SPORTS PROGRAMS CAN MAKE IN THE LIVES OF INDIVIDUALS, THEIR FAMILIES, AND WITHIN COMMUNITIES."

INSPIRING CHANGE AND ADVOCACY

Paul's journey is more than an inspiring story; It's a testament to the power of inclusive sports as a catalyst for change. Paul's success reinforces the value of accessible programs that offer individuals with special needs the chance to try new activities, learn essential skills, and find joy. "It's a chance to pay it forward and give back," Paul explains. His journey reminds us that everyone has a unique passion waiting to be discovered, and that saying "yes" can lead to life-changing opportunities.

Accessible sports programs like those offered by the Monarchs show that everyone deserves an opportunity to excel. Paul's mom sums it up best by reminding us to encourage loved ones to explore their interests. Paul's dedication provides hope and inspiration for families across the special needs community. His story shows the remarkable difference that inclusive sports programs can make in the lives of individuals, their families, and within communities. Through his role, Paul exemplifies one person's impact on others, spreading joy, and encouraging confidence, and connection. •

ABOUT THE AUTHOR:

Chloe Sarrazin-Boespflug is a Junior at Montclair State University's School of Communications and Media. She is studying abroad at this time.

"Letting our young adults make mistakes and letting them learn from those mistakes are difficult tasks for any parent.

It is even more difficult when one's young adult has a disability."

JEFF'S STORY

BY EVELYN LOWRY

My son, Jeff, was born October 7, 1982. The birth was normal and he appeared to be a typical baby. However, I became uncomfortable with the way he was developing, and at two and a half we had him tested. His diagnosis was developmental delay. At one time, he might have been institutionalized and labeled mentally retarded. Instead, he's grown up to become a friend, a hard worker at his job, and a member of his community.

PHOTO PROVIDED BY EVELYN LOWRY

I want to share his story with other parents and professionals so that they can see what parenting Jeff was like. They can see our struggles and frustrations, fears and joys, challenges and accomplishments. My reason for telling Jeff's story from my perspective is that our experiences might give hope to anyone struggling to raise and educate a child with an intellectual disability.

To explain the feelings of having a child with a disability, I must start at Jeff's birth. He was born full term with no obvious deformities or challenges. The actual birth process took a long time, as he was born posterior with his back to my back and had an unusually large head. He took a long time to be able to hold his head up and did not roll over, coo, or make the usual baby sounds. *(Names and locations in this story have been either changed or concealed.)*

I think I knew from an early age that there was something different about Jeff. His doctor assured me that it was my imagination and that he was fine. That, of course, is what I wanted to hear, so we moved on. A few childcare providers expressed concern. Jeff and I took a class together when Jeff was two. The teacher suggested that we should have Jeff tested, as he was not developing like other children.

At that point, I was pregnant with my daughter, Sarah. I switched pediatricians. I needed someone who would listen to me, which my other doctor clearly wasn't. The new pediatrician referred us to The Children's Clinic for an evaluation. Jeff was labeled "Developmentally Delayed." I was crushed. Crying spells and guilt, as well as fear, consumed me. The specialists were not able to identify the cause of Jeff's disability. I was concerned about my unborn child. Would I soon be raising two children with disabilities? Did I do something wrong when I was pregnant with Jeff to cause this? Genetic testing did not provide any solution. I reviewed the birth records with my doctor, and not surprisingly, nothing was identified there.

"At the end of the school year, there was a first-grade picnic for kids and parents. The teacher told me, "I watched your son blossom in my classroom.

I was elated. I will never forget that feeling of satisfaction and success."

Weanwhile, Jeff was the same little boy after the tests as he was before. He was sweet, loving, and healthy. We discovered a seizure concern, so we added neurology to the list of growing professionals in his life. I started taking him to a speech therapist twice a week. Sarah was developing normally. Whatever this was did not affect her, but therapy became part of our lives. We made quarterly visits to the neurologist, and speech therapy two days a week.

I had no idea what I was doing. I was in a mechanical mode. I functioned by trying to be a good mother. I was scared and tired all the time. I kept comparing Jeff with other children, trying to justify my actions and his development. I read everything I could get my hands on, trying to explain why he was developing the way he was. I kept hoping that I wasn't the cause. Dave, my husband, had his work and was able to escape the house and my worries. He was lucky, but he also blamed himself as the cause of Jeff's disability. It was a very trying time. We did our best to support each other and give our children what they needed.

My first introduction to inclusive classrooms and the benefits of allowing children to be children and not just therapy subjects happened during Jeff's preschool years. Inclusion means being part of something and not isolated from an activity or group. For Jeff it meant learning how to be part of a group. For me, it meant Jeff's opportunity to be part of the world at large.

What does it mean to be fully included in life, in school? Does inclusion only apply some of the time, or only to some population groups? I asked myself these questions many times as I was raising my son. Was being in a special education self-contained classroom really in his best interest? Was special education a placement or a set of individualized services? I decided that special education was a set of individualized services.

I went to conferences and talked to other parents. Was it important that Jeff be like other kids? Would he ever be like other kids academically? How was I going to convince the district and myself of the benefits of being around typical children?

Jeff was a child first. The things he needed were the same as any other child. He needed friends. He needed success and accomplishments. He needed to feel important and safe.

When writing down my memories of raising my children, especially my son Jeff, I remember what it felt like to see the reactions of others to Jeff. I remember being in the grocery store with him when he was about four or five. He was sitting in the cart, talking away. I was thinking about groceries when a woman came up to me and asked me what was wrong with him. I was speechless. Who asks that question of a parent? I think I said something like, "He has a speech problem." Later, I thought about what I should have said. "Nothing is wrong with him. What is wrong with you?" It hurt me. It hurts when people do not see what is special about our children. No one asked me those questions about my daughter.

When I think about it, the law that said public schools had to educate children with special needs was only passed in 1976. Jeff was soon to be a pioneer in his own way. When he was in his regular first grade class, he started sitting on his carpet square. He participated in class activities and started verbally communicating. He also started really liking school. He would run out the door and get on the bus without complaint. At the end of the school year, there was a first-grade picnic for kids and parents. The teacher told me, "I watched your son blossom in my classroom." I was elated. I will never forget that feeling of satisfaction and success.

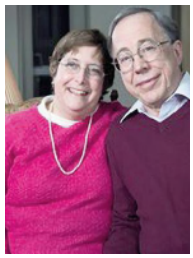
When Jeff spent time in a regular classroom, he loved it and the teachers were so accepting of him. He had an instructional assistant that would follow Jeff through his elementary school days. The little bit of time Jeff spent in regular classrooms as opposed to the self-contained special ed classrooms showed how beneficial the regular classrooms were for Jeff. He excelled further than anyone thought he could.

Adulthood, getting one's own living space, making decisions for and having a job in the world are difficult accomplishments for any young person. I didn't expect my son Jeff to be any different. Getting to that point proved to be a challenge. He needed to go to the community college where the "transition" program was housed for our school district. There was a bus that went from our house to the light rail where everyone was meeting. The district wanted to pick Jeff up at our house in a school bus, and bus him to a central meeting place where he would meet the teacher and other students, instead of letting him take a public bus. I had to talk the teacher (and myself) into driving Jeff close to the bus stop and watch Jeff cross a street and get on the bus. I must admit, I walked there too. The teacher and I kept our distance so Jeff could feel independent at this task.

Letting our young adults make mistakes and letting them learn from those mistakes are difficult tasks for any parent. It is even more difficult when one's young adult has a disability. Jeff became very independent at riding public transportation and was soon able to take many routes with much confidence. He admitted he once fell asleep on the train, finding himself well past his stop, and having to get off the train and get back on track. He figured it out by himself!

My husband and I worked very hard to include Jeff in his community. We tried to organize as well as participate in activities such as: Boy Scouts, traveling, grocery shopping, and public transportation. Jeff participates in Special Olympics (a sports-oriented group for people with developmental disabilities) and Trips Inc. (a travel organization for adults with intellectual disabilities). Although most of Jeff's friends are other adults with intellectual disabilities, he does go to restaurants by himself, movies with friends, and is in a bowling league. Jeff lives and works successfully in his community. •

ABOUT THE AUTHOR:



Evelyn Lowry's favorite job is being a mom of two, now grown children. She has a degree in Elementary Education and taught preschool for a year. When that didn't seem to meet her career goals, she went back to school and became an x-ray technician. She did that, part time, while her children were small. As Jeff grew, she spent more time advocating for him at school, going to workshops, trainings, and helping other parents through the IEP process. She worked briefly organizing trainings for families and professionals on team building. She was hired to work as a family consultant in Oregon's Title V project, and also worked briefly with FACT (a family run training program) on their Parent to Parent Project. She is now retired, reading, writing, playing music and enjoying friends and family.

FROM OUR FAMILIES... TO YOUR FAMILIES

MILITARY SECTION

ARMY
NAVY
AIR FORCE
MARINES

MILITARY LIFE

AN OVERVIEW: ADULTS WITH SPECIAL NEEDS

INTRODUCTION

Adults with special needs are individuals over the age of 18 who have a medical condition or disability. People in this group may include:

- *A spouse with a chronic illness or an acquired disability*
- *A child with a developmental disorder transitioning to adulthood*
- *A family member with complex needs, who requires assistance to live on their own*

Supporting adult family members with complex needs or sustaining your own health and well-being as a person with special needs may involve collaboration with a variety of support systems and community-based services. Assistance may include access to nonclinical case management, referrals to mental health services and public benefits, and provision of assistive technology and adaptive equipment to help with overcoming limitations.

THE ADULT CHILD WITH SPECIAL NEEDS

An adult child with special needs:

- *May receive academic services through an individualized education program, or IEP*
- *May require transition support as they reach the age of majority*
- *May remain under guardianship or incapacitated adult status*
- *May require assistance to live on their own*

MILITARY RESOURCES AND SUPPORT

There are a number of military programs and resources available to support service members as they carry out their duties. These programs and resources include:

- *Military and Family Support Centers:* **www.militaryonesource.mil/non-medical-counseling/military-and-family-life-counseling/the-military-and-family-life-counseling-program**
- *Exceptional Family Member Program:* **www.militaryonesource.mil/special-needs/efmp**
- *Plan My Move:* **https://planmymove.militaryonesource.mil**
- *Military Deployment Support:* **www.militaryonesource.mil/deployment/on-deployment/military-deployment-support**
- *Special Care Organizational Record for Adults With Special Health Care Needs:* **www.militaryonesource.mil/products/special-care-organizational-record-for-adults-with-special-needs-downloadable-142**
- *Personal Financial Management Program:* **www.militaryonesource.mil/benefits/personal-financial-management-counseling-options**
- *Family Advocacy Program:* **www.militaryonesource.mil/benefits/personal-financial-management-counseling-options**
- *Relief societies: Army Emergency Relief* **(www.militaryonesource.mil/benefits/personal-financial-management-counseling-options)** *Navy-Marine Corps Relief Society* **(www.nmcrs.org)** *and Air Force Aid Society* **(www.afas.org)**
- *Service-sponsored websites: Army OneSource* **(www.armymwr.com/programs-and-services/resources/army-onesource)** *Marine Corps Community Services* **(www.usmc-mccs.org)** *Fleet and Family Support Program* **(https://ffr.cnic.navy.mil/Family-Readiness/Fleet-And-Family-Support-Program)** *and Air Force Personnel Center* **(www.afpc.af.mil)**
- TRICARE Extended Care Health Option: **https://tricare.mil/echo**

EQUAL OPPORTUNITY FOR INDIVIDUALS WITH SPECIAL NEEDS

Civilian and military advocates who worked to bring about legal, medical and social changes to address the needs of individuals with special needs, have paved the way for improved services and resources in many areas. These groups have encouraged the passage of three important laws:

- *Individuals with Disabilities Education Act:* **https://sites.ed.gov/idea**
- *Americans with Disabilities Act:* **www.ada.gov**
- *Section 504 of the Rehabilitation Act of 1973* **(www.dol.gov/agencies/oasam/centers-offices/civil-rights-center/statutes/section-504-rehabilitation-act-of-1973)** *and Section 508 of the Rehabilitation Act of 1973:* **www.section508.gov**

For more information about how to receive assistance, visit the Department of Health and Human Services website at **www.section508.gov**

INDEPENDENT LIVING

Support for managing daily life is available to military families. Service members can receive assistance in the following ways:

- *Assistive technology as workplace accommodations – Computer/Electronic Accommodations Program, also known as CAP:* **www.cap.mil**
- *Housing assistance programs – Department of Housing and Urban Development:* **www.hud.gov/topics/information_for_disabled_persons**
- *Home-based services – TRICARE ECHO Home Health Care:* **https://tricare.mil/Plans/SpecialPrograms/ECHO/EHHC**
- *Home modifications and assistive technology – Veteran Affairs:* **https://benefits.va.gov/homeloans**
- *Supported living arrangements*
- *Long-term living arrangements*
- *Relief societies: Army Emergency Relief* **(www.militaryonesource.mil/benefits/personal-financial-management-counseling-options)** *Navy-Marine Corps Relief Society* **(www.nmcrs.org)** *and Air Force Aid Society* **(www.afas.org)**

To find more resources and information to support your family member with special needs:

- *Download the Defense Department Guide for Adults With Special Needs:* **www.militaryonesource.mil/products/guide-for-adults-with-special-needs-141**
- *Download the Support Services for Adults with Special Needs Fact Sheet:* **www.militaryonesource.mil/products/support-services-for-adults-with-special-needs-fact-sheet-968**
- *Visit Center for Parent Information and Resources:* **www.parentcenterhub.org**
- *Visit* **SSA.gov** *to get information on potential benefits for you and your family.*

Military OneSource special needs consultants **(www.militaryonesource.mil/specialty-consultations/special-needs-consultations/special-needs-consultants)** can answer your questions and concerns about the care and education of your child or adult family member with special needs. Call us at 800-342-9647. OCONUS? View calling options. •

– Military OneSource

FELINE FRIENDSHIP: Mojito was adopted by this veteran through the Pope Memorial Humane Society - Cocheco Valley and Chris' Hero Pets.

PET ADOPTION PROGRAM HELPS VETERANS WITH PTSD

BY COLLEEN LENT, M.ED., M.S.

When Jo-Ann Clark, a Goldstar mother from New Hampshire, reflects on memories of her son U.S. Army Spc. Christopher Journeau, she finds it difficult to pick a favorite.

Clark recalls her musical child playing the harmonica as his pet ferret Ginger showcased her dance moves. Visions of her son riding his mountain bike on rocky trails, sharing laughs during family lakeside trips, and testing his mental mettle with video games also take center stage.

PHOTO COURTESY POPE MEMORIAL HUMANE SOCIETY - COCHECO VALLEY

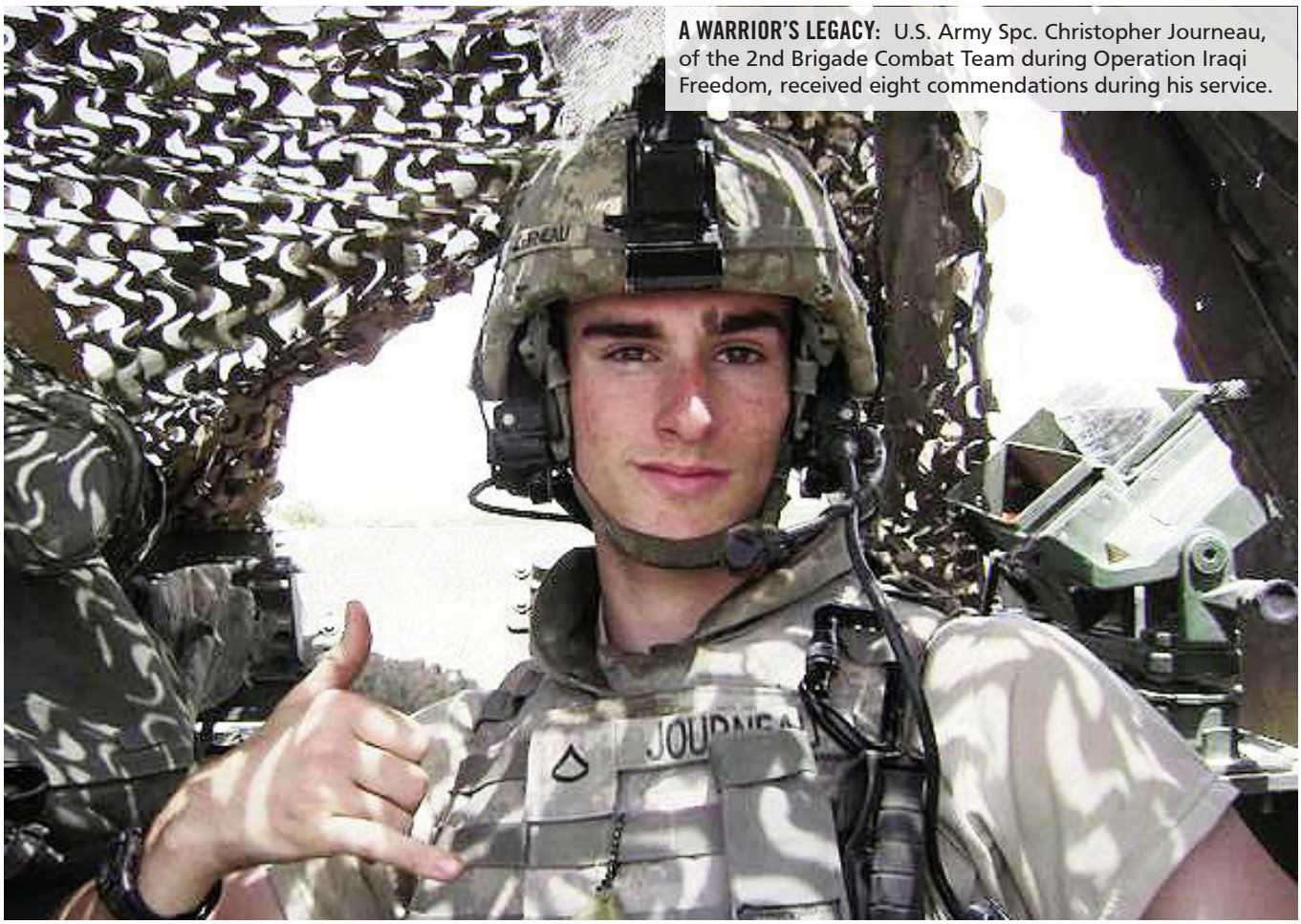
When Christopher decided at age 19 to serve his country in Iraq, replaying indelible mental images of her son kept Clark company while he was deployed overseas.

Clark anticipated Christoper's return to civilian life in January 2010. Her son had earned eight service commendations. He was prepared to find a Native American dog as a buddy and embark on a career as an air marshal or state trooper. Unbeknownst to the veteran's family and friends, an unwelcome foe followed Christopher home, thwarting the veteran's dreams and reunion with his loved ones. Christopher began struggling with bouts of anger, insomnia, depression, isolation, and drinking. "I didn't even know what was going on," Clark says, referring to behaviors that were uncharacteristic of her son.

Five months after serving as an infantryman in the 2nd Brigade Combat Team during Operation Iraqi Freedom, Christopher took his own life at age 23. He had undiagnosed post-traumatic stress disorder, his mother says. Fueled by grief and a quest for answers, Clark researched PTSD symptoms and treatment options to help other veterans. Her discoveries led to the creation of Chris' Hero Pets in 2022 to make it easier for veterans to adopt a companion pet through a local animal shelter and create awareness about the early signs of PTSD.

"Chris' Hero Pets makes it easier for veterans to adopt a companion pet through a local animal shelter and create awareness about the early signs of PTSD."

An article, "8 Health Benefits of Having a Pet," by the Animal Health Foundation[1] supports Clark's research findings that a nonhuman buddy offers individuals mental health assistance. The nonprofit says that pet ownership can reduce cortisol, the stress hormone that can lead to fatigue, anxiety, high blood pressure, and other conditions if left unchecked. The AHF article asserts that people caring for pets have a better chance of sidestepping depression. As pet owners, they become more active. They also have opportunities to socialize with a living creature, even when interacting with family and friends is difficult. In its online article "Dogs and PTSD," The U.S. Veterans Administration's National Center for PTSD also contends that canines can help veterans deal with some parts of PTSD, especially when pet ownership is part of a multi-faceted treatment plan.[2]



A WARRIOR'S LEGACY: U.S. Army Spc. Christopher Journeau, of the 2nd Brigade Combat Team during Operation Iraqi Freedom, received eight commendations during his service.

PHOTO COURTESY JO-ANN CLARK

Clark gathered information about the steps veterans must take before obtaining a companion pet through charitable organizations. The application process was complicated, and the waiting lists were lengthy in many cases. Knowing swift intervention is needed to assist a veteran with PTSD, Clark created the Chris' Hero Pets program with a simplified and quicker application procedure to allow veterans to select a companion pet from a participating shelter. Interested veterans simply need to show their DD-214 or DD-256 discharge paperwork or military identification and then pick a rescue pet. Chris' Hero Pets pays the adoption fee. "If you show you served, you deserve a pet," Clark says. As a program under Hero Pups of Exeter, Clark says Chris' Hero Pets caters to the needs of veterans who may be seeking an animal companion instead of a formally trained support dog. Since Chris' Hero Pets was launched three years ago, 155 veterans have received a pet through the program. Clark says she enjoys hearing anecdotes or seeing photos of veterans with their adopted pets. They have included dogs, cats, rabbits, and other shelter animals. "That's part of the healing process for me," Clark says, referring to how Chris' Hero Pets is giving hope to veterans and homeless animals alike. "On one hand, I'm so happy. On the other hand, I want to cry."

Through the periodic tears that fall when Clark longs to hear Christopher's guitar rendition of Pink Floyd's "Wish You Were Here," the Goldstar mother says that spending time with Mother Nature as her son often did, provides comfort. Recently, a hummingbird flew into a window at Clark's home. The feathered wayward visitor, a symbol of resilience in some cultures, fluttered away after Clark held it in her hand for a few moments. The veteran parent believes the incident was a sign from Christopher that the program created in his memory is making a difference in the battle against PTSD.•

HEALING AND GIVING HOPE : CHRIS' HERO PETS

CHRIS' HERO PETS

A program that makes companion animals more accessible to veterans, dedicated to the memory of Christopher Allen Journeau

https://heropups.com/chris-hero-pets

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1. 8 Health benefits of having a pet. The Animal Health Foundation. (2012, October 6). Animal Health Foundation. https://www.animalhealthfoundation.org
2. VA.gov; Veterans Affairs. (2022, November 8). https://www.ptsd.va.gov/gethelp/dogs_ptsd.asp

ABOUT THE AUTHOR:

As a longtime journalist and educator, Colleen Lent has written over 1,000 articles for more than 20 different publications, including The New Hampshire Journal of Education and Woman's World. She earned an excellence in teaching award from Southern New Hampshire University and a first-place health reporting award from the New England Newspaper and Press Association. Colleen holds a Master of Science degree in communications from Clark University and a Master of Elementary Education degree from Southern New Hampshire University. One of her fondest professional experiences was teaching veterans enrolled in undergraduate courses at Southern New Hampshire University and Manchester Community College. Colleen volunteers for Help R Heroes of Nevada.


Veterans,
when you're struggling,
soon becomes
later becomes
someday becomes
...when?
Don't wait. Reach out.
Whatever you're going through,
you don't have to do it alone.
Find resources at VA.GOV/REACH
ad COUNCIL
VA
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Owning Our Story

When we were trying to figure out what was going on with our son, we couldn't see ten feet in front of us. Now I see that we were able to maneuver the minefield of barriers to care.

One thing that is constant in life is change. Nothing in life seems to stay the same, which includes anything that has to do with autism. I sat down with Broden's new team for our monthly parent meeting. About 5 months ago, Broden's BCBA, whom I adored, left the clinic to teach at a university. Her leaving meant that Broden would have a new BCBA on his team, and I would need to establish a new relationship to ensure we were implementing goals that were best suited for Broden. After a few months passed, I got word that a new BCBA was moving to our clinic and, most likely, Broden would be moved to his caseload. He was an experienced BCBA who was moving up from Florida and had experience working with adults.

The first time I met him, I could tell he was eager to get moving and learn about all the clients on his caseload. At the first parent meeting, he just sat in and observed. We discussed typical behaviors that Broden had exhibited in the past, many of which were due to the need for him to control his environment. His OCD has been quite noticeable in his fascination with peeling stickers from clothing tags and other items around the house, and then sticking them to our bathroom counters. I speculated that Broden was experiencing change, and that this was his way of processing what was happening around him. His new BCBA listened carefully, and said he would be conducting a lot of observations. He would then slowly make some changes to see how Broden would respond. I agreed to the plan if it was done slowly because, with Broden, if we change anything too quickly or change too many things, then we tip the applecart. I've witnessed it before with severe SIB (self-injurious behavior) and screaming. I don't want to go through that minefield, if I can avoid it.

SEASONS OF CHANGE: Broden checks out the neighborhood Christmas lights; "Nothing in life seems to stay the same, which includes anything that has to do with autism."

Our second parent meeting still had our interim BCBA running the meeting, and Broden's new BCBA was still observing. A few days beforehand, we had been notified that TRICARE had refused to continue paying our respite provider their usual rate, so I had received a phone call stating that Broden would no longer have respite. TRICARE did not tell us – the provider had called to tell us the news. This forced us to scramble and notify several entities that this would not only affect us, but every TRICARE family who was using this provider. Due to Broden's supports being pulled out from underneath him, my fun meter had been used up before I stepped into the meeting with Broden's interim BCBA and the new BCBA that would be taking over his program.

His BCBA running the parent meeting leaned her elbows on the table and asked, "How is showering going? I know you've been working on that for a while."

PHOTO PROVIDED BY SHELLY HUHTANEN

Exhausted and burned out, I stated bluntly, "I quit. I'm basically showering him now, because I can't seem to get him to do it. I'll try again later." Both BCBA's stared at me and didn't say anything. There was an uncomfortable silence that had fallen in the tiny room, where only a small table and four chairs were placed. Broden's new BCBA took a deep breath and then asked, "Shelly, how many BCBAs has Broden had?" No one has ever asked me that question before. Broden has been in ABA for almost 17 years. "I have no idea. I'm going to say a lot." His current BCBA looked across the table and said, "Well, Broden has had 5 BCBAs since 2019." The new BCBA's eyebrows raised, "Ok, can you tell me some history? I know you've had to do this so many times, but everyone has a story. What is Broden's story?"

> "Mark came home and said, 'You look exhausted.' I looked up from the counter. 'I had a parent meeting and had to relive the experiences of finding out Broden had autism.'"

Unfortunately, I had been asked that question too many times to count. I gave him the short version starting with us first thinking he was deaf to fighting for an Auditory Brainstem Response (ABR) test, to finally realizing we needed a referral to a developmental pediatric team. I couldn't leave out the tasty tidbit that I threatened to throw myself out of a hotel window in order to find out that my son possibly had autism. I didn't learn that possible diagnosis from a doctor; I had called an early childhood development program in Nebraska and insisted the front office let me speak to their director. I have learned that, sometimes, dire situations require extreme emotional threats when it comes to my child.

I explained Broden's strict diet and my OCD styled lunch I pack for him each day. I explained how his low weight was a mystery to conventional medicine. The only option was to pump Broden full of steroids, if I couldn't find a way for him to maintain and then gain weight. In a panic, I was running door-to-door on Grierson Street at Fort Leavenworth trying to figure out if anyone had experienced their child not able to gain weight with a diagnosis of autism. I finally found a chaplain's wife unloading her groceries from her car. After telling her Broden's story, with a bag in her hand she stopped and said, "Wait, I know someone. I have a friend that has a son with autism who was tiny. They saw an allergist in town. I'll have her call you." Because of my neighbor, I connected with an allergist who tested Broden's hair, stool, blood, and urine. We realized that he had a long list of food allergies and intolerances. With the introduction of a high caloric food supplement and a strict diet of foods his body could tolerate, Broden was able to maintain his weight, thus keeping him from being pumped with steroids.

After 45 minutes of stories about Broden, our parent meeting was over. Broden's team was quiet, and I was emotionally drained. Broden and I finally were able to head back home. I felt like I had relived those experiences all over again. Mark came home from work and saw me standing in the kitchen cutting up Broden's fruit for dinner, "You look exhausted." I looked up from the counter, "I had a parent meeting and had to relive the experiences of finding out Broden had autism." I didn't need to say anything else to him, "Oh man, that sounds exhausting. Go lay down. I got Broden's dinner."

I took his offer and slowly dragged myself upstairs. I turned off the lights and laid on the bed for about an hour. We've been through a lot to get to where we are today with Broden. Change is inevitable, but looking back when we were frantically trying to figure out what was going on with our son, we couldn't see ten feet in front of us. Now I see that, as everything unfolded, we were able to maneuver the minefield of barriers to care, including military moves and transitions. We're still doing it today, we're just older and hopefully a little more wise. •

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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Be a mentor by inspiring young people with disabilities to dream big and achieve their aspirations.

Learn more about the important role family and educators play in helping young people with disabilities develop high expectations for themselves.

What can YOU do?

The Campaign for Disability Employment

www.whatcanyoudocampaign.org

AAPD American Association of People with Disabilities · NBDC · NCLR National Council of La Raza · NGLCC America's LGBT Chamber of Commerce · SHRM Society for Human Resource Management · Special Olympics Be a fan. · USBLN Business Leadership Network Disability at Work · ODEP · JAN Job Accommodation Network

The Campaign for Disability Employment is funded under contract #DOLJ079426341 from the Office of Disability Employment Policy/U.S. Department of Labor.

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