PLUS: **UNITED STATES MILITARY SECTION**

EXCEPTIONAL PARENT • PHYSICIAN • PATIENT • PEOPLE

ep

EXCEPTIONAL PARENT
MAGAZINE
MARCH 2024
$14.95

VISION, HEARING AND SPEECH:

ENHANCING COMMUNICATION SKILLS *in* SPECIAL EDUCATION

PLUS • IDD AND AGING:

IDENTIFYING VISION *and* HEARING CHANGES

AND • EARLY INTERVENTION:

UNLOCKING POTENTIAL

LAYLA TAMIMI:

THE POWER OF PERSEVERANCE

MONTCLAIR STATE UNIVERSITY GRADUATE SPOTLIGHT

ALSO:

JUST BECAUSE SOMEONE IS NONVERBAL DOESN'T MEAN THAT THEY DON'T HAVE SOMETHING *to* SAY

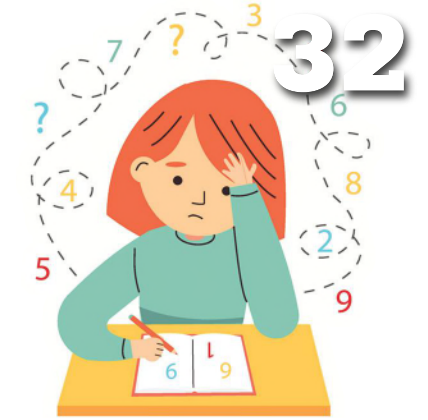
EP MAGAZINE
1971 2024
53
YEARS
CELEBRATES

CONTENTS

MARCH 2024 VOLUME 54 ISSUE 3

VISION, HEARING AND SPEECH

FEATURES



ON OUR COVER

EP Magazine presents Layla Tamimi and her uplifting story, from suffering a debilating paralysis and stroke to graduating this past January with honors from Montclair State University (*Photo credit: John J. LaRosa for Montclair State University).* In addition, we focus on vision, hearing and speech and how these impact the development and education of people with special needs.

CONTENTS

MARCH 2024 VOLUME 54 ISSUE 3

DEPARTMENTS

MILITARY SECTION

GET SOCIAL WITH EP MAGAZINE

Stay current with Exceptional Parent Magazine. New issue updates, exclusive article excerpts, and inspiring and helpful content for the special needs community.

FOLLOW US TODAY ▪ SHARE OUR POSTS ▪ RETWEET

FACEBOOK

facebook.com/
exceptionalparentmag

FOLLOW EP ON TWITTER

[NEW TWITTER ADDRESS]
twitter.com/epmzine

INSTAGRAM

instagram.com/epmzine

SUBSCRIBE FOR FREE AT EPMAGAZINE.COM

The Power to Persevere

"We just have three things we have to do when we're at a halt in life," says Layla Tamimi. "Accept, adjust and adapt."

This month, we are pleased to present the incredible story of Layla Tamimi, whose remarkable odyssey took her from being paralyzed from the neck down and in a medically induced coma to graduating with honors from the College of Community Health at Montclair State University this past January.

Vision, Hearing and Speech is the focus of several articles appearing in this March issue. "In the realm of special education, fostering communication skills is key for the holistic development of students," Jenn Adams writes in her piece entitled "Enhancing Communication Skills in Special Education: A Comprehensive Guide." "As professionals and caregivers, we understand the significance of effective communication in unlocking a world of opportunities for our learners." In her article "Unlocking Potential," mental health therapist Gaby DiFilippo encourages parents and children who are struggling with learning disabilities to take advantage of early intervention programs and offers expert advice to help build a comprehensive understanding of the child's needs. She states "You can empower your kids that they have a superpower within them and that they can do anything they want to. I am glad for my learning disabilities and all the experiences that I have had with them."

> In the realm of special education, fostering communication skills is key for the holistic development of students.

In addition, we offer informative articles on dyslexia, dyscalculia, and tips for parents and early childhood education teachers to better work together.

As always, we request that you share our magazine with friends, family, coworkers and colleagues who might benefit from our substantial content. Your comments, suggestions, and questions are welcome at **epmagazinevp@gmail.com** or **fsimon@epmagazine.com** Your feedback is helpful, as we want to cover topics that help as many people as possible.

We are always trying to let everyone know that this quality information is free, and we appreciate all of you: individuals, businesses, organizations, and social media groups that have been sharing about Exceptional Parent Magazine and EP for Free.

For those of you in New Jersey, EP Magazine will have a table at three events (two in March and one in May). They will be posted on our social media. Come say "hello."

Follow us on **facebook.com/exceptionalparentmag**, Instagram **@epmzine** and **twitter.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

VOLUME 54 ISSUE 3
ESTABLISHED 1971

Publisher
Len Harac
lharac@epmagazine.com

Editor In Chief
Faye Simon
fsimon@epmagazine.com

Art Direction & Design
Leverett Cooper
lev@foxprintdesign.com

Subscriber Services
1360 Clifton Avenue, Ste. 327, Clifton, NJ 07012
www.epmagazine.com

Customer Service/New Orders
Faye Simon fsimon@epmagazine.com
(973) 726-6218

Publishing & Editorial Office
1360 Clifton Avenue, Ste. 327
Clifton, NJ 07012

EXCEPTIONAL PARENT MEDIA

Exceptional Parent (ISSN 0046-9157) is published monthly 12 times per year including the special January EP Guide - Navigating Special Needs Resources by Exceptional Parent Magazine, 1360 Clifton Avenue, Ste. 327, Clifton, NJ 07012 Internet address: www.epmagazine.com. All rights reserved. Copyright ©2024 by Exceptional Parent Magazine,. Exceptional Parent™ is a registered trademark of Exceptional Parent Magazine. Postmaster: Please send address changes to: Exceptional Parent,1360 Clifton Avenue, Ste. 327, Clifton, NJ 07012. Any applicable periodical postage paid at Clifton, NJ and additional mailing offices (USPS 557-810). Basic annual subscription for EP Digital is free. Limited edition print subscription $199.00. Subscriber Service: Direct all inquiries & address changes to: Exceptional Parent, 1360 Clifton Avenue, Ste. 327, Clifton, NJ 07012 08758. Customer Service/New Orders: E-mail: fsimon@epmagazine.com or call (973) 726-6218. Back issues incur a charge of $17 each with shipping, (January issue $20 when requested) and depend upon availability. Call (973) 726-6218. Agreement #1420542

WHAT'S HAPPENING

NEW JERSEY TO SPEND $6 MILLION TO MOVE PEOPLE WITH DISABILITIES TO COMMUNITY BASED LIVING

New Jersey's Division of Developmental Disabilities announced $6 million in funding Wednesday to build and upgrade homes for people with disabilities currently living in nursing homes, said the Department of Human Services, which oversees the DDD.

SHARED SPACE: The initiative signifies a shift towards more inclusive, community-based living.

In a momentous move, New Jersey's Division of Developmental Disabilities has announced a $6 million funding initiative aimed at enhancing living conditions for individuals with developmental disabilities. The funding emphasizes New Jersey's commitment to creating an inclusive society and improving community infrastructure for individuals with developmental disabilities. This initiative will facilitate the construction and upgrade of homes for approximately 100 people currently residing in nursing homes, enabling them to lead more independent lives within their communities.

Funding of up to $60,000 per bed, with a maximum of $240,000 for each home, will be available, the announcement said. Last year, a similar initiative saw an investment of $5 million.

A report issued by the advocacy group Disability Rights New Jersey last October highlighted the plight of hundreds of people with developmental disabilities who are placed in nursing homes lacking adequate oversight and resources.

While the funding initiative is being hailed as a positive step, advocates like Mercedes Witowsky from the New Jersey Council on Developmental Disabilities are emphasizing the need for improved oversight and infrastructure.

"Funding alone cannot solve the problem," Witowsky stated. "We need to ensure that there is proper oversight in place and that our infrastructure can support these community-based living arrangements."

Witowsky's sentiments echo the broader concern about creating sustainable solutions for the long-term care of individuals with developmental disabilities. The focus is shifting towards building inclusive communities where everyone, regardless of their abilities, can lead fulfilling lives.

For many, the announcement brings a glimmer of hope. It signifies a shift away from institutionalized care towards more inclusive, community-based living arrangements. However, it also serves as a reminder of the work that still needs to be done.

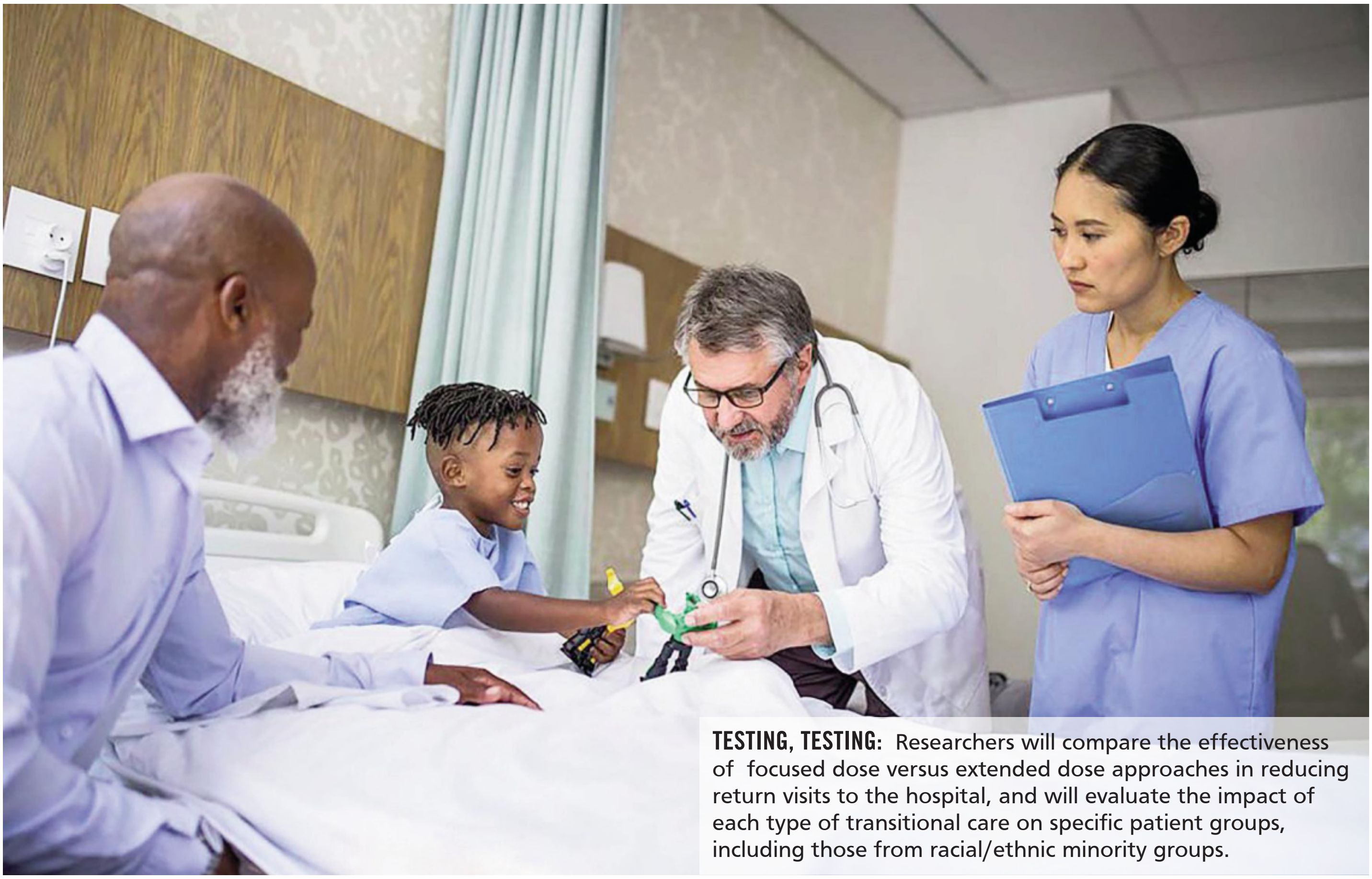
As New Jersey continues to strive towards creating a more inclusive society, the $6 million funding initiative stands as a testament to its dedication. But as advocates rightly point out, it's just one piece of the puzzle. Comprehensive change requires not only financial investment but also systemic transformation.

Organizations interested in applying must be licensed and meet standards that include financial stability, no compliance issues over the past three years and no conflicts between personal interests and their responsibilities to the project.

As the state continues to invest in such initiatives, it sets an example for others to follow, reaffirming the belief that every individual deserves a life of dignity, respect, and inclusion. For futher information about the Division of Developmental Disabilities initiative, please visit **www.nj.gov/humanservices/providers/grants/nofa/NOFAfiles/SNF%20NOFA%20(002).pdf**

WHAT'S HAPPENING

SUPPORTING CHILDREN AND CAREGIVERS DURING TRANSITIONS FROM HOSPITAL-TO-HOME



TESTING, TESTING: Researchers will compare the effectiveness of focused dose versus extended dose approaches in reducing return visits to the hospital, and will evaluate the impact of each type of transitional care on specific patient groups, including those from racial/ethnic minority groups.

CYSHCNet Researchers Receive $5.5 Million from PCORI to Compare Transitions Across Settings for Children and Youth with Special Health Care Needs.

After a child's hospital stay, the transition back home can be risky – particularly for children with chronic health issues and complex medical conditions. To understand how to best support children and youth with special health care needs (CYSHCN) and their caregivers, CYSHCNet researchers received funding for a multi-site study comparing two types of hospital-to-home transitional care.

Nearly one in five children (almost 14 million) in the United States have a special health care need. These children face unique health challenges that may require hospitalization.

"Past studies have shown the benefits of supporting patients and families with transitional care support," said Principal Investigator Dr. David Y. Ming. "This will be the first study to address the knowledge gap specifically for hospital-to-home transitional care for CYSHCN."

The study is funded by the Patient-Centered Outcomes Research Institute (PCORI **www.pcori.org/research-results/2023/hospital-home-care-coordination-children-and-youth-special-healthcare-needs**) and will compare two types of hospital-to-home transitional care for CYSHCN to optimize outcomes. Over a one-month post-discharge period, researchers will:

1. *Compare the effectiveness of two transitional care approaches – focused dose versus extended dose – in reducing return visits to the hospital or emergency department and increasing parent-reported confidence.*
2. *Evaluate the impact of each type of hospital-to-home transitional care on specific CYSHCN patient groups, including those with highly-complex clinical needs and those from racial/ethnic minority groups or living in rural areas.*
3. *Investigate how and why each approach to hospital-to-home transitional care is effective and for whom they work best.*

The study team includes multiple community partners, including parents and caregivers with lived experience, clinicians, policymakers, and health system leaders. A community advisory board, primarily composed of a diverse group of parents/caregivers of CYSHCN, will work closely with the research team throughout the study. This collaborative effort aims to contribute to the equitable improvement of overall care for all CYSHCN transitioning from hospital to home."

"This project was selected for PCORI funding not only for its scientific merit and commitment to engaging patients and other healthcare stakeholders, but also for its conduct in real-world settings. It has the potential to answer an important question about hospital to home transitions for CYSHCN and fill a crucial evidence gap," said PCORI Executive Director Nakela L. Cook, M.D., MPH. "We look forward to following the study's progress and working with Duke University to share its results."

CYSHCNET RESEARCHERS

Dr. David Ming's award has been approved pending completion of a business and programmatic review by PCORI staff and issuance of a formal award contract.

- Dr. David Y. Ming (Principal Investigator): Duke University School of Medicine
- Dr. Neal deJong: University of North Carolina at Chapel Hill School of Medicine
- Dr. Ryan Coller: University of Wisconsin School of Medicine and Public Health

This project is supported by the Health Resources and Services Administration (HRSA) of the U.S. Department of Health and Human Services (HHS) under UA6MC31101 Children and Youth with Special Health Care Needs Research Network. This information or content and conclusions are those of the author and should not be construed as the official position or policy of, nor should any endorsements be inferred by HRSA, HHS, and the U.S. Government.

ABOUT CYSHCNET:

CYSHC NET

CYSHCNet brings academic researchers and lived experience partners together to study the health care system issues that matter most to CYSHCN and their families. We help CYSHCN and their families by advancing knowledge and implementation of optimal health systems through innovative, rigorous multi-site studies, far reaching dissemination of findings, meaningful partnerships with families, and strong training of emerging CYSHCN investigators. Learn more: **https://cyshcnet.org**

BanTec SANITIZING
EXPOSURE RESPONSE

BANTEC SANITIZING IS YOUR ALLY IN THE FIGHT AGAINST COVID-19

With efficient and affordable solutions for cleaning and safely sanitizing residential, school and business settings, Bantec Sanitizing can help you prepare for living, learning and working in a safe and healthy environment.

COMMERCIAL AND RESIDENTIAL CLEANING PRODUCTS & SERVICES


HOME


SCHOOL


OFFICE

EXCLUSIVE OFFER

BANTEC DISINFECTING KIT

Easy for anyone to use in multiple environments to protect themselves by disinfecting touch surfaces they encounter throughout the day. Perfect for use between cleanings. Featuring Enviro-Pro ® products which meet the EPA's criteria for use against the novel coronavirus. Each kit contains:

- 3 gallons CleanSmart Enviro-Pro
- 1 1 oz. dispensing pump
- 1 1/8 oz. dispensing pump
- 2 each 32-oz. Enviro-Pro labeled spray bottles
- 2 each spray bottles triggers
- 1 box of disposable gloves
- 1 pack of 12 machine washable microfiber cloths
- 2 each disposable, non-medical face masks
- 1 pack disposable dusting sheets
- Directions, tips and more.

Clean Smart

www.bantec.store/products/bantec-disinfecting-kit

INDUSTRY INNOVATOR

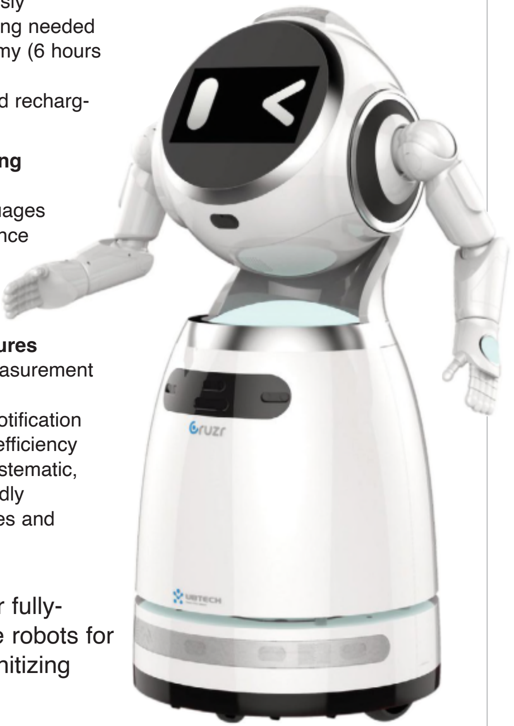
BANTEC AUTONOMOUS SOLUTIONS

Bantec Sanitizing has expanded its variety of products and services to help facility managers, safety professionals, and maintenance personnel to include autonomous health monitoring, sanitizing and teaching self-driving humanoid robots. Systems such as the Cruzr Health Monitor, below, can improve workplace safety and present helpful information.

Autonomous Mobile Solution
- Navigates autonomously
- No manual repositioning needed
- Up to 8 hours autonomy (6 hours to recharge)
- Automatic docking and recharging

Interactive and Engaging Humanoid Robot
- Speaks multiple languages
- Detects human presence
- Deploys information (text, pictures, videos and more)

Heath Monitoring Features
- Body temperature measurement and notification
- Mask detection and notification
- Increases workplace efficiency
- Engaging, reliable, systematic, tireless and user-friendly
- Reduces infection rates and associated costs



Learn more about our fully-programmable mobile robots for health monitoring, sanitizing and education:

https://bantec.store/products/cruzr-health-monitor

BanTec SANITIZING EXPOSURE RESPONSE | A DIVISION OF BANTEC

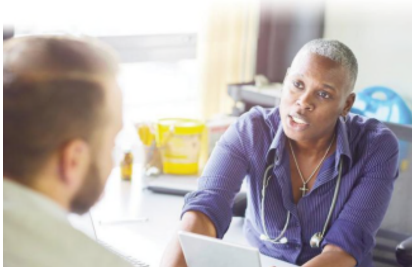
www.bantec.store

WHAT'S HAPPENING

THREE-FOURTHS OF STATES HAVE WAITING LISTS FOR SOME MEDICAID HOME CARE PROGRAMS

Worker shortages could worsen states' waiting list times, which currently average three years.

In a new analysis of survey data from state Medicaid home care programs, the Kaiser Family Foundation found that in most years since 2016, there have been nearly 700,000 people on waiting or interest lists for expanded home and community-based services (HCBS), with a total of 692,000 across 38 states in 2023 and waiting lists averaging three years.



People with intellectual or developmental disabilities make up almost three-quarters of waiting lists. People on waiting lists may not have access to increased hours of home care to support activities such as bathing, dressing, preparing meals and managing medication as well as increased types of community care, such as adult day care and supported employment, which are often designed to meet the needs of specific populations.

States can cap enrollment for these services, resulting in waiting lists (also described as "interest lists") for expanded home care programs when demand surpasses the available slots. While these lists are an imperfect measure of unmet need, there are currently no alternative measures.

Home care waivers that allow states to offer these services have been in place since the 1980s, but their use increased after the Supreme Court's Olmstead decision in 1999, which characterized the unjustified institutionalization of people with disabilities as illegal discrimination. As the 25th anniversary of Olmstead nears, people have cited waiting lists as one reason for continued discrimination based on disability.

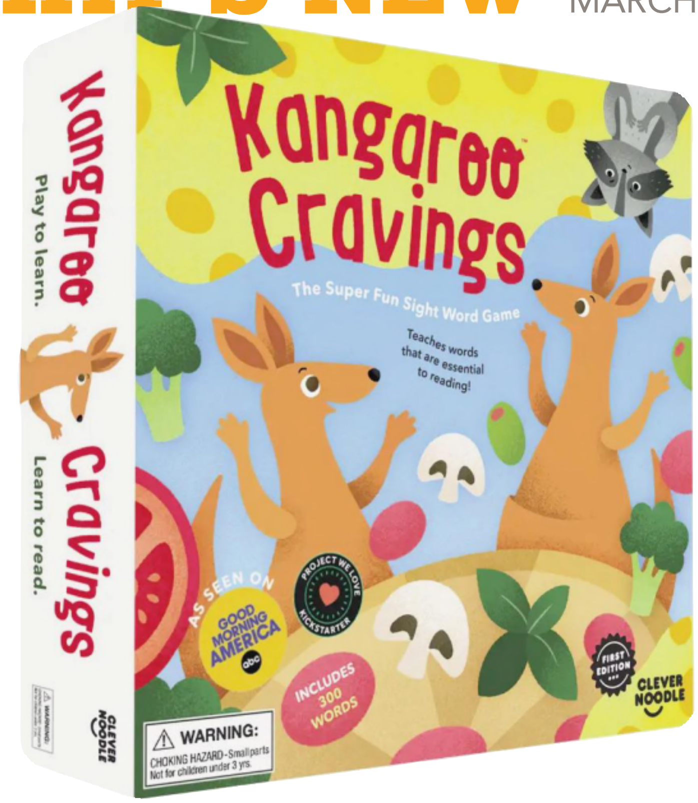
Shortages of home care workers could worsen states' waiting list times. Although states reported increasing provider payment rates and other efforts to bolster the workforce, challenges remain and some state policies for addressing these challenges ended with the conclusion of pandemic-era programs.

Another factor affecting waiting list volumes is whether states screen for Medicaid eligibility before adding people to waiting lists. Between 2018 and 2020, waitlist sizes for expanded home care programs fell by 19% nationally, largely due to eligibility assessments added to waiting lists. Today, all but six states screen their waiting lists for Medicaid eligibility.

Rules proposed earlier this year would require states to report the size of their waiting lists. Learn more about this study at **www.kff.org/medicaid/issue-brief/a-look-at-waiting-lists-for-medicaid-home-and-community-based-services-from-2016-to-2023**

WHAT'S NEW

MARCHING TOWARD SPRING



KANGAROO CRAVINGS

Kangaroo Cravings improves reading fluency, word recognition, memory, concentration, and self-esteem by helping children learn over 300 high-frequency sight words. High-frequency word instruction helps increase a child's ability to read with both speed and ease. Hop along the path to a delicious, cheesy pizza, picking up high-frequency word cards with multi-sensory dancing, singing, acting, and drawing tasks along the way. Play cooperatively to beat the raccoon together, or play competitively for an all-out race.

CLEVER NOODLE

www.clevernoodle.com

FIDDLE STICK

Designed for both kids and adults, Fiddle Stick is a sleek and ergonomic device for anyone. It stays discrete, so you can fidget anywhere, anytime – at school, at the office – you name it! Fidgeting has been proven to increase cognitive ability, concentration and alertness during activities. This makes Fiddle Stick more than a toy. It has nine amazing features, including a soft swivel joystick, a dot matrix array, a finger loop used to spin the stick, a "light'"switch, a worry stone, clicky buttons, a rollerball, a smooth slider, and several spinning cogs. It comes with a LED fidget spinner attachment that you can connect to perform super cool tricks with one hand and burn off all that excess energy. It's a tool to exercise your brain. Each button, switch, slider and spinner are thoughtfully placed on the device. Robust and well made, it will last a a lifetime of enjoyment. Fiddle Stick has benefits that go beyond just FUN!

ELLUSIONIST

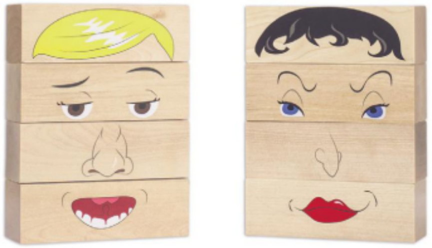
www.ellusionist.com

TALKING FLASH CARDS

These talking flash cards offers double the learning opportunities. Each flash card features different patterns and vocabulary on both sides, allowing kids to learn about animals, vehicles, foods, fruits, colors, vegetables, daily necessities, costumes, nature, persons, jobs, and shapes. Enhances children's language cognitive ability, expands their vocabulary, and allows them to imitate real sounds. It satisfies their curiosity and encourages imaginative play. It can be easily charged using the included USB cable and provides 4 hours of continuous playtime after just 90 minutes of charging.

KIDZ COUNTRY

www.kidzcountry.com



HOW AM I FEELING BLOCKS

Create more than 4,000 face combinations with this simple 8 block set! These blocks are the perfect way to get kids talking about emotions. Each block features colorful illustrations on each side, allowing you to pick between different eyes, mouths, noses, and hairstyles. Encourage kids to identify the emotions they made or build a face to match an emotion-- there are so many ways to play!

NATIONAL AUTISM RESOURCES

www.nationalautismresources.com

Are You Ready to...

- Increase your income?
- Explore your work options?
- Keep your Medicaid/Medicare while you work?
- Gain greater personal fulfillment through work?

Social Security's Ticket to Work program and Work Incentives can help you find meaningful work. If you're age 18 through 64 and you receive Social Security disability benefits, you can take advantage of these free services.

Choose a Ticket to Work employment services provider.
Work with your provider to plan a better future.

Are You Ready to Choose Work?

Information/Resources
Call 1-866-968-7842 or
1-866-833-2967 (TTY)
Visit www.socialsecurity.gov/work
www.facebook.com/choosework

SOCIAL SECURITY ADMINISTRATION

TICKET to Work

EP FOR FREE!

RECEIVE A FREE SUBSCRIPTION TO THE DIGITAL VERSION OF EXCEPTIONAL PARENT MAGAZINE

Simply visit us at

www.epmagazine.com

and click

"EP FOR FREE"

you will receive an email each month when the magazine is published as well as a free newsletter.

Both will come from

news@EPmagazine.com

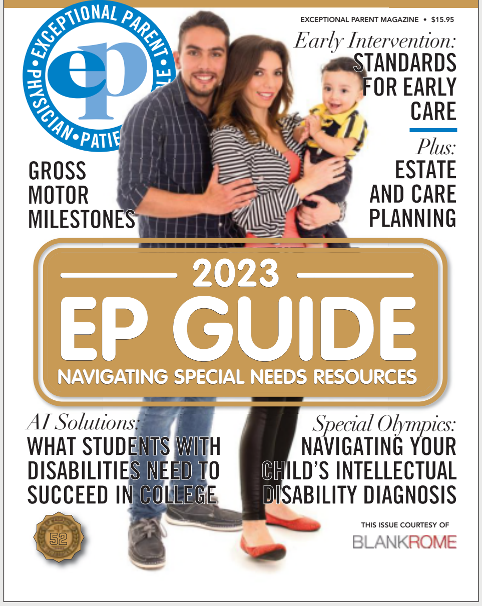
DO NOT REPLY TO THIS ADDRESS.
WE WELCOME YOUR QUESTIONS AND INPUT AT
FSIMON@EPMAGAZINE.COM

Print subscriptions: $199 a year;
Available at www.epmagazine.com
Questions: epmagazinevp@gmail.com

Empowering the
Special Needs
Community
since 1971

Subscribe Today at www.epmagazine.com

EP's ALL-NEW RESOURCE GUIDE FOR 2023



EXCEPTIONAL PARENT MAGAZINE • $15.95

Early Intervention:
STANDARDS FOR EARLY CARE

Plus:
ESTATE AND CARE PLANNING

GROSS MOTOR MILESTONES

2023
EP GUIDE
NAVIGATING SPECIAL NEEDS RESOURCES

AI Solutions:
WHAT STUDENTS WITH DISABILITIES NEED TO SUCCEED IN COLLEGE

Special Olympics:
NAVIGATING YOUR CHILD'S INTELLECTUAL DISABILITY DIAGNOSIS

THIS ISSUE COURTESY OF
BLANKROME

AN AMAZING ADVERTISING OPPORTUNITY

With a dedicated readership and a rapidly expanding audience, more and more advertisers are taking advantage of the unique opportunities that **Exceptional Parent Magazine** can offer. Whether it's a full or half page ad in our print and digital magazine editions, or a dynamic banner ad on our **www.epmagazine.com** website, there has never been a better value enabling your products or services to capture a large and motivated readerhip. Discounts and special offers are available for cross-platform insertions.

We are now offering many additional opportunities for lasting partnerships that can affordably and effectively communicate your brand's message.

For more advertising opportunities, email us at

fsimon@epmagazine.com

UNLOCKING POTENTIAL

BY GABY DIFILIPPO

I am a firm believer that the experiences that we have in life all share a larger purpose. As I get older, the more I believe this to be true. I remember when I was a young child, I was always behind in school. I struggled to be able to understand the material, especially math. I can still recall countless times that I would be watching my classmates finish assignments quicker or sitting at the kitchen table at home, staring at my homework in the hopes that the answers would appear on the page.

BUILDING CONFIDENCE: "As a young child, I thought going to college was not going to happen. However, I was able to do it. I was able to take those skills that I learned at my school and apply them, when I was in college."

Few areas of infant healthcare are as important as newborn screening and early intervention. When it comes to diagnosing and treating babies born with rare diseases, whose symptoms might not be immediately apparent, current comprehensive screening technology has proven to be life-saving.

My parents were aware of these issues, had me switch schools a few times, and always helped me with my homework. My mom was always looking for tutors, learning programs, and reading books to try and understand what was going on with me. My dad spent countless hours doing homework with me and trying to find creative ways to understand the material. My parents were my biggest advocates, they never gave up trying to figure out what was best for me.

By the time I reached middle school, my parents realized that it would be helpful for me to get an academic and cognitive assessment done. When I was 13 years old, I was diagnosed with a few learning disabilities. I remember feeling relieved to know that I was not "stupid" and that I just needed a different type of instruction and learning environment to be successful in school.

After getting diagnosed and after much thought, my parents decided to send me to a special school that was designed for children with learning disabilities. Although it would have been great if done sooner, it was one of the best decisions they ever made. I began to learn different strategies for completing math problems and began to comprehend more of what I was reading. It was awesome! I was actually capable of being able to learn! I learned how to advocate for myself and use strategies that I needed to be successful in school, such as making flashcards or using dialectical programs to help with writing.

Being in school for children with learning disabilities helped me see that I was able to learn and that I was capable of furthering my education. As a young child, I thought going to college was not going to happen. However, I was able to do it. I was able to take those skills that I learned at my school and apply them, when I was in college. I finished my bachelor's and decided that I wanted to be a counselor, so I continued to pursue my master's degree in counseling. Fast forward, I am in the process of finishing my PsyD in School Psychology, with the hope of becoming a school psychologist to assist children with learning disabilities.

Being able to understand school psychology and working towards becoming a future school psychologist has helped me understand how students feel, who are struggling in school, and how to help motivate them so that they can learn. A few weeks ago, one of my teen clients came in for their counseling session and the mom asked if she could speak to me first before her daughter had her session. She discussed that the daughter had recently been diagnosed with some learning disabilities and she was very upset and worried about how her daughter would be emotionally and academically. I disclosed to her that I have a few learning disabilities and understand the struggle, but that her daughter would be just fine. She is going to get the help she needs, to build her confidence and make herself more successful in school. She can do anything even with her disabilities, and since I was studying to be a school psychologist, I could help the mom navigate any Individualized Education Program (IEP) questions, etc.

"HAVING A LEARNING DISABILITY DOES NOT MEAN THAT YOU ARE NOT SMART. IT MEANS YOU JUST NEED TO FIND STRATEGIES AND WAYS THAT HELP YOU LEARN. HAVING A LEARNING DISABILITY DOESN'T MEAN THAT YOU CANNOT LEARN."

At the end of the conversation, the mom said she was "relieved" and glad that we had a conversation. This is one of the many ways that having a learning disability has been beneficial for me in life. Having a learning disability does not mean that you are not smart. It means you just need to find strategies and ways that help you learn. Having a learning disability doesn't mean that you cannot learn. Sometimes, you just have to go a few extra steps to accomplish something, but it is possible. One might need to work harder, but you will get to where you need to go, and you can achieve those goals. You can use your voice to advocate and say what you need. Having a learning disability means that you know what hard work is, and that you never know what you are capable of doing, until you get there. You can empower your kids that they have a superpower within them and that they can do anything they want to. I am glad for my learning disabilities and all the experiences that I have had with them. Every experience we have can help guide us and make us who we are. These experiences that we have can help us with whatever we do in life.

DEVELOPING STRATEGIES : ADVICE FOR PARENTS MONITORING THEIR CHILD'S LEARNING DISABILITY

OBSERVATION AND COMMUNICATION

Parents play a crucial role in understanding their child's struggles. Regularly talking with teachers, counselors, and other professionals helps build a comprehensive understanding of the child's needs. It fosters a collaborative approach, where everyone is on the same page regarding the student's progress and challenges.

DILIGENCE FROM THE START

My journey with learning differences began with my parents' awareness and involvement. Early on, I believe around second grade, they recognized the importance of closely monitoring my educational progress. They had difficulty with payments for psychological testing and believed that tutoring and other extra support would have been helpful, until I was struggling in middle school. Their proactive approach, involving regular discussions with teachers and seeking assessments, laid the foundation for effective support strategies. Although I was happy to get an assessment finally in middle school, I encourage parents to get an assessment earlier than that. I encourage all parents to be diligent from the start, and as early as possible, get an assessment and support for your child. It can significantly impact a child's educational journey.

IEP MEETINGS

Participate actively in Individualized Education Program (IEP) meetings, where the collaborative effort to shape a customized plan occurs. These meetings provide a platform for open communication, allowing parents to share insights into their child's strengths, challenges, and preferred learning styles. The collaboration between parents and educators during IEP meetings ensures that the educational plan is tailored to meet the specific needs of the student.

STRENGTHS-BASED LEARNING

Fostering a strengths-based approach involves recognizing and nurturing the unique talents and abilities of each student. Encouraging students to explore their strengths becomes a cornerstone of building confidence and self-esteem. By shifting the focus from challenges to capabilities, educators and parents contribute to creating a positive and empowering learning environment.

SELF-ADVOCACY SKILLS

Teaching students to articulate their needs and preferences is a skill that extends beyond the classroom. Empowering students with self-advocacy skills allows them to actively participate in their educational journey. This includes expressing their learning preferences, seeking additional support when needed, and developing a sense of agency over their academic path.

CONTINUOUS MONITORING AND ADJUSTMENTS

Regular Assessments:

Ongoing assessments are crucial for monitoring a student/s progress. These assessments serve ascheckpoints to evaluate the effectiveness of interventions and support strategies. Regular evaluations provide valuable insights into a student's evolving needs, allowing for adjustments in the learning protocol to ensure continuous support throughout their academic journey.

Adapting Strategies:

The process of continuous monitoring involves not only assessing academic progress but also adapting support strategies. It requires a collaborative effort between parents, educators, and professionals to identify evolving challenges and implement effective solutions. The flexibility to adapt strategies ensures that students receive the dynamic support needed for their individual learning paths.

Earliest possible assessment is key. It helps kids understand how they learn and get them going for school. It also assists with their self-esteem.

ABOUT THE AUTHOR:

Gaby is a mental health therapist for children and teens. Gaby was diagnosed with a learning disability (LD) when she was 13. She attended a school designed for children with LDs. She went from a child, who didn't think she could learn, to an A student. She learned that her LD was a plus in life and her career. She is currently getting her PsyD in School Psychology and started her own private practice, The Helpful Corner Counseling, LLC.

EVERYONE HAS A VOICE

BY NANCI BENTLEY

THE LANGUAGE OF LOVE: The author with her husband Mike and their son MJ; "Without our family and MJ's educational team learning about DeafBlindness and CVI, our ability to connect with MJ would have been just a hope."

PHOTOS PROVIDED BY NANCI BENTLEY

When I thought of communication, I had always thought of traditional language, hearing a voice, and conversations. This is my journey of communication with my son, who is deafblind. My now 11-year-old son MJ has shown me communication can happen in many ways. A voice can be heard without your ears.

MJ was diagnosed with a rare chromosome disorder, Pallister Killian Syndrome, at six months old. That was when we, as a family, would begin our journey into special needs.

WE SOON LEARNED ABOUT EARLY INTERVENTION, ITS IMPORTANCE, AND COMPLEX CARE.

MJ was not achieving his milestones. He presented with low muscle tone, a cataract and was always quiet. At two years old, he developed epilepsy. There were many unknowns, both medically and developmentally. The unknowns were caving in on us. Milestones were not being met, and the forecast kept getting dimmer.

Among the plentiful amount of information we received through the years, we were told that MJ had a hearing and vision loss. This was when we learned about DeafBlindness. At that time, I perceived DeafBlindness as an inability to see or hear at all. I knew he could see and hear because of some of his responses. I needed to learn more about DeafBlindness.

CAUSE AND EFFFECT: MJ plays with one of his favorite switch adapted toys.

I LEARNED THAT DEAFBLINDNESS IS WHEN YOU THINK OF COMBINED HEARING AND VISION, ALSO KNOWN AS DUAL SENSORY LOSS, AS A SINGLE CONDITION.

DeafBlindness encompasses a spectrum from mildly hard of hearing plus mildly visually impaired, to totally deaf and blind, or combinations of the severity of vision and hearing loss.

All of MJ's needs had to be considered when treating DeafBlind, including communication. It was a multi-disciplinary approach. I had to learn how input/output happens simultaneously with our eyes and ears. I learned this would impact everything MJ does developmentally, and how this would impact his access to his environment. Keeping the impact of DeafBlindness at the forefront of our minds has been transformational for MJ accessing communication and the environment.

Vision and hearing are foundational for development. I encourage everyone to think about all that happens with their eyes and ears in just one minute. You may be sitting in a room where the acoustics are loud and visually crowded. It can be overwhelming, and you may lose focus. Think about when you have to turn the TV or music down, so you can read something or just focus on what you are doing. These examples could be what everyday life can look like for an individual with DeafBlindness. Imagine trying to balance auditory and visual input all day. For most of us, our neurological system does that for us.

I had been given several prognoses for MJ, including the possibility of him communicating, would be little to none. Hearing this as a parent was gut-wrenching. My son would not talk with me. Some providers did not have hope that he would connect with his environment. I could see the determination when I looked into his eyes. He would show us he was connected.

When he was about a year old, MJ began to respond a little to light-up toys, sounds, and music. He never reached for anything and always kept his hands close to his body. He never seemed to be looking directly at an object. Everything became trial and error. We were hanging onto every little bit of hope that MJ would communicate with us. Every little sound, from a giggle to a grunt, was studied. We kept wanting him to meet us where we were, instead of meeting him where he was. We had to change our way of thinking. At this time, MJ began working with a Teacher of the Visually Impaired (TVI), and we received a sensory box (the "site of senses box") with items hanging from it. The purpose of the sensory box was to give MJ the opportunity to experience cause and effect, offer different types of movement, auditory and visual input. There are wooden items that may not make much sound and shiny metal spoons clanking, that may feel different to the touch. The ability to use multiple senses is endless, when the right items are chosen. The sensory box offers the ability to choose the input in an independent way. We never force MJ to touch anything. We would lay MJ in there, and he would not touch anything. He would look, but you could see his eyes were not entirely focused on anything. I was ready to donate this sensory box. It was just another trial that did not work.

Then suddenly, one day after about six months, he reached for these little shiny mini wind chimes. It was magical; he made independent, purposeful movements and communicated through play. He was engaging in his environment. That was it. The light bulb went off, and it was truly communication through play. We learned MJ was attracted to shiny items from this box. From there, he grew and continued manipulating items in this sensory environment, while vocalizing, playing, and moving independently. He is now 11 and still scoots his way into this box and independently plays. His sensory box has enriched his life in many ways. It has helped him find his independence and confidence, to go outside his personal space. This sensory box gave us so much information on what MJ prefers. We used play to help MJ learn choices, and cause and effect. We advanced to holding preferred play items up (light up, musical, shiny toys) and MJ would visually look at preferred items. Eventually he was reaching for them as well.

WE LEARNED THAT MJ NEEDED TIME TO PROCESS AND WE NEEDED TO BE PATIENT. ALLOWING PROCESSING TIME HAS BEEN A FOCUS FOR US THROUGHOUT OUR JOURNEY.

At about three years old, MJ was introduced to the New York Deaf-Blind Collaborative (NYDBC), which supports students with DeafBlindness, their educational team and family. My husband and I took some training classes, and NYDBC visited my son's school. That visit confirmed that my son has Cortical Visual Impairment (CVI). The short explanation of CVI is that there is a processing disorder between the brain and the eye. Modifications vary depending on what Phase of CVI a person is in. The good news is that CVI can improve with continued modifications. There is no medical treatment for CVI. Some ophthalmologists recognize CVI, but others do not. We found it best to rely on our TVI and NYDBC for support.

CHANNELS OF COMMUNICATION: *(Above left)* MJ uses multiple communication devices and a visual schedule *(above, right)* that help with anticipating and planning for his daily activities.

We learned about CVI and how this would impact MJ's access to his environment, including communication. Allowing MJ time to process information has been a key in making connections. When MJ is looking at something, especially unfamiliar, he may look at it and then look away multiple times. This is visual latency. Although MJ may really want to look at the object/environment, he needs processing time and that is when he looks away. MJ may also look at something from the corner of his eye, but will not directly look at it until there has been some processing time. Sometimes people have thought MJ doesn't like something, but he does. He just needs to process the visual input. This is a guideline we use for processing time and CVI. One of the biggest misconceptions about CVI is that vision fluctuates from day to day, or is variable. It is not the student's vision that fluctuates, but rather the complexity of the environment and materials presented to the student that fluctuate. Intervention should be geared toward understanding the impact of complexity on visual processing, balancing the complexity on visual processing, balancing the complexity of tasks and the environment, to maximize visual functioning throughout the day. This consideration directly impacts MJ's communication.

WE HAD TO LEARN THAT MJ NEEDED LESS VISUALLY COMPLEX ITEMS, PREFERRED: COLORS, SOME ITEMS DISTINCTLY OUTLINED, AND CONTRASTED BACKGROUNDS.

A CVI Range was completed to help guide us on what modifications were needed. We began using pre-symbolic communication called 3D tangible symbols. MJ advanced to 2D symbols (pictures) because of proper modifications. We used symbols to create a visual schedule that would help with planning and anticipation for MJ's days. We continued to match the item with the 3D symbol and eventually transitioned to just the image.

We began creating a 2 column communication chart. This was where we would identify body gestures and sounds that may mean something. MJ began tactile communication by touching his body. He has also learned some signing. Another way we communicate with MJ is through consistent and repetitive activities. On school mornings, we put MJ's long socks that he wears with his braces on him to let him know he is going to school. We are sure to do it only when going to school. We have found positioning to be a great communication avenue for MJ, to anticipate what is happening. We always try to use MJ's wheelchair as his safe space. This is one of many best practices for MJ's communication. When we go to the doctor, we transfer MJ out of his wheelchair, so he knows he will be examined. He transfers back to the wheelchair to know he is finished. Often, he claps his hands and becomes excited. We try to follow consistent position schedules at school and home, to help MJ feel grounded. I can't imagine going through my day not knowing what will happen next, and that any activity has no beginning or end. Developing a consistent routine helps MJ with anticipation and not have a high level of stress about what is going on. This allows him to focus on his activities. We always make sure to let MJ know we are in his presence, and ask others to do so. We have specific steps to entering MJ's personal space and use consistent tactile input (i.e., touching the same place on his arm). Creating a best practices list specific to respectful communication for MJ has been very helpful.

MJ is a multi-modal communicator. This means we use multiple forms of communication to include body posture, facial expression, gesture, communication devices, vocalizations, picture symbols, and seating positions. As noted, he does not stay in his wheelchair, so we have had to plan for him to access his modes of communication in multiple settings. Our goal is to move all his communication to his iPad. However, we want to leave every mode available for MJ to communicate. Currently, MJ uses his iPad to play apps that are CVI-friendly.

MJ continues to improve his expressive communication by vocalizing, shaking his head, tapping his shoulder, reaching, making choices between symbols, and looking. The challenging part is when MJ tells us he needs, feels, or wants something, and we cannot figure it out. It is especially difficult when he doesn't seem to be feeling well.

WE HAVE LEARNED TO STUDY HIS BODY LANGUAGE, WHAT IS HAPPENING AT THAT TIME, AND THINK THROUGH EVENTS THAT HAVE HAPPENED, AND ENVIRONMENTAL CHANGES.

Fluid transparent communication is imperative between the school and home teams. This applies even more so when a child does not have language yet. We use a daily sheet to pick up on patterns, celebrations, and concerns. For example, if we notice a pattern on his daily sheet, where MJ has been rocking his body consistently in a certain class or area, we will assess his positioning, wellness, and environment to see what might be impacting him causing him to rock. There are times MJ is not eating well at home, but eats well at school. That lets us know he is eating, but did not prefer to be at home. More recently, MJ pulled himself up into a standing position in the bathroom after toileting. This was a big celebration and milestone. We had a time where MJ was falling asleep at school. We began tracking when he was falling asleep, because it was perceived as he wasn't feeling well. What we determined was that MJ was not engaged in the activities being presented, so he fell asleep. Once materials were modified, MJ became more engaged and sleeping was not so much of an issue. We hold team meetings with the school bi-weekly to share information. MJ has a very supportive educational team that includes an incredible 1:1 Aide, who receives training in DeafBlindness that is specific to MJ's needs. This 1:1 Aide position could be recognized as an Intervener or Para, as well. Having a well-connected consistent 1:1 Aide is critical to providing MJ access to his educational environment. We have found that having multiple Aides working with MJ is not successful for MJ or his educational team. The consistency becomes fragmented and MJ and his team have a communication breakdown. We have also observed that MJ develops behaviors showing he is not connected, like falling asleep. We have identified these needs on MJ's IEP. We believe the Aide support is the most important role of the team, because that is MJ's consistent voice.

TIL WE MEET AGAIN: MJ pushes a switch to say goodbye to his 1:1 aide, Mrs. Jenkins.

MJ HAS TAUGHT US THAT WE NEED TO BE ABLE TO EFFECTIVELY COMMUNICATE AS A TEAM, TO SUPPORT HIM IN ACHIEVING HIS MILESTONES.

More recently, led by his educational team, we have begun using recorded buttons for MJ to choose the word and build his expressive communication. Sometimes, it is heartbreaking when MJ is communicating with us, but we cannot figure out what he is telling us. However, it is beautiful to be a part of it when we figure out what he is communicating. To make that connection with MJ is electrifying for me.

MJ HAS TAUGHT US THAT EVERYONE HAS A VOICE. YOU MAY NOT ALWAYS HEAR THAT VOICE, BUT IF YOU LOOK, FEEL, AND LISTEN WITH MORE THAN YOUR EARS, YOU WILL HEAR THAT VOICE.

I think that because MJ does not have conventional receptive communication, some people think he does not understand what is being said to him, or what's happening around him. It is like he is less respected when it comes to personal space, and acknowledging him as a person.

We have found this often, when we have encounters with individuals. Sometimes, people talk just to us instead of MJ. We are sure to move the conversation, so MJ is included. We welcome curious questions from others. For medical encounters, we make sure the provider talks with MJ, introduces themself, and only enters his personal space once they talk through everything with MJ. Anyone working with MJ is oriented that they should get to know him before touching him or asking him to do anything.

BUILDING TRUST IS KEY TO SUCCESSFUL COMMUNICATION.

My favorite encounters are the ones where I am not acknowledged, and MJ is directly spoken to. MJ responds to sounds and his environment. He vocalizes excitement when he notices that we are heading down the road to our home. He gets excited when he hears his bath water running. He loves ceiling fans and checks for them in unfamiliar places. MJ has shown us that he is brilliant and has the ability to problem-solve and compensate in the toughest moments. He has challenged us to expand our communication, because conventional communication is fundamental to him.

It has been ongoing and has taken us years to build communication channels with MJ. I attribute understanding the impact of DeafBlindness and CVI, as the foundation of MJ's communication.

Without our family and MJ's educational team learning about DeafBlindness and CVI, our ability to connect with MJ would have been just a hope. We are grateful for MJ's educational team, families, and other professionals that continue to support our journey. MJ may have continued to be misunderstood, and we would still be searching for his voice. We learned never to leave any stone unturned, even if it seems too heavy to lift. •

ABOUT THE AUTHOR:

Nanci Bentley is a Family Engagement and Outreach Coordinator for New York Deaf Blind Collaborative. NYDBC is partners with the National Center on DeafBlindness, which is part of the Helen Keller National Center. Prior to joining the NYDBC team 2 plus years ago, Nanci's son had been receiving support from NYDBC. Before Nanci had her son MJ, she worked in the business sector. Nanci enjoys community service, serving on Boards, Advisory Councils, and helping families find their voice. Nanci lives in Upstate New York with her husband Mike and son MJ. Nanci's biggest enjoyment in life is being with MJ. In 2022 after a few years of fundraising, Nanci's family along with a few other members opened the first universally designed playground in the United States. Learn more Dream Big (**dreambiginclusion.org**).

– Note: This article was republished from EP Magazine, March 2023

TABLA ROSA: For non-verbal individuals, AAC systems offer a lifeline to effective communication. From basic PECS to advanced speech-generating devices, these tools bridge the gap and empower students to express their thoughts, needs, and desires.

ENHANCING COMMUNICATION SKILLS IN SPECIAL EDUCATION:

A COMPREHENSIVE GUIDE

BY JENN ADAMS

In the realm of special education, fostering communication skills is key for the holistic development of students. As professionals and caregivers, we understand the significance of effective communication in unlocking a world of opportunities for our learners. We will delve into practical strategies to nurture and enhance communication skills, tailored specifically for special education settings.

CREATING A LANGUAGE-ENRICHED ENVIRONMENT

To cultivate strong communication skills, it's essential to immerse students in a language-rich environment. This encompasses exposure to diverse forms of communication, including spoken language, sign language, written language and augmentative and alternative communication (AAC) systems. These are all types of communication that learners need repetitive and continued exposure to, in order to understand how to use it themselves. By incorporating visual aids such as charts, schedules, and picture cards, we can facilitate comprehension and vocabulary expansion.

CLEAR CUT: Using simple and concise language that is easy for the student to understand is crucial in engaging multi-sensory approaches.

HARNESSING THE POWER OF VISUAL SUPPORTS

Visual supports serve as invaluable tools in empowering students with emerging language skills. Implementing: visual schedules, social stories, and communication boards, aids in comprehension and provides a structured framework for communication. Visual schedules help students to understand what is happening around them and even what may be happening next, which can decrease anxiety. Social stories are often read with students to help them understand appropriate behaviors to exhibit in different situations. Communication boards can provide students with opportunities to share their wants and needs in a simple way. Utilizing tools like: picture exchange communication systems (PECS) and symbol systems enhances expressive language and fosters meaningful communication interactions.

INTEGRATING AUGMENTATIVE AND ALTERNATIVE COMMUNICATION (AAC) SYSTEMS

For non-verbal individuals, AAC systems offer a lifeline to effective communication. From basic PECS to advanced speech-generating devices, these tools bridge the gap and empower students to express their thoughts, needs, and desires. Introducing AAC systems early and providing comprehensive training ensures students can navigate and utilize these resources effectively.

Two examples in which using AAC will be effective in increasing communication skills in students:

1. In a special education classroom, a non-verbal student with autism spectrum disorder (ASD) is learning to communicate using PECS. The teacher has created a PECS board with various symbols representing common activities and items in the classroom, such as “eat,” “drink,” “play,” and “restroom.” When the student feels hungry, instead of becoming frustrated or resorting to behaviors like crying or hitting, the student is encouraged to approach the PECS board and select the symbol for “eat.” By doing so, the student effectively communicates the need for food, and the teacher promptly acknowledges the request and provides a snack. Over time, as the student become more familiar with the PECS system, the student gains confidence in expressing his or her wants and needs, leading to a decrease in frustration and an increase in independent communication.
2. A teenager with cerebral palsy relies on an advanced speech-generating device as the primary mode of communication. During a vocational training session at a local bakery, the student uses the AAC system to interact with peers and instructors. The student utilizes the pre-programmed phrases and customizable messages on the device to ask questions, give instructions, and engage in social conversation. For instance, when collaborating with classmates on a baking project, the student uses the AAC device to communicate specific tasks he or she can perform, such as measuring ingredients or decorating cookies. Despite the physical limitations, the AAC system empowers the student to actively participate in the activity, contribute to the team effort, and develop essential communication skills necessary for future employment opportunities.

Often students who need these types of supports are referred for speech and language services that are delivered by a speech and language pathologist.

EMBRACING MODELING AND IMITATION STRATEGIES

Modeling and imitation serve as powerful teaching techniques in language development. By demonstrating desired language behaviors and encouraging students to replicate them, we reinforce communication skills effectively. Utilizing clear and repetitive language models, we highlight key concepts and facilitate comprehension.

ENGAGING MULTI-SENSORY APPROACHES

Modeling and imitation serve as powerful teaching techniques in language development. By demonstrating desired language behaviors and encouraging students to replicate them, we reinforce communication skills effectively. For example, if we're teaching a student to say “thank you,” we can model the phrase in various situations, such as when receiving a gift or a compliment. By consistently demonstrating the appropriate response and encouraging the student to imitate, we help them understand the context and usage of the phrase.

Utilizing clear and repetitive language models is crucial in this process. This involves using simple and concise language that is easy for the student to understand. For instance, when teaching vocabulary related to daily activities, such as “eat,” “drink,” or “play,” we can accompany each word with a clear visual representation, such as pictures or gestures. Repetition is key to reinforcing learning, so incorporating these language models consistently in different contexts helps solidify understanding and retention for the student.

FOSTERING SOCIAL INTERACTION OPPORTUNITIES

Recognizing the social nature of language, create opportunities for meaningful interaction. Encouraging students to engage with peers, teachers, and family members in structured activities promotes language development and strengthens communication skills. For instance, during a group activity like a cooking class, students not only learn new vocabulary related to cooking, but also practice communicating with their peers to collaborate on the recipe.

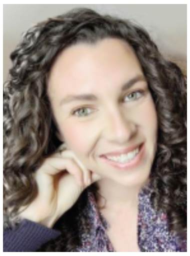
By facilitating collaborative projects and group discussions, we nurture social connections and foster communication growth. These interactions provide real-life contexts where students can apply their language skills, enhancing their ability to express themselves and understand others effectively.

TAILORING INSTRUCTION TO INDIVIDUAL NEEDS

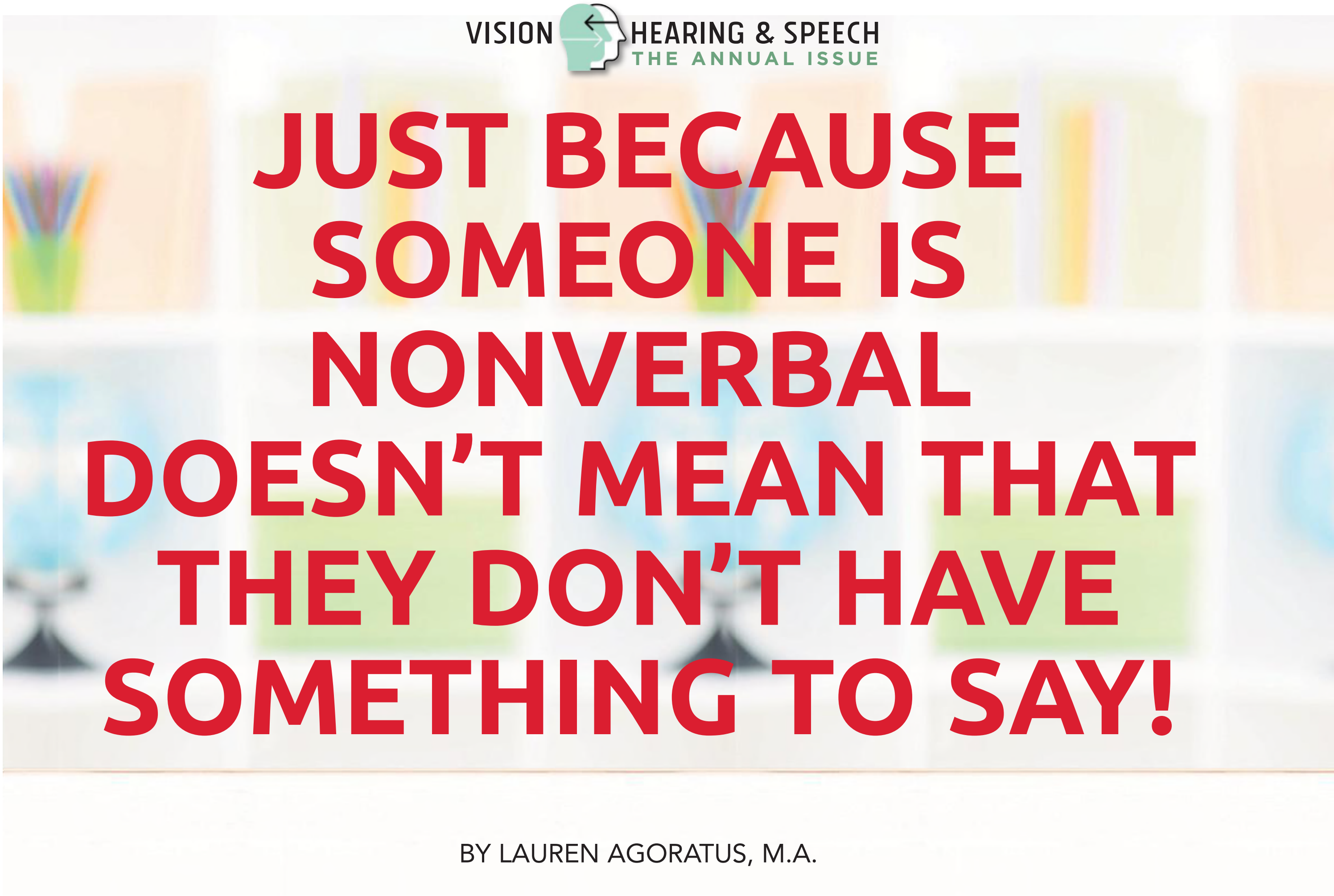
Every student is unique, with distinct strengths, challenges, and learning styles. It's imperative to tailor instruction to meet individual needs effectively. By assessing students' current abilities and preferences, we can design personalized learning experiences that maximize engagement and promote communication skill development.

In conclusion, mastering communication skills is a journey that requires dedication, patience, and a commitment to individualized support. By creating a language-enriched environment, harnessing visual supports and AAC systems, employing task analysis techniques, embracing modeling and imitation strategies, integrating multi-sensory approaches, fostering social interaction opportunities, and tailoring instruction to individual needs, we empower our students to communicate confidently and effectively. Together, as educators and caregivers, we can pave the way for their success in both academic and real-world settings.

ABOUT THE AUTHOR:



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



JUST BECAUSE SOMEONE IS NONVERBAL DOESN'T MEAN THAT THEY DON'T HAVE SOMETHING TO SAY!

BY LAUREN AGORATUS, M.A.

Some individuals with disabilities use alternative forms of communication.

PREVALENCE

Approximately 10% of people have speech, language, or voice disabilities (communication disabilities).[1] They may rely on American Sign Language (ASL) or other modes of communication through the use of technology. Some children without hearing issues but who have developmental disabilities may benefit from using ASL which reduces their frustration and challenging behaviors, and some later became verbal.

STIGMA

Unfortunately, difficulties with speaking may lead to underestimating a person. Sometimes, others inappropriately speak louder or slower, talk to them like a child, or even worse, ignore them altogether, and instead speak to a family member or other person who is with them. This is despite the fact that the ability to speak has little to do with intelligence or ability.

OPTIONS

Some options may include the use of ASL or other communication devices. These can include AAC – augmentative and alternative communication devices. These can be picture or symbol boards, as well as synthesized speech using a computer program (text to speech). For an explanation of AAC to families and also the latest research on AAC devices, see Resources below.

ROLE MODELS

Some excellent role models include people with disabilities who were or are able to communicate differently and express their thoughts and talents. Perhaps the best known was physicist Stephen Hawking, a brilliant scientist. Several years ago "Carly's Voice", book/blog presented the story of Carly Fleischmann who has autism, nonverbal, and explained to others what it is like to be on the spectrum. More recently, Samuel Habib who uses AAC hosted My Disability Roadmap[2] with other disability advocates, and his film just won an Emmy!

AAC ETIQUETTE

On **https://spokenaac.com**, their blog gives tips on appropriate communication with AAC users, which can be used for anyone with communication challenges. These include:

- ➢ Give them time to answer
- ➢ Avoid interrupting them
- ➢ Address the individual directly
- ➢ Maintain eye contact
- ➢ Respect personal space and equipment
- ➢ Treat them chronologically appropriately
- ➢ Speak in a normal tone and speed

---

[1] https://pubmed.ncbi.nlm.nih.gov/35858270

[2] www.wbur.org/cognoscenti/2023/12/13/diability-roadmap-epilepsy-wheelchair-adult-independence-dan-samuel-habib

NOW HEAR THIS: Augmentative and alternative communication devices can include picture or symbol boards as well as computer programs that synthesize speech, such as text-to-speech assistive technology.

PERSON CENTERED

It is essential that any communication technique used by a person with a disability is person-centered. This means that the individual is expressing their own thoughts in their own way. No one is speaking "for" them or "suggesting" what they mean. For more on person centered communication, see EP's February 2022 issue at **www.epmagazine.com**. •

ABOUT THE AUTHOR:

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

SPEAK UP : AUGMENTATIVE & ALTERNATIVE COMMUNICATION

ASHA

ASHA
(AMERICAN SPEECH-HEARING-LANGUAGE ASSOCIATION)
Augmentative and Alternative Communication
www.asha.org/practice-portal/professional-issues/augmentative-and-alternative-communication

Cincinnati Children's

CINCINNATI CHILDREN'S HOSPITAL
Augmentative and Alternative Communication: Explanation for families
www.cincinnatichildrens.org/service/a/aaron-perlman-center/assistive-technology/communication

NIH

NIH (NATIONAL INSTITUTES OF HEALTH)
Augmentative and Alternative Communication (AAC) Advances:
A Review of Configurations for Individuals with a Speech Disability
www.ncbi.nlm.nih.gov/pmc/articles/PMC6515262/

Spoken

SPOKEN INC.
Proper AAC Etiquette: How to Communicate Respectfully with AAC Users
https://spokenaac.com/blog/proper-aac-etiquette

ESTING, TESTING: An appropriate healthcare professional should evaluate a person who exhibits visual loss signs to determine if these causes are treatable or if assistive devices, such as glasses, could be helpful.

IDENTIFYING VISION AND HEARING CHANGES IN PEOPLE WITH IDD AS THEY AGE

BY CRAIG ESCUDE, MD, FAAFP, FAADM

As most of us age, we begin to experience changes in our vision and hearing. We commonly associate aging with difficulty seeing closer and difficulty hearing..

Some with intellectual and developmental disabilities may have trouble communicating these changes, and the first signs of them may appear as changes in their behavior. Below is what we might observe that could indicate a vision or hearing change in someone with an intellectual disability.

VISION

Several conditions can cause visual changes as we age, including presbyopia, which is difficulty seeing close due to a decreased lens elasticity, which affects our ability to focus. Others include age-related macular degeneration, glaucoma, cataracts, and diabetic retinopathy.

In a person who is unable to communicate changes in their vision using words, we might observe behaviors that involve frequent touching or rubbing of their eyes, finger flapping in front of their eyes, gazing at bright lights, a change in their usual head positions, including moving their head but not their eyes to look at things, and frequent shaking of their head. Visual changes might also present as a person moving their head in a circular motion to find an area of better focus. The person may also put their hand over one eye if they cannot see out of it clearly. You may also see frequent frowning as an attempt to strain to see better. Frequent blinking may also be noted. Problems such as a cataract may cause someone to avoid bright lights or to blink heavily at bright lights.

You may also see a change in the person's activities where they avoid close-up work, because they can no longer see it well. When it comes to drawing, they may draw tiny pictures or very large pictures. They may also seem to see bright colors better than dark ones. You might also note visual changes expressed as someone who appears to have a short attention span. Someone beginning to exhibit poor self-care skills may also be experiencing visual loss, because they can no longer see themselves clearly. You might also see dramatic changes in a person's behavior. They may become upset or anxious for no apparent reason, or startled by noises because their vision is affected, and they can't see what's happening around them.

Other indications of visual loss include not recognizing people unless spoken to, because they cannot visually recognize the person. They also may not make eye contact, or they may stare for long periods at someone, as they are trying to figure out who they are. They might also become startled when approached without being warned. You may also see them favoring areas of bright lights or moving objects to areas with better lighting. They may have trouble making out items that are similar in color, such as a white plate on a white tablecloth.

They may be anxious or unwilling to walk alone, they may fall or crash into objects, or they may seem clumsy or uncoordinated. These changes may be particularly noted in areas that are poorly lit. They may also mistake dark areas in flooring, such as a dark rug on a light-colored floor, as a hole or a step and may be afraid to walk in that area.

HEARING

Hearing loss can come from different causes. One more common and easily treatable cause is cerumen impaction, also known as excessive ear wax. This can usually easily be removed by a clinician. Other problems include ear infections, sensory-neural hearing loss, damage to the hair cells that sense sound waves, or a combination of different causes. Presbycusis is age-related hearing loss due to the loss of the tiny hair cells in the interior of the ear that pick up sound waves.

RISK AND REWARD: Recognizing hearing loss earlier rather than later can not only help people remain more engaged in life, but can help reduce the risk of dementia.

In one study of hearing loss in people with and without disabilities, people with intellectual disabilities showed anywhere from three to nine times greater loss, compared with other people the same age who did not have a disability. Recognizing hearing loss earlier rather than later can not only help people remain more engaged in life, but can help reduce the risk of dementia. People who experience hearing loss are significantly more likely to experience cognitive decline and dementia, than people who do not experience hearing loss. And correcting that hearing loss early can have a significant, positive impact on the outcome.

People who experience hearing loss as they get older may seem distracted, particularly in noisy areas. They may turn up the volume on the television or radio louder than usual. They may not seem to understand conversations and ask people to repeat themselves. They may become disengaged from others and appear less interested in activities they used to enjoy. They might be startled when someone "suddenly" appears in from of them, because they did not hear them come into the room. They may also not seem to follow requests, such as "let's go eat," because they cannot hear it.

WHAT TO DO

Be aware of any changes you see in people around you who may have difficulty communicating using words. An appropriate healthcare professional should evaluate a person who exhibits visual or hearing loss signs, to determine if these causes are treatable or if assistive devices, such as glasses or hearing aids, could be helpful. Early treatment can help people remain active and engaged in life, contributing to a better overall quality of life. •

ABOUT THE AUTHOR:

Dr. Craig Escudé is a board-certified Fellow of the American Academy of Family Physicians and the American Academy of Developmental Medicine and is the President of IntellectAbility (**https://replacingrisk.com**). He has more than 20 years of clinical experience providing medical care for people with IDD and complex medical and mental health conditions serving as medical director of Hudspeth Regional Center in Mississippi for most of that time. While there, he founded DETECT, the Developmental Evaluation, Training, and Educational Consultative Team of Mississippi. He is the author of *Clinical Pearls in IDD Healthcare* and developer of the "Curriculum in IDD Healthcare," an eLearning course used to train clinicians on the fundamentals of healthcare for people with IDD

– Note: This article was republished from EP Magazine, March 2023

MONTCLAIR STATE UNIVERSITY GRADUATE SPOTLIGHT

THE POWER OF PERSEVERANCE

BY SYLVIA A. MARTINEZ

Layla Tamimi chokes up when sharing that she went into the hospital on July 11, 2018, and woke up more than two months later paralyzed from the neck down. It's difficult for the once active, healthy jogger to recall and retell the story of how close she came to dying at age 27.

She was in a medically induced coma and her organs had started to fail. Her family had been prepared for the worst. Miraculously, Tamimi awakened to the news that she'd suffered a stroke in addition to three rare spinal strokes while hospitalized.

She remembers bits and pieces of her ordeal, the rest filled in for her by family members. Lying in her hospital bed, she'd forgotten she had a daughter. But when the 7-month-old baby was brought to her bedside, she knew what she was fighting for. "I remembered her, and it made me want to fight more, to get up and do what I needed to do so that I could go back to her," Tamimi recalls.

The young mother left the hospital in a wheelchair. "I couldn't really do much on my own," she says. "I had to learn how to speak

CROWNING MOMENT: Public Health Professor Eva Goldfarb hugs Layla Tamimi '23 after presenting her with the Department of Public Health Outstanding Achievement Award, as Stephanie Silvera, professor of Public Health and acting associate dean of the College for Community Health, looks on.

PHOTO BY JOHN J. LAROSA FOR MONTCLAIR STATE UNIVERSITY again. I had to learn how to swallow again, how to stand, how to sit.… It was weeks before I was able to sit on my own. I was sitting in a tilt wheelchair, which is one that they strap your neck in so that you don't fall over because you don't have that strength or the ability to keep yourself up."

PORTRAIT OF STRENGTH: Layla Tamimi's graduation photo upon completing her Bachelor of Science in Public Health.

Tamimi fought her way back, not just from the brink of death but to stand and walk on her own two feet and with the assistance of a walker. It was that same hard work and dedication – and a vow she made – that would lead her back to school and eventually to Montclair State University, where she earned a Bachelor of Science in Public Health. She was set to participate in Montclair's Winter Commencement on January 8 but a pending surgery derailed those plans.

Tamimi refers to herself as "a part-time wheelchair user," but says, "I still have hope that I'll be able to walk on my own one day." Even with ongoing health issues, she knows how far she's come.

Incredibly, she's come to view her harrowing experience as "a little gift that God gave me that was wrapped in ugly paper but when I opened it, it was the most beautiful gift possible."

That's because it made her focus on the things that mattered, she says. "My disability has slowed me down in life, in my day to day," she says, "but I feel like it pushed me 10 years forward. So that's how I look at it because I was able to go back to school, and I was able to get my life together in ways that I never thought I could."

LIFE INTERRUPTED

Born in the occupied West Bank, Tamimi arrived in the United States at age 1. One of six children, she grew up in a two-bedroom apartment in Paterson, New Jersey. She enrolled in college at 18 but after her father was diagnosed with leukemia, she dropped out to help care for him and to work three jobs, including retail and as a pharmacy technician, to help her mother make ends meet. After her father's death, she returned to school at age 21 but says she was too depressed to keep going; she also began experiencing joint pain and other health problems. She was diagnosed with rheumatoid arthritis.

Fast forward to age 27, Tamimi's health further declined, and she says she suffered from postpartum depression. One day, while doing yoga, she didn't have the strength to get up off the floor. She knew something was terribly wrong. Eventually, she was diagnosed with systemic lupus erythematosus, an autoimmune disease in which the body's immune system attacks its own tissues. It was in the hospital that Tamimi had multiple strokes.

Grueling therapies – physical, speech, occupational and more – followed her hospitalization. Everyday movements and tasks were difficult for her. "I took for granted the ability to hold a pen, and I thought to myself, 'God if you let me hold this pen again, I'm going back to school. I don't care how difficult it is.'

She regained that ability but lacked fine motor skills. Undaunted, she made good on her promise and enrolled at Bergen Community College and took notes on dry erase boards with jumbo markers, she says. "I knew it was going to be difficult but I figured, this is the hardest thing I could possibly go through, so school should be a breeze" by comparison, she says.

Tamimi transferred to Montclair in fall 2021. She decided to study Public Health, in part, she says, to educate other young people to not take being healthy for granted. "I want the youth to be aware that just because you're young, you're not immune to getting sick or becoming disabled," she says. "It can happen to anyone, no matter how healthy you think you are."

Initially, Tamimi would take a Lyft to campus; the driver would get her as close to her destination as possible, a security gate on Webster Road behind University Hall, and then she'd begin the arduous block-long walk with her walker to University Hall for her Public Health courses. One day, she was spotted by Yvelices Núñez, who drives the shuttle for students with disabilities, who told her she would ferry her to all of her classes. "Yvelices was a godsend," Tamimi says.

Meanwhile, Tamimi was learning to drive again but she was reluctant to drive to Montclair on Route 46 from her home in Lodi. In January 2022, she started driving and commuting to campus, where the shuttle would meet her and take her to her classes. Montclair's shuttle service allowed Tamimi to get around campus with the use of her wheelchair and a cane for short distances.

> **"Tamimi fought her way back, not just from the brink of death but to stand and walk on her own two feet and with the assistance of a walker."**

Tamimi says prior to that. "I never looked at life as a disabled person, so I thought I have to figure it out myself," she says, "but the University made things so easy for me."

PUBLIC HEALTH PATH

Tamimi, now 33, is grateful for the support she received while at Montclair. Her anxiety of being on a large campus slowly subsided, she says. When she needed something to overcome an obstacle, she asked. "I felt like I was blessed," she says, adding "it was definitely like the best decision of my life to go into the public health field."

Moreover, every achievement made her stronger.

"A lot of it came with going to the University because it gave me the confidence to do more instead of staying at home and doubting myself," she says. "Every time I got my grades back, it just made me more confident. My GPA was 3.97 when I graduated, so I was really proud about that."

Public Health department faculty also are proud of Tamimi. Professor Kurt Conklin, who had her in several classes, including Applied Statistics in Public Health, says she enriched the classes because of her life experiences.

Early in her final semester, Tamimi contacted Conklin because she'd been injured during physical therapy and couldn't attend class. "She had fallen off a treadmill and sustained injuries," he recalls. "We didn't want to lose her for another semester, so while she recovered, we were able to use Zoom to patch her into the existing in-person course. She did fantastically, and the course involves a lot of student-group projects, which can be very demanding. She did a great job."

> **"Accept that your situation is happening, because if you don't accept it, you can't acknowledge how to fix it."**

That situation brought Tamimi to the attention of Public Health Department Chairperson Lisa Lieberman. "She was actually taking five courses that semester, and she did stellar work in all five of them," Lieberman says. "She had this additional injury on top of her existing challenges, and she just excels, as she does in everything."

That same semester, in April 2023, Tamimi won the Department of Public Health Outstanding Achievement Award, "presented to a student who has gone above and beyond to represent the Department of Public Health by embodying its core values of social justice and health equity, instilling those values in others, and achieving recognition among faculty and students for their accomplishments."

Says Lieberman, "She does not let her disability stop her in any way. Her consistent effort both in classes and working for the betterment of the community [she interned at Project COPE] is just simply outstanding. We are so infinitely proud of her."

Tamimi is now working on a master's degree in Health Systems and Policy at Rutgers University. She has an interest in working in maternal health or on policies on behalf of people with disabilities. Despite the Americans with Disabilities Act, Tamimi says "there's a long way to go before we can make the world fully inclusive to people with disabilities."

Conklin and Lieberman have no doubts Tamimi has a bright future ahead of her. "Wherever she ends up, she'll excel, and whoever hires her will be lucky to have her," Lieberman says.

ACCEPT, ADJUST AND ADAPT

Looking back, Tamimi acknowledges that even she is surprised by what she has achieved. "Where I am today is beyond what I ever envisioned," she says, noting that she's particularly proud of rearing her now 6-year-old daughter and completing her degree.

"I'm grateful because I was able to raise her as well as possible considering my situation, and she came out to be a great kid, very empathetic, very understanding," she says. "I'm going to be honest, if it wasn't for her, I don't know if I could have done it. She pushed me so much to do my best."

Today, Tamimi is able to walk more with a walker and "sometimes a cane for short distances," she says. "I still work hard. I try my best to work out at home, I still have hope that I'll be able to walk on my own one day."

She also hopes to start a nonprofit organization, operating a barrier-free gym for people with disabilities.

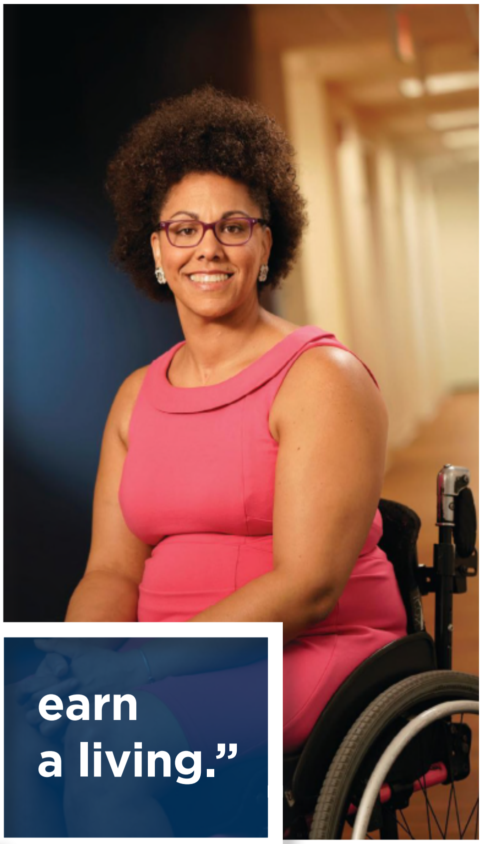
"As humans, we're unstoppable," Tamimi marvels. "We just have three things we have to do when we're at a halt in life: accept, adjust and adapt. Those are my three laws in life. Accept that your situation is happening, no matter what it is, because if you don't accept it, you can't acknowledge how to fix it. Adjust for the changes, whatever the changes are. Whether you're a single parent or you become disabled or you're having difficulty in life, whatever the obstacle is, you adapt to that, then you're doing everything everybody else is doing, just a little differently than you used to." •

ABOUT THE AUTHOR:

Sylvia A. Martinez is a Staff Writer for the The Communications and Marketing Department at Montclair State University. Contact her at **martinezsy@montclair.edu**

“Working lets me...

keep contributing.”



earn a living.”

provide for my family.”

be there for the team.”

Working Works.

America works best when *all* Americans can work. Ensuring workers can stay on the job or return to work following an injury or illness is essential to America’s economy.

WhatCanYouDoCampaign.org

ODEP
Office of Disability Employment Policy

OFFICE OF DISABILITY EMPLOYMENT POLICY
UNITED STATES DEPARTMENT OF LABOR

What can YOU do?
THE CAMPAIGN FOR DISABILITY EMPLOYMENT

DEMYSTIFYING DYSCALCULIA

TIPS FOR RECOGNIZING AND OVERCOMING A MISUNDERSTOOD MATH DISABILITY

BY DR. CHELSI BROSH

Dyscalculia, a math-specific disability that affects the individual's ability to comprehend and perform numerical operations, often recedes in the shadow of its more well-known counterpart, dyslexia. However, for millions of students worldwide,[1] the challenges posed by dyscalculia can impact their math performance in school and beyond.

This article sheds light on dyscalculia through the personal experience of former principal and education consultant Brandon Hess and his son Ben. Families and caregivers will also learn to recognize the signs of dyscalculia, the importance of collaboration with schools and teachers and practical ways they can provide personalized support at home.

Former principal and education consultant Brandon Hess first noticed that his son, Ben Hess, showed early speech delays and relied heavily on sign language to express his words as a young child. Ben would point to a cabinet and grunt for cookies when his parents and teachers would have expected him to speak.

As Ben got older, Hess and his wife noticed Ben's difficulty with handwriting. This would later lead to a diagnosis of dysgraphia, a condition in which someone has difficulty turning their thoughts into written language.

Soon afterward, Ben was also diagnosed with dyscalculia, a math-specific disability that affected his ability to understand and perform operations with numbers. Tricky to spell and often challenging to recognize, dyscalculia can significantly impact a person's ability to master numerical concepts. This learning disability is not solely a dislike of math or math anxiety, though it can cause both. It remains under-researched, under-diagnosed and undertreated. Yet, research (The Diagnosis and Treatment of Dyscalculia - PMC www.ncbi.nlm.nih.gov/pmc/articles/PMC6440373) shows that between 3% and 7% of students around the world have dyscalculia, roughly the same as the much better-known dyslexia.

---

[1] The reference for the statement "for millions of students worldwide" is based on the estimated prevalence of learning disabilities among the student population globally. According to the Learning Disabilities Association of America (www.ncbi.nlm.nih.gov/pmc/articles/PMC6440373), dyscalculia is estimated to affect at least 3% of the population. When considering the UNESCO data that reports there are more than 1.5 billion students in the world, even the conservative estimate of 3% suggests that at least 45 million students could be grappling with the challenges of dyscalculia.

"This is a math processing issue unique to individuals with dyscalculia and can be problematic when peers, teachers, administrators, and parents don't understand, because sometimes that misunderstanding can lead to people thinking it is an intellectual challenge, which isn't at all true," Hess said.

Getting an early dyscalculia diagnosis, as well as, special tools and classroom support, can help students with dyscalculia overcome their learning differences. Today, Ben attends college equipped with the skills to recognize what he needs to complete his math assignments. Here's what you need to know about the signs of dyscalculia, how to build a support community, and ways you can provide personalized support at home.

RECOGNIZING THE SIGNS OF DYSCALCULIA

Students with dyscalculia not only have challenges performing complex problems, but can also have difficulty manipulating numbers, estimating quantities, or performing mental math without writing things down.

Unlike math anxiety, dyscalculia is a lifelong math learning disability that can impact a student's academic career, future employment, and self-esteem. It is listed as a disability under the Individuals with Disabilities Education Act (IDEA) and the Americans with Disabilities Act (ADA).

Examples of dyscalculia include difficulties with:

- *Number sense (understanding the meaning and relationships of numbers)*
- *Memorizing math facts*
- *Performing math calculations, reasoning mathematically, and solving math problems*

Not everyone with dyscalculia struggles in all of these areas. Hess said Ben particularly had difficulty memorizing his multiplication tables.

"It made no sense to him at all. You could ask, 'What's seven times five?' and he would respond, 'I don't know,' because the way he worked through a problem included working backward from the answer to understanding the process." Hess said. "As he got older, he wasn't being tested on the actual multiplication; he was being tested on the steps in the process. He got it wrong every time, because he didn't know the answer when he had to multiply."

Parents and caregivers who suspect dyscalculia in their children should observe their interactions with basic number concepts, mathematical operations, and spatial awareness measurements, during everyday activities. These could include:

- *Struggling with keeping score during family games*
- *Challenges with following recipes that involve measurements or conversions*
- *Having difficulty sorting items by size*
- *Understanding spatial relationships when completing household tasks*

These signs demonstrate how dyscalculia can affect a child's everyday experiences and interactions, underscoring the need for early recognition and intervention.

THE IMPORTANCE OF COLLABORATING WITH YOUR CHILD'S SCHOOL AND TEACHERS

Parents and caregivers who suspect their child might have dyscalculia should take proactive steps to get a diagnosis and build a community that can support their child. Free dyscalculia screeners (dysctest.com) can help you gain insights into your child's difficulties. After you receive the results, you can consult an educational psychologist or learning difficulty specialist, who can conduct assessments and provide a dyscalculia diagnosis based on your child's performance on standardized tests and observations. After that point, an expert can recommend suitable interventions and strategies based on your child's needs.

Working with your child's special education teacher or school math interventionist is vital to developing an Individualized Education Program (IEP) or 504 plan that outlines specific accommodations that speak to your child's math challenges.

For the Hess family, getting Ben assessed early and advocating for his success were key to ensuring he got the support he needed for dyscalculia and other learning differences.

"My wife and I are both educators, so we started to notice early on that there were some delays, and as those delays progressed, we opted for private assessment," he said. "It can be hard for a parent to see those signs if you don't know about them, but there are online resources, and working with your primary care practitioner can better help parents understand what to look for."

> ***"Parents and caregivers can get individualized interventions that help the students manage their dyscalculia by obtaining the proper assessments and collaborating with educators."***

As Ben moved through elementary and middle school, he faced situations where teachers didn't understand the full extent of his learning disabilities.

"So, sometimes, our advocacy for him included showing the teacher how the instructions were written and that the assignment's goal were really important. Sometimes that can easily be pushed aside as just a letter grade or points, but that's not at all what it is. It's about presenting information to Ben in a way that he can understand and build upon," Hess said.

"Ben was very literal, and it was important that the teacher had clear instructions, clearly stated goals and then confirmed with Ben that he understood the instructions and goal before beginning. Often, the instructions were vague, and his literal brain would do exactly what was asked 'In your answer, list the causes of erosion.' He would list (1, 2, 3) when the teacher wanted a narrative. Even though he had the right answer because it was listed, he got points deducted when in fact he knew and wrote the correct answer. The 'pushed aside as a letter grade or point' was when we challenged the teacher on this request, she said 'if it's just about the points, he can have the points.' That wasn't our intent, our intent was for the teacher to understand his disability and provide clearer instructions".

By getting the proper assessments and collaborating with educators, parents and caregivers can get individualized interventions that help the students manage their dyscalculia.

PROVIDING PERSONALIZED SUPPORT AT HOME

Parents and caregivers can play a critical role in helping enhance their child's nderstanding of mathematical principles by incorporating personalized learning strategies into their school and home activities. It's important to dispel the idea that using aids, charts, calculators, or other supports will contribute to a child being "lazy" at math. Instead, parents and caregivers should empower their students by giving them the tools and practice they need to overcome their challenges.

Here are a few things you can practice with your child at home:

- ***Multisensory Math Practice:*** *A method that involves using tangible objects like beads or blocks to represent arithmetic operations, can aid them in better understanding numerical concepts.*
- ***Real-World Math Applications:*** *Encourage children to apply math skills in practical scenarios, including cooking or shopping. This helps students grasp the relevance and application of math in everyday life.*
- ***Visual Aids and Memory Aids:*** *Including personalized math charts or mnemonic devices can help your child retain and recall mathematical information. By personalizing these aids, you can help make mathematical knowledge more accessible and relatable for your child.*

Parents and caregivers should expect to continue to advocate for their students, as their needs change. By maintaining open communications with teachers, pursuing necessary accommodations, as well as specialized support services at school, and reinforcing mathematical practice at home, families can continue to set their children up for academic success.

For the Hess family, supporting Ben's success in math meant ensuring he had access to his multiplication chart, tutors, and electronic devices to complete certain activities.

"Accommodations, laying out the processes, and having intentional conversations with educators have set Ben up for success, and have given him the tools and confidence to advocate for himself, now that he is away at college," Hess said. "I hope to see more opportunities for teacher professional development that focuses on these hidden disabilities and some instruction around supports that can build inclusive classrooms for all students, as well as more acceptance that students with learning disabilities can thrive with those supports and accommodations."

Dyscalculia doesn't end with a diagnosis. To overcome math hurdles, students require ongoing support, understanding and inclusive classrooms that support their unique learning differences, throughout their academic careers. Working together, families and educators can ensure that no student's potential is limited by the challenges posed by dyscalculia or other learning differences. •

ABOUT THE AUTHOR:

Dr. Chelsi Brosh, a former classroom teacher of elementary students with disabilities, is the Vice President of Product Innovation at TouchMath, an organization committed to maximizing student potential through their comprehensive, multisensory math program designed for all students struggling with math. After receiving her masters in Curriculum and Instruction from Arizona State University, she earned her PhD in Special Education from the University of North Carolina at Charlotte. Dr. Brosh's roles have spanned strategic leadership, product development, and innovative concept creation, focusing particularly on enhancing curriculum access for students with autism and intellectual disability.

Mental Health Care MATTERS

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

The average delay between symptom onset and treatment is

11 YEARS

PEOPLE WHO GET TREATMENT IN A GIVEN YEAR

43% of adults with mental illness

64% of adults with serious mental illness

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

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

25% of Asian adults

31% of black adults

32% of adults who report mixed/multiracial

33% of Hispanic or Latinx adults

49% of white adults

49% of lesbian, gay and bisexual adults

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

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

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

NAMI National Alliance on Mental Illness

DOES YOUR CHILD HAVE DYSLEXIA?

WHAT TO DO IF THEY DO

BY DR. CORAL P.S. HOH

Dyslexia is one of the most common childhood conditions, affecting one in five children. Yet about half of students with a learning disability do not receive special services at school. From my thirty years of fieldwork with this population, I find that many are undiagnosed with this condition or classified under other labels in special education at school.

READING THE SIGNS: If your child's grades are considerably lower than you would expect from their intelligence or they experience undue anxiety over doing schoolwork and tests, you may want to have them take a dyslexia exam.

To solve this problem, we first must understand what dyslexia is exactly. It is a reading difficulty due to inefficient language processes in the brain. Parents can help spot dyslexia by looking out for these tell-tale signs:

- *Resistant to reading: not learning to read, not wanting to read, reading slowly with many errors.*
- *Unable to remember how to spell small, common words, like* ***the.***
- *Chronically below the 30th percentile in state or standardized reading tests (the dyslexia threshold used in research).*

Twice exceptional children are exceptional in two ways, having a disability and a gift/talent. Some children who are passing reading class may still have dyslexia (i.e., language processing issues). The twice-exceptional children may be masking their reading difficulty with their giftedness. Some signs of intellectual giftedness:

- *Sense of humor: children of high intelligence like the mental challenge of creating humor.*
- *Sophisticated vocabulary: this may seem paradoxical, but some children who are poor at reading may have a rich vocabulary when speaking. Their vocabulary may include unusual words, like* ***discombobulated****. As a linguist, I look for a layered vocabulary, instead of just a generic word like walk. A precocious child may use* ***saunter*** *or* ***trek*** *instead.*

For the twice-exceptional child with dyslexia, look out for these signs:

- *Although they pass reading and other subjects, their grades are considerably lower than you would expect from their intelligence.*
- *Undue anxiety over doing schoolwork and tests: if there is a processing difficulty, they have to expend more mental energy than typical. It is as if their legs must tread furiously just to keep their heads above water.*
- *They can give the gist of a story but cannot locate specific information in the text: this could mean that they are using various cues to guess at the meaning without actually reading the passage.*

Now if you checked off the above, what should you do next?

If your child is having trouble reading and exhibiting several of these signs, you may want to have them take a dyslexia exam.

Parents have the legal right to ask schools for an appropriate evaluation for dyslexia. Since dyslexia is due to inefficient language processes, the logical step is to identify which specific processes are affected in the least intrusive manner and most cost-effective way.

In the interim, before your child's language processing, and by extension, dyslexia, is corrected, what can you do?

LIGHTENING THE LOAD : WHAT TO DO BEFORE YOUR CHILD'S LANGUAGE PROCESSING IS CORRECTED

Give your child props to lean on: when the brain is not working efficiently, reduce its processing load so that it does not get overwhelmed and shuts down. Some examples below:

SPEECH

Some children with language issues have difficulty formulating questions or requests. When I asked a 4th grader with dyslexia why he did not ask his teacher what to do when he was lost, he said, "I don't even know how to ask, what to ask for." In such cases, tell your child to use the same request structure every time, so that he only needs to fill in the blank, like this: "I'm not sure about _____. Can you please help me?

WRITING

For older students, they still need to write at length despite their current (hopefully temporary) difficulty. Like the speech tip above, use prefabricated patterns. A small set of sentence patterns should suffice to enable a student to convey information. Some patterns to repeat are, for example: If______, then _____. Since _____, then ____. _____ because ____. Not only _____ but also ____. Writing in this way may be clunky, but at least they can get their message across in the interim and get their assignments completed.

BREAK IT DOWN

Tell your child's teachers to break up information into even smaller chunks: teachers know how to communicate with children, yet students with dyslexia still fail to understand them at times. A 5th grader explained: "my teacher tried to help me by breaking things into smaller pieces, but they were still not small enough for me to grasp." Relay information in even smaller bits to children who struggle to understand, store and retrieve it.

SLOW THE PACE

Delay the instruction of some skills: language processing has to work well before some skills, like spelling, can be acquired. Many of our students were taught the same spelling rules repeatedly. "They didn't make any sense," said a 4th grader. Skills can't be acquired when the brain can't function efficiently to execute them. The effort is not just wasted, but students get demoralized when they *think* they cannot learn. We should only teach the skills that their brains are receptive to acquiring at that time.

After correcting language processing, learning spelling and high-frequency words is important for students in order to catch up with their classmates. To summarize, take these steps:

1. *Check for signs of dyslexia.*
2. *Ask for an evaluation of your child's language processing at school.*
3. *If there are language processing difficulties, get them corrected.*
4. *In the interim, get your child the support mentioned above.* •

References

1. National Institute of Child Health & Human Development, NIH, https://www.nichd.nih.gov/about/profiles/KnowNICHD/miller
2. Snowling, M.J. (2000). Dyslexia. Oxford, UK: Blackwell.

ABOUT THE AUTHOR:

Dr. Coral P.S. Hoh is a clinical linguist with 30 years of fieldwork on language disorders of exceptional populations. She has published and refereed for premier publishers, e.g., MIT Press. Her work was funded by the National Science Foundation and presented at international conferences and to medical groups. She served on an editorial board of the National Association for Gifted Children and co-authored Dyslexia Dissolved: Successful Cases with Learning Disabilities, ADHD and Language Disorders. She is the architect of the Dysolve® AI system and co-inventor of U.S. and international patents for AI technologies for language disorders.

10 TIPS FOR WORKING TOGETHER IN EARLY CHILDHOOD CLASSROOMS

BY ANNE GRITT, MS CCC-SLP

As a speech-language pathologist, I know the importance of strong collaboration for our young students. Working within early childhood classrooms, where authentic learning opportunities and play-based experiences are plentiful maximizes progress in the students, because we can better address these opportunities.

I learned this firsthand. At one time, I served multiple classrooms within 12 preschools across the county, visiting each classroom just once a week. Once I recognized that I could have a greater impact on my students by collaborating more closely with those that were with these children the most (teachers, aids, parents, and caregivers), I noticed stronger progress in my clients.

In working with other disciplines, we can support the whole child's development, rather than having a narrow focus on one area. We can work together to plan individualized and developmentally appropriate learning experiences for our students. For example, in a single activity, an occupational therapist can address a child's fine motor skills, a speech-language pathologist can support communication, and a teacher can notice opportunities for cognitive and social-emotional growth.

Classroom-based collaboration allows us to build trusting, respectful relationships with each other. When we interact more frequently with each other, we can more easily appreciate the others' roles in the student's progress. We can share real examples, demonstrate techniques, and answer questions. When we have trust and respect, we are more open to learning from and teaching each other.

TAKE TEN : WORKING TOGETHER TO PLAN DEVELOPMENTALLY APPROPRIATE LEARNING EXPERIENCES

Here are my 10 tips for professionals to work together effectively in the early childhood classroom:

1. DEFINE ROLES

Avoid misconceptions by clearly communicating each person's role on the team, from the beginning. Introduce yourself to the team and talk about your goals and responsibilities for the student. When you schedule a visit, share details about what you will do during that visit. Open communication from the beginning leads to trust, which is necessary for harmonious collaboration.

2. BE EFFICIENT

Accomplish as much as you can within the time you are together. This can reduce extra meetings.

3. USE COLLABORATION TOOLS

Add a brief huddle at the start of your visit. This could be five minutes, in which you and the classroom staff come up with a plan for your visit. A clear plan supports productive use of the time you have. Debrief at the end of the visit for a few minutes, to summarize what occurred.

4. CHECK IN

Sending a brief email a couple days before your scheduled visit can help you be efficient when you are face-to-face. It also maintains a team-based approach by getting input from the student's classroom team. Use your check-in email to summarize your previous recommendations, open discussion for questions and concerns from teachers/caregivers, and set up a plan for your next visit.

5. FOLLOW-UP

This can be a few minutes at the end of your visit or a quick email or phone call. The early childhood classroom is bustling with activity. It's hard to have a lengthy conversation in the classroom, and this can detract from our important work with the children. Set up a system that works for all team members for those topics that need more discussion.

6. ASK AND WATCH

Watch the other providers closely and ask questions about what you observe, as they work with the student. Build trust with each other so that these questions are welcomed. Avoid assumptions, which can lead to misunderstandings.

7. RESPECT

This goes both ways. As itinerant providers, we can recognize that we are visitors in the classroom. We need to respect the structure and routine. Classroom teachers can also foster respect through openness, trust and flexibility. This can be hard, especially when you have multiple providers in and out of your classroom. Understand that these providers are there for your student(s) and not to critique. Ask questions and allow them to work within your room.

8. SHARE POSITIVES

Communicate successes to other team members. Celebrate progress together. When we see students making progress from our collaboration, we are more likely to continue putting efforts into working together. As an added bonus, it shows others the impact of the techniques and strategies we are using.

9. START SMALL

As you build trust with your team, begin with small changes and recommendations. These are easier to implement. It can be overwhelming to give a teacher a long list of recommendations, after a single visit. Instead, prioritize a few changes that they can immediately implement. As they see the impact, you can build on the success.

10. BE CLEAR AND CONCISE

Talk and write in a way that others who are not in your profession can understand. Avoid acronyms and technical terms. Be clear and concise (We don't have time to read pages and pages of reports).

Strong collaboration benefits our young students and leads to more fulfilling work for ourselves. •

ABOUT THE AUTHOR:

Anne Gritt, M.S., CCC-SLP is a pediatric speech-language pathologist with expertise in early intervention, developmental language disorder, and complex communication needs. She is a clinical assistant professor in the Department of Speech, Language, and Hearing Sciences at Purdue University (West Lafayette, Indiana), where she co-leads the Preschool Language Program, a preschool for children with communication disorders. In this role, she supports future clinicians in fostering their skills for future interprofessional collaboration.


Direct to Consum

UNTANGLING THE WEB OF MULTIPLE DIAGNOSES

BY MARTA CHMIELOWICZ

Navigating an autism diagnosis can be a challenging journey on its own, but add in depression, anxiety, attention-deficit/hyperactivity disorder (ADHD), gastrointestinal disorders, sleep disorders and a host of other co-occurring conditions, and the journey gets exponentially more complex.

Research shows that having a co-occurring medical, behavioral or mental health condition is much more common in children with autism spectrum disorder (ASD) than the general population. In fact, a CDC study shows that more than half of autistic children have four or more co-occurring conditions.[1] Often, these co-occurring conditions can make it difficult to get an accurate diagnosis, manage symptoms and navigate the world, greatly affecting quality of life.

---

[1] https://pubmed.ncbi.nlm.nih.gov/29524016/

ASK AN EXPERT : LEARNING TO COPE WITH CO-OCCURRING CONDITIONS

In this Q&A, we'll explore common co-occurring conditions with Dr. Amanda Bennett, a developmental and behavioral pediatrician at the Children's Hospital of Philadelphia (CHOP). CHOP is part of the Autism Speaks Autism Care Network (ACNet), a network of 20 medical centers across the U.S. and Canada that are improving clinical care for people with autism. To find your local ACNet site, visit autismcarenetwork.org/locations.

Marta: How can co-occurring conditions complicate an autism diagnosis?

Dr. Bennett: Sometimes, co-occurring medical or behavioral symptoms make it difficult to recognize the autism symptoms, particularly if a child has medical conditions or severe symptoms that impact health and development in other ways.

DR. BENNETT

Completing the medical assessments that may be needed, such as laboratory tests for nutritional concerns or electroencephalograms (EEGs) for seizures, may also be more difficult because of communication deficits or behavioral difficulties associated with ASD. Some autistic patients may have difficulty communicating their symptoms or health needs with their care team, because of their social communication challenges.

Co-occurring conditions can significantly affect quality of life for some autistic individuals, particularly if they have difficulty accessing quality medical and/or behavioral healthcare when it is needed.

Marta: How can people with autism and their families seek effective interventions in the presence of multiple co-occurring conditions?

Dr. Bennett : It's always great when a family has access to a healthcare network like the ACNet that includes an autism center with multiple subspecialty partners, but that is not necessarily available to everyone depending on where they live. I think the number one priority is to find a primary care provider that the family can trust, and who is either experienced with ASD or willing to learn about ASD. Depending on what co-occurring symptoms the autistic person is experiencing, they may also need to partner with other specialists who can help address specific medical or behavioral health needs.

There are a number of resources available online that families can access directly and/or share with their care team. I frequently refer families to the Autism Speaks website to access the free Tool Kits (**www.autismspeaks.org/tool-kit**) that are designed to support families in addressing some of the most common co-occurring conditions. Families can find resources related to managing constipation in children, having an EEG, understanding feeding behaviors and pica, coping with sleep problems and more.

There are also resources that can help families find specialists in their community who have experience with ASD. The Autism Response Team (ART) at Autism Speaks is one resource that can help connect families to local services. To contact ART, email **help@autismspeaks.org** or call 1-888-AUTISM2 (1-888-288-4762). They also have a Spanish language toll-free number and email: 1-888-772-9050, **ayuda@autismspeaks.org**.

Lastly, for providers who want to learn more about ASD (or families who want to refer a provider who wants to learn more), I often recommend participating in a virtual teleconsultation program: ECHO Autism. (**https://autismcarenetwork.org/echo-autism**) ECHO Autism offers clinicians in a variety of specialty fields the opportunity to ask questions and learn about how to support and care for autistic individuals.

Marta: What advice would you give to autistic people coping with co-occurring conditions and their families?

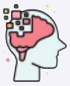
Dr. Bennett: My first piece of advice to anyone who has or loves someone with ASD is to recognize and reach out to the tremendous community of support that exists. I think that may be especially true in places where there are no big academic medical centers that offer all the specialty care you might need under one roof.

When you are in the midst of dealing with any medical or behavioral health issues, it can feel very lonely and frustrating. Don't be discouraged! I am constantly inspired by the energetic, enthusiastic, and motivated families and colleagues I have met over my past decade-plus caring for people with autism.

Find local experts and/or advocates. Participate in a research study or community advocacy group. Find an online community if you can't find a local one. The resources are there, in one form or another, if you just keep looking.

BREAKING IT DOWN : A CLOSER LOOK AT CO-OCCURRING CONDITIONS

Many medical, behavioral and mental health conditions intersect with autism, further shaping the experiences of people with ASD and their families. To learn more about co-occurring conditions in autism, download the Autism Speaks 100 Day Tool Kit for Young Children (www.autismspeaks.org/tool-kit/100-day-kit-young-children) or School Age Children (www.autismspeaks.org/tool-kit/100-day-kit-school-age-children).



MENTAL HEALTH DISORDERS

Many children diagnosed with ASD receive an additional mental health diagnosis, such as ADHD, obsessive compulsive disorder (OCD), depression or anxiety disorder. In many cases, symptoms of ASD are similar to the symptoms of conditions like ADHD, making them more difficult to diagnose. Because people with autism often have trouble assessing and expressing how they feel, behavior often provides the best clues in diagnosing co-occurring conditions, like anxiety or depression. It is important for your child to be evaluated by a professional who has expertise in both autism and other mental health conditions to provide the best treatment options for your child.

EPILEPSY

Experts propose that some of the brain differences that are associated with autism may contribute to seizures. Seizures associated with autism usually start early in childhood or during adolescence, but may occur at any time. If you are concerned that your child may be having seizures, tell your child's healthcare provider. They may order tests that may include an EEG, a Magnetic Resonance Imaging (MRI) scan, Computed Axial Tomography (CAT) scan or a Complete Blood Count (CBC).

GASTROINTESTINAL (GI) DISORDERS

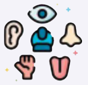
Chronic constipation, diarrhea and abdominal pain are common among children with autism. Pain caused by GI issues can sometimes be recognized by changes in behavior, such as an increase in self-soothing behaviors, like rocking, outbursts of aggression or self-injury. Bear in mind that your child may not have the language skills to communicate the pain caused by GI issues. Treating GI problems and relieving that discomfort may reduce the frequency or intensity of behavioral challenges.

GENETIC SYNDROMES

Some children with autism have an identifiable genetic condition that affects brain development. These genetic disorders include: Fragile X syndrome, Angelman syndrome, Tuberous sclerosis, Chromosome-15 duplication syndrome and other single-gene and chromosomal disorders. Experts recommend that all people with an autism diagnosis get genetic testing to find these genetic changes. The results can help guide treatment, awareness of associated medical issues, and life planning.

SLEEP DISORDERS

Sleep problems are common in children and adolescents with autism. Sleep problems may be caused by medical issues, such as obstructive sleep apnea or gastroesophageal reflux. Addressing the underlying medical issues may solve the problem. When there's no medical cause, sleep issues may be managed with behavioral interventions.



SENSORY PROCESSING DISORDER

Many autistic children have unusual responses to sensory stimuli and process sensory input differently than non-autistic people. This means that while information is sensed normally, it may be perceived much differently. Sensory systems that can be affected include vision, hearing, touch, smell, taste, sense of movement and sense of position. Heightened or diminished sensory responses can profoundly impact daily functioning, requiring occupational therapy and sensory integration interventions.

FEEDING AND EATING DISORDERS

Feeding issues are common in children with autism. Many children have sensory differences that make eating certain foods challenging, heavily restricting their diets. Others have rigid rituals surrounding their eating habits. Pica is one common eating disorder involving eating things that are not food. If you're worried about pica or another feeding behavior, contact your child's healthcare provider. They can help you assess if your child needs a behavioral intervention, or if it is something you can manage at home.

KNOWLEDGE IS POWER

Many people with autism struggle to get accurate diagnoses and effective treatment for their symptoms. For some, genetic testing has opened the door to deeper understanding of their co-occurring conditions, allowing for early detection and better interventions.

"Genetic testing will not give answers to everyone, but for many people, it can help explain the possible causes of autism and reveal future medical issues caused by co-occurring conditions. It can also help guide therapies or care plans to help individuals cope with their symptoms and improve quality of life," says Dr. Dean Hartley, PhD., senior director of genetic discovery and translational science at Autism Speaks.

If you are interested in genetic testing, start by speaking with the provider who diagnosed your child with autism. That person should be able to refer you to a neurodevelopmental pediatrician, a medical geneticist or a clinic that specializes in autism or developmental disorders, and has experience in genetic testing. Families can also join a genetics research study to help researchers find new genetic variations linked to autism that will help more people in the future. Autism Speaks' MSSNG program is a good place to start – for more information, email genetics@autismspeaks.org

ABOUT THE AUTHOR:

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

VOLUNTEERS ARE NEEDED. IF INTERESTED, EMAIL IESBRAINRESEARCH@GMAIL.COM

THE IRENE AND ERIC SIMON BRAIN RESEARCH FOUNDATION

We are back in 2024!

FIRST EVENT SINCE COVID

Endorphin Golf
Outing & Dinner

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

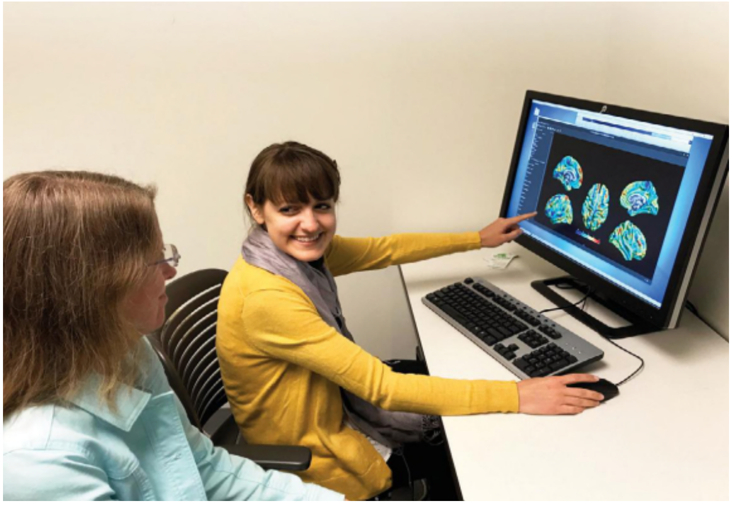
SUMMER FELLOWSHIPS

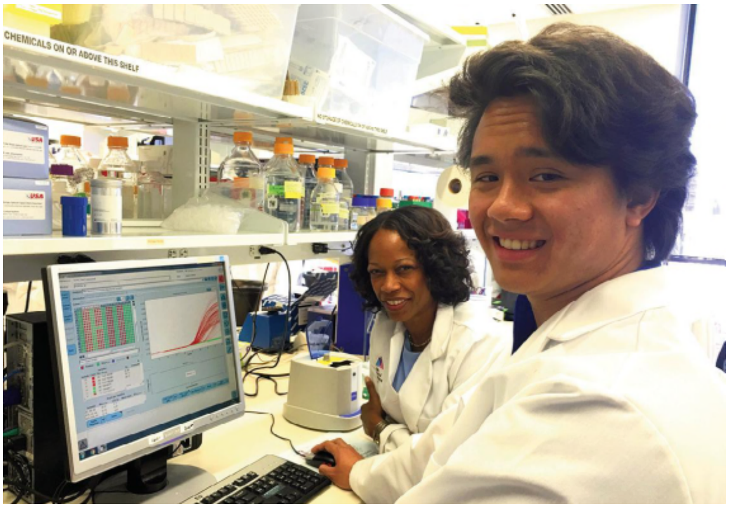
will resume

SPECIAL CELEBRATIONS IN 2024

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

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





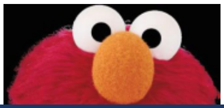
www.iesBrainResearch.org

(973) 726-6218 • iesBrainResearch@gmail.com

www.facebook.com/IESBrain | www.twitter.com/IESBrain | www.instagram.com/iesbrainresearch

MILITARY ONESOURCE

is available to help with your concerns regarding military life.



WE OFFER

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

Sesame Workshop
http://www.sesameworkshop.org

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

WE'RE HERE FOR YOU

No question is too small and no issue too big for Military OneSource. Real help is available anytime, anywhere, at no cost to you:

- Speak to a specialty consultant about education, special needs, and health and wellness questions.
- Receive confidential non-medical counseling services on relationships, anger management, parenting and coping skills.
- Navigate your PCS checklist and plan for your financial readiness with expert help.
- Access resources and valuable information including articles, podcasts and videos to build your knowledge on safe sleeping environments, childhood milestones and healthy boundaries.
- Explore child care options, connect with your local school liaison and discover parenting tools for every age.

WE SERVE

Active-duty service members, National Guard and reserves, recently separated service members, military families and survivors

Connect with Military OneSource

Learn all of the ways Military OneSource can support you. Call **800-342-9647** or visit us at **www.MilitaryOneSource.mil** to find OCONUS calling options or to connect online. We're ready to assist by phone and online, around the clock.

FROM OUR FAMILIES... TO YOUR FAMILIES

MILITARY SECTION

ARMY
NAVY
AIR FORCE
MARINES

BRIDGING THE GAP: 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 may be available through a variety of support systems and community-based services.

AN OVERVIEW OF ADULTS WITH SPECIAL NEEDS

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 (**https://installations.militaryonesource.mil**) 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/military-deployment-support**
- *Special Care Organizational Record for Adults With Special Health Care Needs:* **www.militaryonesource.mil/military-deployment-support**
- *Personal Financial Management Program:* **www.militaryonesource.mil/benefits/personal-financial-management-counseling-options**
- *Family Advocacy Program:* **www.militaryonesource.mil/preventing-violence-abuse/unhealthy-relationships/family-advocacy-program-support**
- ***Relief societies** – Army Emergency Relief:* **www.armyemergencyrelief.org** *Navy-Marine Corps Relief Society:* **www.nmcrs.org** *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** *Air Force Personnel Center:* **www.afpc.af.mil**
- *TRICARE Extended Care Health Option, or ECHO:* **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 – to 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*
- *Military aid societies – Army Emergency Relief:* www.armyemergencyrelief.org *Navy-Marine Corps Relief Society:* www.nmcrs.org *Air Force Aid Society:* www.afas.org

To find more resources and information to support your family member with special needs who has a medical condition or disability, visit:

- *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:* www.ssa.gov

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 (www.militaryonesource.mil/resources/tools/international-calling-options) •

– Military OneSource

U.S. MILITARY ★ BOOK EXCERPT 16TH OF A SERIES

THE RESILIENT WARRIOR

SWIMMING FOR HEALTH

BY JEFF MILLER

Book Editor's Note: Featuring self-help, mental health, and mind and body tactics from a variety of sources – veterans, former and active U.S. Marines, Navy, Army Rangers, Green Berets, family members and caretakers – ***The Resilient Warrior*** *is collaborative collection providing needed wisdom for complete well-being for all of us. The first step to thriving is surviving, and the first step to surviving is knowing how to get what you need, when you need it. The following excerpt of this essential self-help guide to living a healthy, resilient, fulfilled and better life is the sixteenth in a series that EP Magazine has featured over the last several months.*

Harness the "low-impact" style of swimming exercise to assist with injuries, and ultimately mix up your physical fitness routine.

After 28 years of Army mandatory fitness, and even 7 years of grade school and high school sports before that, I finally made the decision that I am sure others with similar backgrounds do. I decided that I had earned the right to stop working out. Partly, it was because I was no longer expected to do it for the Army, but the truth is that it was not fun, and I was not motivated to change that fact.

Fast forward two and a half years and one doctor visit later, it was clear a change needed to be made. I had been "planning on going to the gym" for months and months, but found no motivation to do it. It wasn't until after receiving my dirty bill of health from my doctor and some encouragement from my kids and friends, that I decided it was time to make a change. I went to the local YMCA and signed up. Why the YMCA? Because it had a pool.

I have always loved swimming. Due to some back and knee issues I developed in the Army, it being a low impact form of exercise made it my best option. I started out slow, only spending about 30 minutes swimming, with lots of breaks for rest. The thing I figured out for me, was it was not hard to push my limits with swimming. After having goals of making it 200 meters without stopping, it quickly moved to 400, then 600. After only a week of swimming 3 days a week, I was up to 800 meters with only one or two 30-second breaks. This was an instant motivator for me. I felt like I was making massive gains in my endurance, and with it being low impact, I did not have the after pains that I expected.

This is when I started to turn back into the Army guy who'd left me for greener pastures, a few years ago. I began to demand more of myself, and to maintain my dedication for getting in shape. I told everyone at work what I was doing. These were people who would not only listen, but would ask me how I was doing. I also told my friends and family, and while I wasn't going to let them down, mostly I needed this for myself.

Currently, I am swimming 1,600 meters per session without stopping. I do not touch the bottom of the pool or push off the wall, so I have the feeling of truly swimming with no break. I am limited on my time in the pool (60 minutes per session), so I am trying to develop different training strategies to increase my workout. While in an Infantry unit, we would conduct water survival training. Swimming while wearing your field uniform is quite challenging, as it adds drag to your swim. I will be incorporating this theory by wearing a long-sleeved shirt. I have also ordered a weight belt to add resistance.

Since I have started swimming, not only have I lost a substantial amount of weight, but my energy levels have also been soaring. I am more active during work and after, and I feel more positive about my direction in life. I look forward to going to the gym and plan to add other activities back into my life. Keeping physically fit is invaluable in maintaining mental fitness. •

TAKE IT TO THE LIMIT: Due to some back and knee issues I developed in the Army, swimming being a low impact form of exercise made it my best option. The thing I figured out for me, was it was not hard to push my limits with swimming.

ABOUT THE AUTHORS:

Jeff Miller Staff Sergeant (ret) spent 28 years with 1st Squadron 113th Cavalry Regiment, 2nd Brigade Combat Team, 34th Infantry Division. He proudly is continuing service with the Department of Veterans Affairs.

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

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

The Politics of Dating

Hayden taught me something that day. Hayden knows Broden's world, and he cares about who's in it.

Over the years, I've witnessed my son, Hayden, maneuver through relationships throughout his life. As we've moved to different installations, Mark and I have not been the only ones who have had to explain Broden's autism to others who are new to our family. The other day, I called Hayden, who is currently a sophomore in college, and asked him if he would be open to answering some questions about dating. Over the years, I have been curious if having a brother with severe autism has shaped the decisions that he has made in the past on who he has dated. Is it harder for him to date? Does having a brother with autism affect his choices in who he wants to date? I had Hayden on speaker at the kitchen table. Mark wanted to hear what he had to say, so he came over and sat next to me to listen. We've never had a conversation like this before and I was intrigued to know what Hayden's thoughts were on the matter.

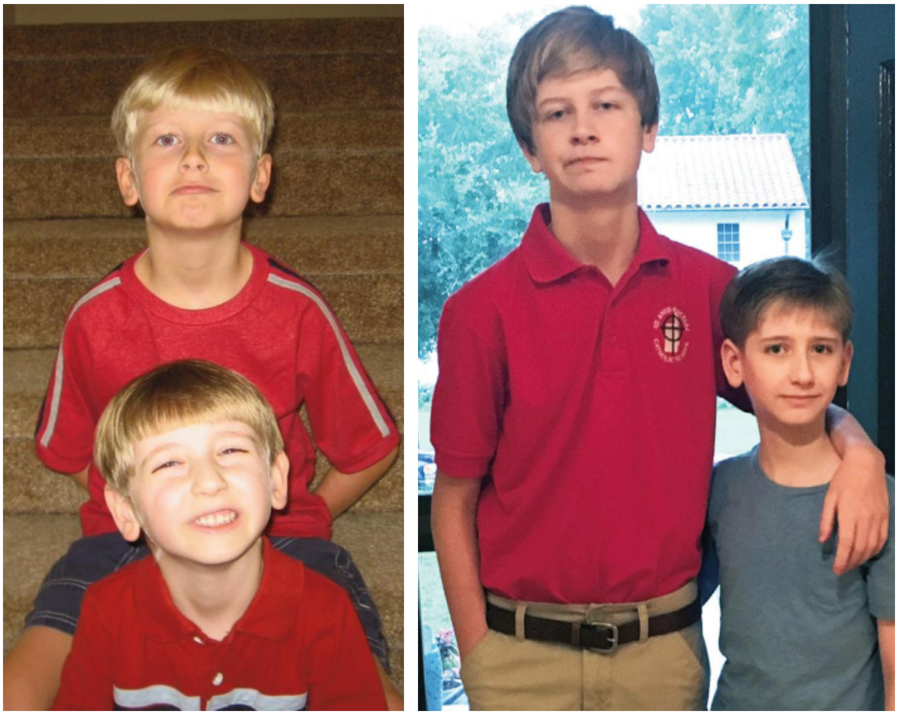
Hayden is only 20 months older than Broden. When Broden was diagnosed with autism, Hayden was around 3½ years old and still in preschool. Hayden only knows how to be a brother to someone with autism. Mark and I have realized that this experience has shaped him in ways that we could never imagine. Hayden shared with me during our conversation about dating that not only do they have a connection; their connection is non-negotiable.

When I spoke to him the other day, I asked Hayden if Broden's autism ever made dating more complicated, or if he hesitated to tell someone about Broden, "I don't hesitate at all. When we talk about each other's siblings, I bring up Broden and that he has autism." He later explained that Broden is just part of his life, "Broden having autism is all I've ever known. If they say something that is a turnoff about Broden, then I'm done. That's a gamechanger for me."

When I asked Hayden if he had ever experienced a negative reaction about Broden, he initially said no. Then he changed his mind after thinking about the question, "Actually I did have something that turned me off once. In a past relationship, I had a girl assume she knew how to interact with Broden. She kept pushing a relationship with him. I felt like she kept taking the wheel and not allowing me to guide her on how to interact with him. That really bothered me." After listening to him, I learned that he is protective of Broden and feels that he is responsible for whoever he brings into our home. If that person does not respect Broden's space or accept

GOING PLACES: Hayden explained that Broden is just part of his life. "Broden having autism is all I've ever known. If someone says something that is a turnoff about Broden, then I'm done."

PHOTOS PROVIDED BY SHELLY HUHTANEN



GROWING STRONG: When Broden was diagnosed with autism, Hayden was around 3½ years old and still in preschool. This experience has shaped him in ways that we could never imagine.

Hayden's lead on how to interact with Broden, then Hayden will be frustrated.

When Hayden came home after his first semester this year, he sat down next to me on the couch and said, "Mom, there's this girl I've been talking to that I really like and I want her to come to the house to meet you guys." He's brought a few girls by the house before, so this wasn't too surprising. He always tells me in advance when he wants to bring someone new to the house, as a courtesy. I usually ask if the person he's bringing knows about Broden, and every single time that I ask, he tells me he's informed them in advance.

> "For Hayden to trust the person he was with, they would need to let him guide the relationship with Broden."

A few days before Hayden was supposed to head back to college, Hayden, his girlfriend and I were sitting on the couch talking. His girlfriend was giggling and telling me that Broden kept picking certain wrappers out of the trash and laying them out on the bathroom counter. I eventually said, "Broden will live with us until we are too old to care for him. There may be a day when Hayden will decide what he wants Broden's living arrangements to look like when we're too old. Does he want to take him in? If not, then what will it look like?"

His girlfriend looked over at Hayden waiting for him to respond. He stared down looking at his hands, "It would be hard. I would be working every day, and I would need to make sure he's getting everything he needs." His girlfriend looked over at Hayden, "Yes, but he's your family. We take care of our family. You wouldn't be alone. You would most likely be married. You would have help." Hayden nodded as he listened to her. She later said, "If that was me, I would help you." He looked up with a soft smile on his face.

Hayden later explained, "When my girlfriend came over last month, she stood back and let me guide the interaction with Broden. She didn't just barge into his room and try to engage him. I was in control. I liked that."

The more I listened to him, the word "trust" came to mind. For him to trust the person he was with, they would need to let Hayden guide the relationship with Broden, because Broden is a part of Hayden that is special and protected.

It seemed that even Broden's room was somewhat of a protective space, "I normally just have my visitor say hello to Broden from the hallway. I don't bring them into his room right away. I wait to see if it's the right time." I thought that was very perceptive of Hayden, because Broden is very particular of where things are in his room. If you move something on a dresser or a shelf, he will move it back. His space is special to him, and Hayden acknowledges and respects that aspect of Broden.

Ws we said our goodbyes on the phone, Hayden said, "I'll say one thing that I have experienced with my girlfriend that I haven't experienced before. She really cares about me and she cares about my family. I've realized that's very important to me." For so many years, I would say that Hayden and Broden were like two only children. They never went to the same school. They never shared friends. They were in two different worlds, but Hayden taught me something that day. Hayden knows Broden's world, and he cares about who's in it. This is something he doesn't take lightly and, in the end, it will influence who he chooses to be in his life. Broden is his family and will always be. •

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.

CLEANING/SANITIZING SOLUTIONS

BANTEC SANITIZING
www.bantec.store
Easy to use disinfecting products and safe, environmentally friendly hygiene strategies that are efficient and cost effective.

FINANCIAL PLANNING/ ESTATE PLANNING/ INSURANCE

MASS MUTUAL SPECIALCARE
www.massmutual.com/specialcare
Financial planning products and services by a company that cares.

THE AMERICAN COLLEGE OF FINANCIAL SERVICES
www.theamericancollege.edu
A private college focused on professional training for financial practitioners

NON-PROFIT

IRENE AND ERIC SIMON BRAIN RESEARCH FOUNDATION
www.iesbrainresearch.org
Helping to further research and find answers to addiction, pain and other brain diseases and disorders.

SCHOOLS AND CAMPS

PERKINS SCHOOL FOR THE BLIND TRANSITION CENTER
Perkins.org/TransitionSupport
Explore our tailored programs, discover expert resources and services for families, and join our upcoming caregiver community.

COMING NEXT MONTH IN EP:

THE ANNUAL ISSUE

TO LEARN MORE ABOUT ADVERTISING OPPORTUNITIES

CALL 973-726-6218
OR EMAIL EPMAGAZINEVP@GMAIL.COM

ADVERTISE IN EP MAGAZINE

Exceptional Parent Magazine, a print and digital publication for over 50 years, provides information on disabilities and special health care needs and is available for free (EP for Free) at **www.epmagazine.com**

EP provides informative articles, resources and inspirational stories for children and adults with disabilities and special healthcare needs. The information covers all ages from infancy to elderly. *EP Magazine* also includes a military section dedicated to the unique challenges of military families caring for loved ones with disabilities, including returning veterans.

EP Magazine has a varied and constantly growing readership of individuals, families, caregivers, education and medical professionals. Our partnership with various organizations and universities greatly increases our exposure nationwide.

We offer digital and print advertising opportunities for companies whose PR plan includes corporate warmth and/or companies with products & services they would like to advertise to our readers. Custom advertising packages can be created to meet your needs. Contact Faye at
epmagazinevp@gmail.com

talk
they hear you®

SHE WANTS TO HANG OUT WITH FRIENDS OUTSIDE OF SCHOOL.

Help her plan to resist peer pressure.

Fifty-three percent of people ages 12 to 17 got prescription pain relievers from a friend or relative. Talk to your children about having an “exit plan” if they are offered prescription pain relievers that don’t belong to them. Having a plan to avoid drug misuse can help children make better choices. For tips on how—and when—to begin the conversation, visit:

www.underagedrinking.samhsa.gov

SAMHSA
Substance Abuse and Mental Health
Services Administration