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2023

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EP MAGAZINE 1971 2023 52 YEARS CELEBRATES

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JANUARY 2023 VOLUME 53 ISSUE 1

## 2023 EP GUIDE

### ON OUR COVER

Our first issue of the year is always our longest and 2023's EP Guide: Navigating Special Needs Resources is no exception. It's a super-sized edition packed with advice, resources and unique insight from some of the top experts in their respective fields. *Coverage begins on page 17.*

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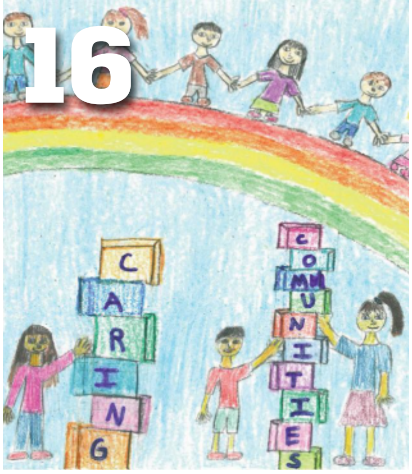

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We Help You Help.

# Resolutions

## The new year is bringing a new focus to improve the magazine and to better serve our audience.

As we ring in the new year, EP is proud to present the 2023 EP Guide: Navigating Special Needs Resources. Our first issue of the year is always our longest and this year is no exception, with a super-sized edition packed with advice, resources and unique insight from some of the top experts in their respective fields. Just a few of the topics covered in the 2023 EP Guide include early intervention, reading and literacy, estate and care planning, and school-to-work transition. And don't forget, past issues of the EP Guide are also filled with valuable resources and articles, and are always available by visiting **www.epmagazine.com** and clicking Archive in the menu banner.

> "Our first issue of the year is a super-sized edition packed with advice, resources and unique insight from some of the top experts in their respective fields."

The new year is bringing a new focus to our magazine. 2023 marks the 52nd year of continuous publication for *EP Magazine*, and our resolution, as always, is to improve the magazine and to better serve our audience. This year, significant changes have been made to our editorial calendar, with the goal of expanding our coverage of subjects like adaptive recreation, accessible travel, and care across the lifespan. We are committed to continue featuring inspirational and influential figures who advocate for those in their community. We are resolved to remain a significant resource of information and advice and to expand our reach to as many people with special needs as possible.

We invite our readers and supporters to offer any suggestions or ideas for topics they would like to see covered more or subjects we have yet to explore. We consider all feedback to be invaluable in our effort to enhance the magazine and make it even more helpful to our audience. Join the ongoing discussion of how to make *EP* better by contacting me at **epmagazinevp@gmail.com** with comments, suggestions or feedback.

All of us at EP wish all of our readers a happy new year and ask that you share our publication, and the fact that they can read it for free, with as many family members, colleagues and associates as you can. We make it easy for anyone to subscribe and to receive "EP for Free" – just visit us at **www.epmagazine.com** and click Subscribe! While you're at it, please share our Instagram feed at **instagram.com/epmzine** and be sure to like us on Facebook at **facebook.com/exceptionalparentmag** .

Faye Simon

Editor In Chief

### THE EDITOR IN CHIEF'S DESK

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

*Information and Support for the Special Needs Community*

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# WHAT'S HAPPENING

## REMOTE WORK EVENS PLAYING FIELD FOR WORKERS WITH DISABILITIES WITH RECORD EMPLOYMENT

An overall labor shortage and a wider acceptance of remote working have presented historic opportunities for some of the country's most skilled and underutilized workers.

**REMOTE POSSIBILITIES:** Despite the accommodation requirements of the ADA, some companies stuck with the idea that work can only be performed successfully in a physical location, which left many people out of the employment pipeline.

Employment rates among people with disabilities dropped, along with the rest of the labor market, early in the pandemic. However, they recovered quickly. People with disabilities aged 25 to 54, the prime working age, were 3.5 percentage points more likely to be employed in 2022 than they were pre-pandemic.

The labor market recovery for those with disabilities was markedly faster than for those without disabilities. We know that those with disabilities and those without faced similar market conditions. Remote work appears to offer the major differentiator that enabled workers with disabilities to be productive.

There had been some gains over recent years as employers dipped into previously untapped pockets of potential employees to fill open positions to include people with disabilities. Remote work was one area where such workers had been making some progress in the days before the pandemic, although telework was still underused in most workplaces. Despite the accommodation requirements of the ADA, some companies stuck with the idea that work can only be performed successfully in a physical location, which left many people out of the employment pipeline.

The labor force participation rate of people with disabilities, or the share of the population working or looking for work, was about 37 percent in August 2022, according to an analysis by the Kessler Foundation and the University of New Hampshire. This is about a 5 percent increase compared with April 2020.

Enabling people with disabilities to work remotely offers the opportunity for them to either establish or leverage an existing setup that meets their needs and enables them to contribute successfully. At the end of the day, no one is more qualified to know what setup they need to be successful than they are.

> *"The labor force participation rate of people with disabilities, was about 37 percent in August 2022, about a 5 percent increase."*

Russell Rawlings, 45, who lives in Sacramento, CA with cerebral palsy told the *Los Angeles Times* that, up until the pandemic, he was going into the office at a nonprofit independent living center Monday through Friday.

The commute was just two miles from his home, but Rawlings got up at 5 a.m. to make it to work by 8. It took that long for him to get ready and into his powered wheelchair to the bus stop and to his desk. It was even harder on rainy days; he needed someone to help him put on his poncho before heading out.

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In March, Rawlings started a new job as an education organizer for Hand in Hand, which assists domestic workers. The newly created position is fully remote. Now, thanks largely to the widespread acceptance of remote working, he's not only eliminated that difficult commute, but is also working in a position that gives him a greater sense of self-worth and accomplishment.

"For all my years spent on SSI, it just seemed impossible," he said. "I never thought I would be able to do community organization remotely."

As remote work is normalized, this may be the tipping point where organizations take advantage of an unprecedented opportunity to tap into a potentially new and vibrant labor market among Americans with disabilities. With issues around recruitment, retention and talent acquisition remaining at the fore, offering the option to work remotely simply makes sense. The necessity to pivot and move employees to home spaces has demonstrated that remote work can be highly successful, even in the face of what used to be considered less-than-optimal circumstances.

PHOTO COURTESY MARC A. HERMANN/MTA

# WHAT'S HAPPENING

## SOCIAL SECURITY AND DISABILITY BENEFICIARIES BEGIN RECEIVING 8.7% COST OF LIVING INCREASE

The Social Security Administration (SSA) has announced an 8.7% increase in Social Security and Supplemental Security Income (SSI) benefits for 2023, the largest cost-of-living increase (COLA) in years, due to recent inflation.

Increased payments to Social Security recipients begin in January 2023, while increased payments to SSI recipients will be included in their checks or deposits on December 30, 2022. Other numbers regarding eligibility for disability and average benefits have also changed for 2023.

**COLA AND A SMILE:** Social Security anticipates an average disability benefit of $1,483, an increase of $119.

### WHAT ARE THE SOCIAL SECURITY BENEFIT AMOUNTS IN 2023?

While the exact Social Security retirement and disability benefit amount that a person can receive depends on their lifetime earnings, here are the average benefit amounts that Social Security anticipates for 2023:

- *Average retirement benefit: $1,827 (an increase of $146)*
- *Average disability benefit: $1,483 (an increase of $119)*
- *Average widow's or widower's benefit: $1,704 (an increase of $137).*

The maximum Social Security retirement benefit that can be collected at full retirement age is $3,627 per month in 2023, though few people (very high-earners) are able to collect this amount.

### HOW ARE YOUR SSDI PAYMENTS CALCULATED?

SSDI payments depend on your average earnings over the past 35 years (actually, Social Security will use the 35 years in which you had the highest income). Social Security will average your earnings over these 35 years to come up with your "average indexed monthly earnings" (AIME). The agency then takes certain percentages of your AIME (called bend points) to come up with your primary insurance amount. In 2023, the bend points are:

- *90% of the first $1,115 of your AIME*
- *plus 32% of your AIME from $1,115 to $6,721*
- *plus 15% of your AIME over $6,721.*

For details on the calculations, see our article on how much you'll get in SSDI.

### HOW MUCH IS SSI IN 2023?

The new SSI federal base amount is $914 per month for an individual and $1,371 per month for a couple (up from $841 and $1,261 in 2022). The SSI payment amounts are higher in states that pay a supplementary SSI payment. Most SSI recipients, however, receive less than the federal base amount because of income or free room and board.

### DOES WORKING AFFECT ELIGIBILITY FOR DISABILITY?

An applicant for disability benefits through the Social Security disability insurance (SSDI) or SSI programs must be making less than $1,470 per month (up from $1,350 per month in 2022) to qualify for benefits. (Blind applicants can make up to $2,460 per month). Anyone working above those limits is considered to be doing "substantial gainful activity" (SGA).

### SSDI LIMITS ON WORKING

People who are currently receiving SSDI and who attempt to return to work can make more than that during a trial work program. SSDI recipients can get up to nine months of trial work. A month counts as a trial work period month when an SSDI recipient makes more than $1,050 per month (up from $970 per month in 2022).

### SSI LIMITS ON WORKING

For people who are receiving SSI, the new federal income limit for SSI is $914 per month, but complicated rules govern what income is countable and what income is not. Over half of the income made by an SSI recipient isn't counted toward the limit, so you can actually receive SSI until you make up to $1,912 per month in 2023 (if you have no other income).

But any income you receive between $0 and $1,912 will reduce your monthly benefit. (For instance, if you earn $1,225 a month and have no other income, your SSI check will be only $344.) To learn how the SSA calculates the reduced benefit, see our article on countable income for SSI. In some states that make extra payments to SSI recipients, the income limit for SSI recipients may be higher.

The income exclusion amount for students receiving SSI is now $2,220 per month (up to an annual limit of $8,950).

### DOES WORKING DURING EARLY RETIREMENT AFFECT BENEFITS?

If you collect early retirement benefits but continue to work, Social Security will reduce your benefits if you make over $21,240 per year ($1,770 per month) in 2023. But during the year you reach full retirement age, you can make up to $4,710 per month without having retirement benefits taken away. (After you reach full retirement age on your birthday, your benefits aren't reduced at all, regardless of the amount of work or earnings.) Any early retirement benefits that Social Security deducted while you were working are added back to your retirement check over the next 10 to 15 years.

### HOW MUCH IN TAXES DOES SOCIAL SECURITY WITHHOLD?

The maximum amount of earnings that is subject to the Social Security tax is $160,200 in 2023, up from $147,000 in 2022. There is no limit to the amount of income subject to the Medicare tax.

# WHAT'S HAPPENING

## JENNIFER LAWRENCE PORTRAYS A VETERAN STRUGGLING WITH A BRAIN INJURY IN 'CAUSEWAY'

New film starring Jennifer Lawrence depicts experience of U.S. Veteran with traumatic brain injury with scientific accuracy and depiction of invisible wounds

The new movie *Causeway* from Apple Studios and A24 stars Jennifer Lawrence as Lynsey, a soldier who has returned from Afghanistan. At home in New Orleans, she bonds with James (played by Brian Tyree Henry).

The film follows Lynsey, a military engineer who suffered a traumatic brain injury while deployed in Afghanistan, and her struggles with rehabilitation and depression adjusting to life back home.

Lynsey must learn how to walk again, and rejuvenate her memory. Returning home to Louisiana also surfaces new mental traumas about her childhood. During her new job as pool cleaner, she meets Tyree, Henry's character. As their friendship blossoms, they rely on each other more and more for support.

**HIDDEN TRAUMA:** A soldier struggling with invisible wounds tries adjust to being back home in New Orleans.

Often considered an invisible disability, a traumatic brain injury, or TBI, is not one that anyone can recognize by outward appearance. The film shows explores how this type of injury can impact a person's life, both physically and mentally. It also depicts the difficulty the people around Lynsey havin in understanding the impact TBI has on her, and how serious and longlasting the effects can be.

The film hails from esteemed studio A24, and represents director Lila Neugebauer's debut film. Response to the project has been positive. Causeway is already generating awards buzz for Lawrence and Tyree Henry. Early critical reviews praised Lawrence's performance as a strong return to form in her movie career.

*Causeway is streaming on Apple TV+ through the Apple TV app on your device, or in a web browser at tv.apple.com.*

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# WHAT'S HAPPENING

## $1.7 TRILLION SPENDING BILL BOOSTS SPECIAL ED, DISABILITY PROGRAMS, BANS SHOCK TREATMENTS

More funding for special education, the expanding access to ABLE accounts, and restricting the use of electric shock on people with disabilities are included in the newly approved $1.7 trillion federal spending bill.

**WELCOME ADJUSTMENTS:** The bill allocates almost $773 billion for domestic programs, like education, healthcare and affordable housing.

The legislation was signed by President Joe Biden on December 29th and funds the government through September. The White House said Thursday that the bill "caps off a year of historic bipartisan progress for the American people."

The spending plan Congress approved includes over $15 billion for special education, a $904 million jump over last year, and it extends Money Follows the Person, a Medicaid program that helps people with disabilities move from institutions to community-based living, through September 2027.

The new bill includes a welcome adjustment to the age at which an individual is eligible to open an Achieving a Better Life Experience (ABLE) account.

ABLE accounts permit people with disabilities to save up to $100,000, tax-free, without fear of losing certain federal disability benefits.

Previously, you could only set up such an account if you had become disabled prior to age 26. Starting in 2026, you will be eligible for an ABLE account if you became disabled before age 46.

The higher age limit, which is expected to make an additional 6.2 million people eligible, had been long sought by disability advocates and others in order to broaden access and increase the number of ABLE accounts opened to help ensure that the program is sustainable.

In addition, the Housing for Persons With Disabilities Program has received an increase in funding of $8 million. This program seeks to aid people with disabilities with very limited income in living independently within their community by securing housing that is within their means and offers supportive services.

> *"The measure increases the eligibility age for ABLE accounts, allowing people with disabilities a way to save more money without jeopardizing their government benefits."*

The legislation also creates guidelines that will allow the Food and Drug Administration to ban what are known as electrical stimulation devices, which send shocks through electrodes attached to the skin in order to condition people not to engage in self-injurious or aggressive behaviors. According to the FDA, these devices are used at the Judge Rotenberg Educational Center in Canton, Mass., which serves children and adults with developmental disabilities as well as those with behavioral and emotional problems, the last institution in the U.S. known to engage in such therapy.

With the new legislation, Congress has clarified that the FDA has the right to institute such a ban. For years, advocates have pushed to end the practice and in 2020 the FDA finalized a ban on electrical stimulation devices citing an "unreasonable and substantial risk of illness or injury." The regulation was overturned, however, when the U.S. Court of Appeals for the D.C. Circuit determined that the agency had overstepped its authority.

Now, "This opens the door for FDA to pass another ban without fear that it will be struck down on the same grounds," said Autistic Self Advocacy Network director of advocacy Zoe Gross, describing the development as "a step forward."

Congress did not elect to increase asset limits for Supplemental Security Income recipients within the government funding measure despite a strong bipartisan push. Currently, individual SSI beneficiaries can have no more than $2,000 in assets at any given time under limits that have remained static for decades.

"It's very disappointing that Congress didn't take the opportunity to help lift people with disabilities out of poverty, by simply bringing the SSI asset limit out of the 1980s into this century. We will continue to push for this change in the new year." said Peter Berns, CEO of The Arc.

# PANDEMIC MEDICAL INNOVATIONS LEAVE BEHIND PEOPLE WITH DISABILITIES

BY LAUREN WEBER

**Divya Goel, a 35-year-old deaf-blind woman in Orlando, Florida, has had two telemedicine doctors' appointments during the pandemic. Each time, she was denied an interpreter.**

Her doctors told her she would have to get insurance to pay for an interpreter, which is incorrect: Under federal law, it is the physician's responsibility to provide one.

Goel's mother stepped in to interpret instead. But her signing is limited, so Goel, who has only some vision, is not sure her mother fully conveyed what the doctors said. Goel worries about the medical ramifications — a wrong medicine or treatment — if something got lost in translation.

"It's really, really hard to get real information, and so I feel very stuck in my situation," she signed through an interpreter.

Telemedicine, teleworking, rapid tests, virtual school, and vaccine drive-thrus have become part of Americans' routines as they enter Year 3 of life amid covid-19. But as innovators have raced to make living in a pandemic world safer, some people with disabilities have been left behind.

**COMMUNICATION BREAKDOWN:** Lise Hamlin experienced frustration over a lack of interpretive services during telehealth visits.

Those with a physical disability may find the at-home covid tests that allow reentry into society hard to perform. Those with limited vision may not be able to read the small print on the instructions, while blind people cannot see the results. The American Council of the Blind is engaged in litigation against the two dominant medical testing companies, Labcorp and Quest Diagnostics, over touch-screen check-in kiosks at their testing locations.

Sometimes the obstacles are basic logistics. "If you're blind or low-vision and you live alone, you don't have a car," said Sheila Young, president of the Florida Council of the Blind, pointing to the long lines of cars at drive-thru testing and vaccination sites. "Who can afford an Uber or Lyft to sit in line for three hours?"

One in 4 adults in the U.S. have some sort of disability, according to the Centers for Disease Control and Prevention. Though barriers for the disabled have long existed, the pandemic brings life-or-death stakes to such long-running inequities.

"The only thing that I see is that folks with disabilities are cared for last and are dying first," said Matthew Dietz, a founding member and the current litigation director of the Disability Independence Group in Florida.

People directly affected by accessibility barriers, especially those living in communal settings or the homebound, often don't have the time, money, or energy to file legal complaints.

Federal, state, and local governments also violate disability statutes. A KHN investigation last year found that government vaccine registration websites were inaccessible to the blind. Spurred by that story, the Department of Justice reached an agreement with five New York local and state government agencies to correct such issues. The DOJ has since reached settlements with Rite Aid, Hy-Vee, Kroger, and Meijer to ensure accessible registration for vaccination appointments.

Following an outcry from disability advocates, the CDC updated its list of those with increased risk of severe covid to include people with disabilities. And in mid-February, the National Institutes of Health's Rapid Acceleration of Diagnostics Tech program announced an effort to create accessible at-home covid tests, while the Department of Health and Human Services called on manufacturers to assess at-home covid tests' operability for those with disabilities.

But as many doctor appointments have shifted online to keep patients safe amid covid surges, the inaccessibility of telemedicine has become more of an issue, said Howard A. Rosenblum, CEO of the National Association of the Deaf. The Americans with Disabilities Act and other disability statutes are being violated, he said, when health care providers do not provide telemedicine technology with captioning or the ability for interpreters to be in the same teleconference.

When Lise Hamlin needed to see her nurse practitioner in the 2020 depths of the pandemic, she was initially thrilled to set up a telemedicine appointment to avoid the risk of covid exposure. Until she realized the virtual visit wouldn't have captioning.

As a person with hearing loss, Hamlin lip-reads and uses captions to help understand video meetings. The resident of Germantown, Maryland, could barely follow along during the appointment. As director of public policy for the Hearing Loss Association of America, she was enraged. But she was hesitant to do much about it.

"You're in the middle of a pandemic, how much do you want to alienate your doctor?" she asked.

A small number of health care providers, such as UAB Medicine in Birmingham, Alabama, and MedStar Health in the Washington, D.C., area, do offer interpretive services. Zoom also has a caption-

PHOTO COURTESY ERIC HARKLEROAD / KHN

ing option. But more than 35% of physicians have no idea what their legal responsibilities are to disabled patients under the ADA, according to a Health Affairs article published in January.

"There's no ADA police," Hamlin said. "All the burden is on the consumer."

Lise Hamlin sits in an office chair, petting her black laborador/golden retriever mix hearing dog, Shine.

**MIXED SIGNALS:** Lise Hamlin with her hearing dog, Shine; Hamlin uses captions and lip-reading to better understand video meetings.

Lise Hamlin with her hearing dog, Shine. Hamlin uses captions and lip-reading to better understand video meetings. When she realized her telemedicine appointments wouldn't have captions, she was enraged, but hesitant to do much about it. "You're in the middle of a pandemic, how much do you want to alienate your doctor?" she asks. Goel's doctors broke the law, but they are not being punished or penalized for it. And she doesn't know whom she would talk to about suing.

Although the technology advancements in Goel's lifetime – like the free interpretation service used to conduct this interview with her – have given her more independence and connection with others, the pandemic has stripped much of it away, she said. It has limited her ability to use Uber to travel places due to increased cost and pandemic risk, and isolated her at home with her parents. "Instead of growing in independence, it just feels like I've gone backwards," she said.

The accelerating shift toward at-home testing that used to be done in doctors' offices is another growing problem for disabled Americans, said Bryan Bashin, CEO of the LightHouse for the Blind and Visually Impaired in San Francisco.

Take colon cancer screening, he said. Many doctors now recommend patients do a fecal collection at home: Put a portion of one's poop in a test tube, write the date on it, and send it to the lab.

"Let me tell you, I will never subject a friend of mine to help me with this," said Bashin, who is blind. While he was eventually able to schedule a screening appointment with his doctor after talking to his insurance company, it delayed his care.

"Accessibility needs to be part of what we do as a government, as a society," Bashin said. "The ADA says that you don't just have accessibility when things are running normal."

Michelle Hackman, a blind *Wall Street Journal* reporter in Washington, D.C., tried to get her rapid covid tests reimbursed via her Aetna health care flexible spending account. But Aetna insisted she print out and mail or fax the receipts, even after she called and explained how difficult that would be for her. It then asked her to have someone help her – something Hackman is all too used to hearing.

"That's really the indignity," she said, especially when she didn't want to risk infecting anyone. Eventually, she talked a manager at Aetna into letting her forward her Amazon receipts.

"Imagine going through this for every single receipt I want to submit," she said.

When asked about its response to Hackman's situation, Aetna spokesperson Ethan Slavin said: "We're committed to making all of our services accessible to our members and make appropriate accommodations for members with disabilities." The company then reached back out to Hackman to process her forms. Slavin also sent KHN a medical information release form for Hackman to fill out, which would have allowed the company to discuss her situation. But she would have had to print, write on, and rescan it – the problem she called them about at the start.•

### ABOUT THE AUTHOR:

Lauren Weber, KHN Midwest Correspondent, writes about the public health challenges, supply chain scrambles, rural health ramifications, and equity issues associated with the covid-19 pandemic from her hometown of St. Louis. She was a member of the KHN-AP reporting team on the Underfunded and Under Threat project on public health that won a gold AAAS Kavli Science Journalism Award and the Online News Association's University of Florida Award for Investigative Data Journalism. Formerly a health policy reporter for HuffPost based in Washington, D.C., while there she created "The Morning Email," a weekday rundown of the news, and was the distinctive voice of HuffPost on Amazon Echo. She was a 2017 USC Annenberg Health Journalism National Fellow.

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## TANGLE

This Tangle toy has proven to be a great stress reliever and fidget toy for individuals with Autism Spectrum Disorder as well as Sensory Processing Disorder. With bumps and grooves, Tangle provides tactile and visual sensory stimulation making it impossible to put down. The puzzle-like nature of the toy provides an extended time of fun and different possibilities, enhanceing fine motor skills and dexterity.

**AUTISM COMMUNITY STORE**
www.autismcommunitystore.com

PART III OF A SERIES

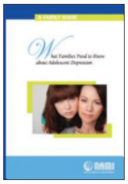
# CHILDREN'S MENTAL HEALTH: A NATIONAL FAMILY GUIDE

SUBMITTED BY SPAN ADVOCACY NETWORK

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

## MEDICATIONS : GUIDES ON MEDICATION USE AND FINDING BALANCE

Medication use is a personal decision. Families need to realize, however, that mental illness is "biologically based." Families may also be concerned about the "black box warnings" on certain medications for children. The warning, although warranted, has predictably lowered the amount of certain prescriptions; however, there must be recognition that untreated depression is the highest risk factor for suicide. There are some excellent guides on medication use which should help parents, which also address this issue of balance.



### NAMI'S FAMILY GUIDE ON ADOLESCENT DEPRESSION

www.nami.org/caac/depression/familyguide"

Includes information about treatment, medication, and the "black box warning." It includes good questions to ask providers such as:

- *What are the benefits vs. the risks of the medication?*
- *What are the side effects of the medication?*
- *How can the child be involved in the decision-making process?*

### PARENTS MED GUIDE

www.parentsmedguide.org

A series of guides endorsed by the American Psychiatric Association and American Academy of Child & Adolescent Psychiatry:

- *The ADHD Parent's Medication Guide is available in English and Spanish.*
- *Parent's Medication Guide for Bipolar Disorder is only available in English.*
- *Depression: Parents' Medication Guide is only available in English.*

### NYU LANGONE HEALTH

med.nyu.edu/departments-institutes/child-adolescent-psychiatry

NYU Medical Center has a listing of different types of medications for children's mental illness and their uses.

**BUILDING BRIDGES:** 2011 G.E.A.R. Parent Network winning poster, “Hand in Hand,” by an 11-year-old artist from Maine.

## SUPPORTS AND SERVICES : RESOURCES FOR INDIVIDUALS AND FAMILIES

### SAMHSA

Substance Abuse and Mental Health Services Administration

**www.samhsa.gov**

Emphasizes a Wellness/Recovery Model. Prevention as well as getting better, are the key ideas. This idea of wellness is based on “evidence- based practices” (proven to work). The key recovery concepts are hope, education, personal responsibility, support and self-advocacy.

**www.samhsa.gov/recovery.**

Treatments by condition

**www.samhsa.gov/treatment/mental-disorders**

Searchable treatment locator

**http://findtreatment.samhsa.gov/locator**

### NAMI

**www.nami.org**

Choosing the right treatment

**www.nami.org/Content/ContentGroups/CAAC/ChoosingRightTreatment.pdf**

Classes for families dealing with mental illness

**www.nami.org/Local-NAMI/Programs?classkey=e4bf6c93-2a0e-490f- 982b-c1352ec1298e**

Additional resources from their Child & Adolescent Action Center

**www.nami.org/Your-Journey/Family-Members-and-Caregivers/Learning-to-Help-Your-Child-and-Your-Family**

Coping with Crisis: Helping Children with Special Needs”

**www.nasponline.org/resources/crisis_safety/specpop_general.aspx**

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Sometimes parents just want to talk to other families who have “been there.” Parent-to-Parent matches trained volunteer families to other families with the same condition

**www.p2pusa.org**

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Mental Health America support groups local affiliates

**www.mentalhealthamerica.net/find-affiliate**

### A SPECIAL NOTE ON NATURAL DISASTERS

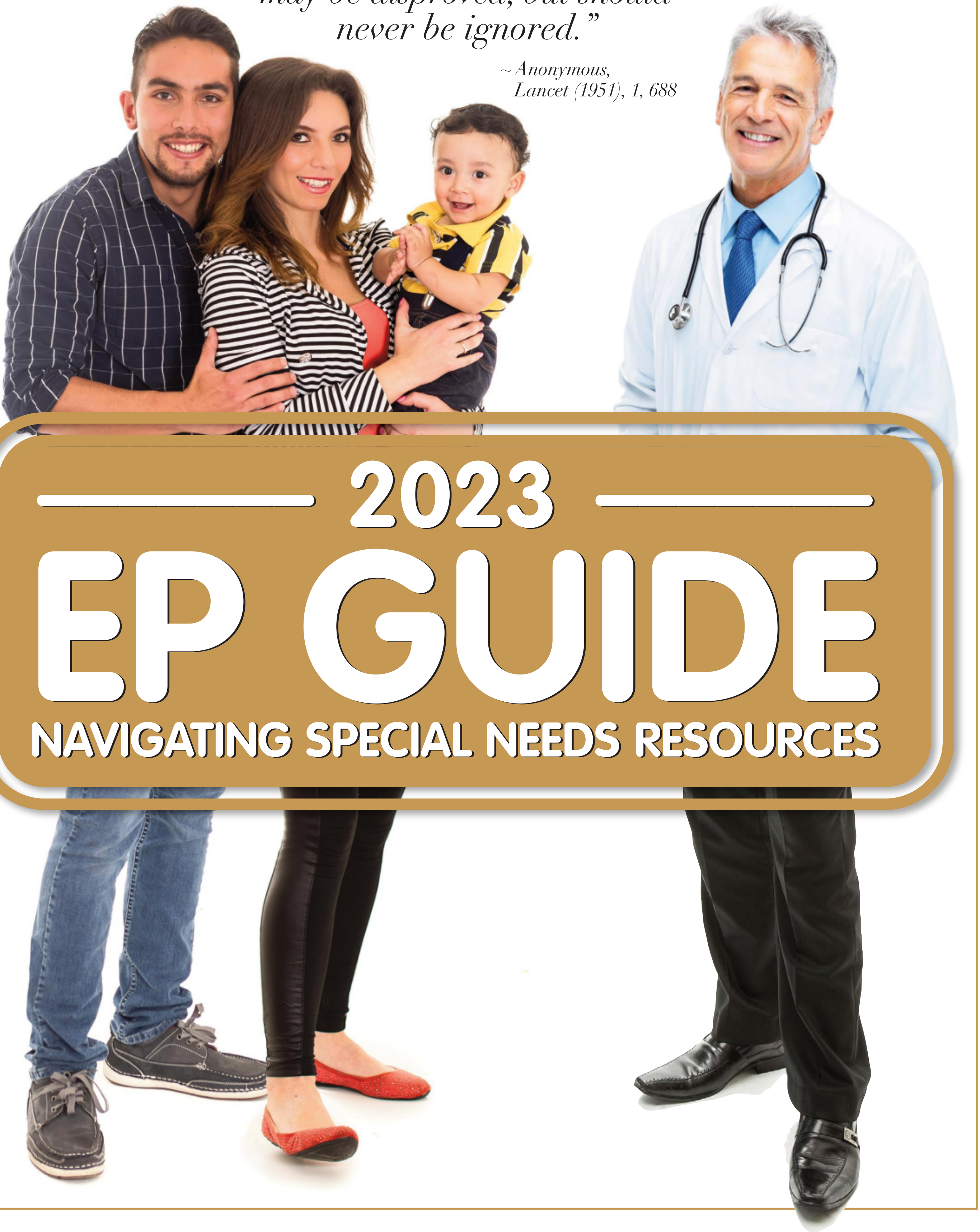
Natural disasters have an impact on children’s mental health. We have a guide for families who were affected by hurricane Sandy which has resources for families at

**https://studylib.net/doc/6900122/tips-for-agencies-working-with-families**

IMAGE COURTESY THRIVEINITIATIVE.ORG

## EP's ALL-NEW RESOURCE GUIDE FOR 2023

> *"An observant parent's evidence*
> *may be disproved, but should*
> *never be ignored."*
>
> *~Anonymous,*
> *Lancet (1951), 1, 688*



### 2023

# EP GUIDE

### NAVIGATING SPECIAL NEEDS RESOURCES

## Concerned about Development?

# How to Get Help for Your Child

Talking to the doctor is the first step toward getting help for your child if you are concerned about his or her development (how your child plays, learns, speaks, acts, or moves). **Don't wait.** Acting early can make a real difference!

### 1 Make an appointment with your child's doctor

- When you schedule the appointment, tell the doctor's staff you have concerns about your child's development that you would like to discuss with the doctor.

### 2 Complete a milestone checklist

- Before the appointment, complete a milestone checklist by downloading CDC's free ***Milestone Tracker* mobile app** from the App Store or Google Play or printing a paper checklist from **www.cdc.gov/Milestones**.
- Write down your questions and concerns; take these with you to the doctor's appointment.

### 3 During the doctor's appointment

- **Show the completed milestone checklist to the doctor**
  - If your child **is** missing milestones, point them out, and share any other concerns that you have.
  - If your child **is not** missing milestones but you still have concerns, tell the doctor about them.
- **Ask the doctor for developmental screening for your child**
  - Developmental screening is recommended whenever there is a concern. It gives the doctor more information to figure out how best to help your child.
  - For more information about developmental screening, go to **www.cdc.gov/DevScreening**.
- **Ask the doctor if your child needs further developmental evaluation**
  - If your child does, ask for a referral and call right away. If you have difficulty getting an appointment, let the doctor know.

### 4 Make sure you understand what the doctor tells you, and what to do next

- Before you leave the appointment, check the notes you have written and make sure all of your questions have been answered.
- If you do not understand something, ask the doctor to explain it again or in a different way.
- When you get home, review your notes and follow the steps the doctor has given you. Remember, you can always contact the doctor's office if you have any questions.

## You Know Your Child Best

If your child's doctor has told you to "wait and see," but you feel uneasy about that advice:

Talk with others (doctor, teacher, another provider) to get a second opinion

**AND**

Call for a free evaluation to find out if your child can get free or low-cost services that can help.

- **If your child is under age 3:** Call your state's early intervention program. Find the phone number at **www.cdc.gov/FindEI**.
- **If your child is age 3 or older:** Call the local public elementary school.

**You do not need a doctor's referral to have your child evaluated for services.**

Find more information, including what to say when you make these important calls, visit **www.cdc.gov/Concerned**.

**Don't wait. Acting early can make a real difference!**

CDC Centers for Disease Control and Prevention

www.cdc.gov/ActEarly

1-800-CDC-INFO (1-800-232-4636)

**Learn the Signs. Act Early.**

**Download CDC's free *Milestone Tracker* app**

Download on the App Store

GET IT ON Google Play

# INSIGHTS INTO GROSS MOTOR MILESTONES

BY AVIVA GANS, PT MS

Lists of gross motor milestones abound in resources for parents, caregivers, educators. But they can be confusing and anxiety producing. While parents are strongly encouraged to report their concerns early, it is important to know that not all delays are a sign of disability. Gross motor milestones are best interpreted within the context of a child's whole developmental pattern, health, social/cultural environment, and more.

## WORRIED PARENTS

Parents sometimes ask, "My baby is not rolling yet. Should I be worried?" Others wonder, "My friend's daughter is walking. Mine is barely standing up. Is there a problem?" Usually, despite deviations from accepted guidelines, there is no problem. Everyone wants to do the right thing. A better understanding about what the checklists represent can be helpful.

## WHAT ARE GROSS MOTOR MILESTONES?

Gross motor skills are movements that involve the large muscles of the body. Rolling, sitting, standing, walking, and running are gross motor skills. These skills tend to emerge in a particular order and are achieved within a given range of time. Gross motor milestones of key gross motor skills are used for tracking motor development.

## EARLY DETECTION IS RECOMMENDED

Treating developmental delays is most effective during infancy and early childhood. The Center for Disease Control's (CDC's) Learn the Signs. Act Early. program encourages parents, teachers, and health care providers to address developmental concerns promptly. The CDC and other organizations, provide lists and apps to help caregivers track development.

### INTERPRETING MOTOR MILESTONES: WHAT PERCENTILE DO THEY REPRESENT?

Most websites and infographics offer little advice on interpreting the gross motor milestones. From 2004 until March 2022, the CDC milestones described what 50% of infants and children did at a given age. Essentially, the CDC was trying to describe what the "average" child did. In early 2022, the CDC presented a new, more evidence-based list of milestones. There was an uproar among many parents and health professionals, because it appeared that the standards had been lowered. But, this was not the case. Instead, the new list of developmental milestones describes what 75%, or 3/4, of children can do at a given age. In statistical conventions the top 75% usually represents a typical pattern.

This change was done to encourage earlier referral. The thinking was, that if a milestone reflects the 50th percentile, pediatricians recognized that 25% of typically developing infants, or children, did not achieve that milestone, at a particular age. The Academy of Pediatrics and the CDC understood that this thought process resulted in a "wait and see approach."

By changing the list of milestones to represent the 75th percentile, pediatricians will be less likely to delay referral for formal assessment and intervention. While there remains some controversy over the changes, it is helpful to understand the thought process behind revising them.

Several changed gross motor milestones confused parents and upset therapists. For instance, the time frame for walking went from 15 months to 18 months. The CDC was not lowering the standard. The standard is essentially the same. 50% of toddlers are walking at 15 months but 75%, or more, are walking at 18 months.

If parents are concerned that a delay is not being picked up, there are precursors of walking, like "Walks holding on to furniture." (12 months), or "Takes a few steps on his own" (15 months). "Takes a few steps on his own" and "walks without holding on" both describe walking. By distinguishing these phases and describing them specifically, the CDC adds clarification. This should guide caregivers more effectively.

**MOVING AHEAD:** When it come to skills like running, jumping, and throwing, cultural and contextual factors can determine the rate of achievement.

### WINDOWS OF DEVELOPMENT

The World Health Organization (WHO) has proposed another way of looking at gross motor milestones. Their research studied typically developing, well-nourished children from 6 countries: Brazil, Ghana, India, Norway, Oman and the USA. They found that the sequence of development was consistent across cultures, except 4.3% of the babies never crawled. The WHO looked at what 99% of infants do. Their study revealed that milestone achievement can occur over wide ranges, which they call "Windows of Achievement." Some infants sat independently at 3.8 months while some achieved sitting at 9.2 months. For unsupported walking, the range was even wider: from 8.2 months to 17.8 months. The study demonstrates how variable motor development can be, even for children without challenges.

### CULTURAL, ENVIRONMENTAL, AND CHILD REARING PRACTICES MAY IMPACT MOTOR DEVELOPMENT

Most gross motor screening and assessment tests available to practitioners have been developed in the US or Canada. The tests are based on research done in Western, Educated, Industrialized, Rich, and Democratic (known as WEIRD) countries. In these countries, there is some homogeneity in child rearing practices and culture.

Cross-cultural studies show that child rearing practices, as well as cultural beliefs, may influence early child development. Some practices accelerate development of motor skills. In cultures like Kenya and Cameroon, 5-month-olds are frequently put in unsupported sitting postures. These infants tend to achieve independent sitting earlier than those from cultures like the US, where this practice is not considered safe. Some cultures like Jamaica or the Au hunter-gatherers of Papua New Guinea, frown on putting babies on the ground for either practical, hygiene, or religious reasons. Crawling has many benefits but these infants develop typically though they do not crawl.

### KEY CONCEPTS : GROSS MOTOR MILESTONES

*Remember: No need to hesitate or delay, seeking advice is the better way.*

- Gross motor development tends to occur in a specific sequence.
- Checklists are meant to start a conversation.
- Different checklists may represent different percentile rankings.
- Culture and child rearing practices may influence skill development.
- There is no "average" child. Some variation is expected.
- Parents know their children best. All concerns are valid.
- Seek advice early.

There is some evidence that “The Back to Sleep Campaign” to decrease the incidence of Sudden Infant Death Syndrome, may slow emergence of some early motor milestones. The research indicates that typically developing children tend to catch up and achieve walking within the same time frame as babies positioned on their bellies. The question remains how the minor delays affect children with motor challenges.

Beyond infancy, when it comes to skills like running, jumping, and throwing, similar cultural and contextual factors can determine the rate of achievement. For instance, one study showed that Portuguese children tend to outperform American children on locomotor (running and jumping) skills and cardiorespiratory fitness. But American children have better grip strength and throwing speed. These discrepancies were ascribed to differences in the emphasis of physical education classes and culturally favored sports. Portuguese boys, (not girls as much) tend to play more soccer. American children perfect throwing for sports like baseball, softball, American football, and basketball.

Now that people migrate globally, it is important for parents and health practitioners to recognize that variations in development may be a result of cultural background, and that tests standardized in western countries may not apply to all children.

## CONSIDER HOW THE INDIVIDUAL CHILD IS DEVELOPING

Caregivers and professionals also need to look at a child’s overall development. Children tend to have spurts of development in particular domains. For instance, little Joey may be standing at 8 months, but barely says more than “Mama” and “Dada.” His mom remembers that his sister crawled at 8 months and imitated other words. Neither child is delayed. For a variety of reasons, their developmental focus is not the same. In due time, Joey should go through a spurt where learning language becomes predominant and gross motor skills may plateau.

## PARENTS, CAREGIVERS, AND TEACHERS : RESOURCES

**CDC**

Learn the Signs. Act Early.

www.cdc.gov/ncbddd/actearly/index.html

**WORLD HEALTH ORGANIZATION**

https://cdn.who.int/media/docs/default-source/child-growth/child-growth-standards/indicators/motor-development-milestones/who-motor-development-study-windows-of-achievement-for-six-gross-motor-development-milestones.pdf

**AMERICAN ACADEMY OF PEDIATRICS**

Evidence-Informed Milestones for Developmental Surveillance Tools

https://publications.aap.org/pediatrics/article/149/3/e2021052138/184748

## CHECKLISTS ARE NOT THE SAME AS FORMAL SCREENING OR ASSESSMENT

Lists of milestones help parents observe their children. They can be used to start a conversation with a health practitioner, but they do not determine whether there is a problem. Instead, pediatricians or other health professionals may use a screening test. These instruments clearly define what is meant by each test item, and give specific instructions on how to assess each of them. The test items have undergone rigorous research on large numbers of children.

The screening tools may pick up a significant delay. But it should be recognized that they are not diagnostic. One could say that they are like getting an ultrasound or MRI for a condition that can only be definitively determined with surgery.

A referral to a specialist is warranted if a screening is not conclusive, or when a health practitioner or parent still has concerns. In the case of gross motor issues, the referral would be to a pediatric physical or occupational therapist, a pediatric neurologist, a neurodevelopmental pediatrician, a pediatric orthopedist, or a pediatric physiatrist. These practitioners have even more specific, standardized assessments. They also do clinical testing. A therapist will look at strength, range of motion, postural control, motor planning, sensory status, reflexes, achievement in other domains, and more. Physicians may order additional tests like x-rays, MRI, nerve conduction velocities, blood work, and more. A significant deficit is determined based on the interrelationship of a child’s abilities and these other findings. •

### ABOUT THE AUTHOR:

Aviva Gans, PT MS is a NJ based Pediatric Physical Therapist. Aviva worked as a school-based physical therapist for 29 years and has taught at the university level. She serves as the Chair of the Pediatrics Special Interest Group of the American Physical Therapy Association of New Jersey. She is also involved with the APTA’s Academy of Pediatric Physical Therapy. Her primary interests are teaching motor skills to children with learning disabilities, gross motor development, motor learning, and advocating for children, especially children with disabilities. Aviva mentors early career physical therapists, and is available to consult, or speak, with teachers, parents, and parent groups.

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2023
EP GUIDE
NAVIGATING SPECIAL NEEDS RESOURCES

# HOW CAN EARLY INTERVENTION SERVICES HELP STUDENTS?

BY JENN ADAMS

*When I first started teaching in special education, I was unaware of the early intervention services available in my local community or what kinds of services they offered. The support they could provide, not only to the children but to the families as a whole, was not made clear to me either. I'd like to share what information I now know about early intervention services in order to help teachers and families help children that may need support.*

## WHY IS IT IMPORTANT TO START AS EARLY AS POSSIBLE?

Brain development is something that has been studied for many generations. New technology makes it possible to get more insight and knowledge about how the brain is developing. We have also learned what stimulates development. The first two years of life is a critical period of learning tasks. There is a burst of synapse production in the brain. It's the time when the brain is most likely to adapt and learn.

There are many types of support available with early intervention services that can help children with disabilities or delays to catch up in their development. Some of them include:

- *Physical development, including vision and hearing*
- *Cognitive development*
- *Communication development*
- *Social or Emotional development*
- *Adaptive development*

**SPEAKING UP:** Through early intervention, children learn how to use language to convey messages, express feelings, and interact with their families and peers.

The first step is working with a family physician to look for deficits or signs that the child is not reaching certain milestones. Next, there should be a referral to an early intervention program where the child is assessed and screened in different areas. The results of the assessment will help create a plan of action and determine the amount and type of services the child needs. Then professionals will be assigned to work with the child in the home or other environments to support those needs. These professionals can help start the right interventions for the child, as well as guide and support the teachers and the family to meet those special needs.

## BENEFITS OF EARLY INTERVENTION SERVICES

***Provide Resources, Support, and Information:*** Early intervention provides parents with resources, support, and information to enhance their child's skills in many areas. Working together with a provider trained in early childhood enables parents to feel confident that they are facilitating their child's development. Professionals can help families with modeling strategies and supports that will encourage an increase in development for the child. Through the use of research-based strategies and collaboration, families and professionals can work towards common goals and build consistency for children trying to learn new skills.

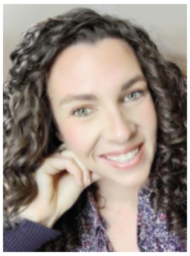
***Improve Communication & Relationships:*** Early intervention services are not just about the child. They incorporate the entire family, and find strategies that can be easily used to help children perform skills under different conditions and continue to exhibit the skills over time. For example, when communication and language is delayed, understanding and interacting with other children will be delayed. This makes it difficult to develop relationships with siblings and friends. With services, the child and family can solve problems and learn to negotiate conflicts between siblings, and the child can learn to develop relationships with friends. Through early intervention, children learn how to use language to convey messages, express feelings, and interact with their families and peers.

***Improve Behavior with Early Intervention Services:*** Children with delayed development may get frustrated and exhibit challenging behavior to compensate for their delays. It is difficult to express wants and needs when communication is delayed, so often a physical response such as biting or hitting takes place. Early intervention will provide behavior support and strategies to facilitate a child's needs. This means providing: resources, materials, and strategies that will support positive behavior in the home and eventually in school too.

***Promote Future Success in School:*** Early development sets the stage for learning, and influences later success in school. There is evidence suggesting that having a good command of language, behavior, and physical abilities goes hand-in-hand. If these skills are worked on early in life, children will have the ability to imagine and to create new ideas and, eventually, to read and write. It can also close the gap that often happens in schools for children that come to kindergarten with deficits.

***Make Learning Fun:*** Early intervention will help families add support to everyday activities that they do with their children. This provides lots of opportunities for children to learn – not only when playing, but also when getting dressed, brushing their teeth, preparing meals, eating, bathing, helping with family chores, getting ready for bed, and lots of other activities. The intervention also brings the family a greater understanding of their child's needs, and how to break learning down into small steps for their child. When children know what they are expected to do and can be successful, they have fun learning in almost any activity, and want to learn more. •

### 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.

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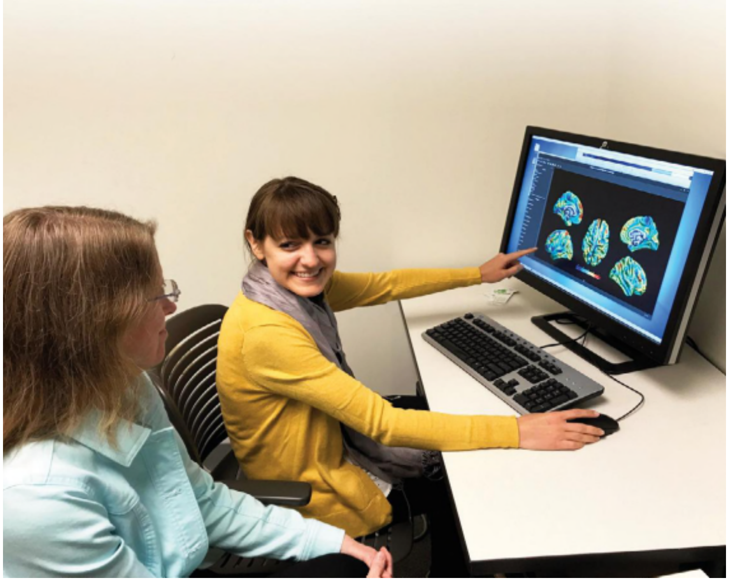

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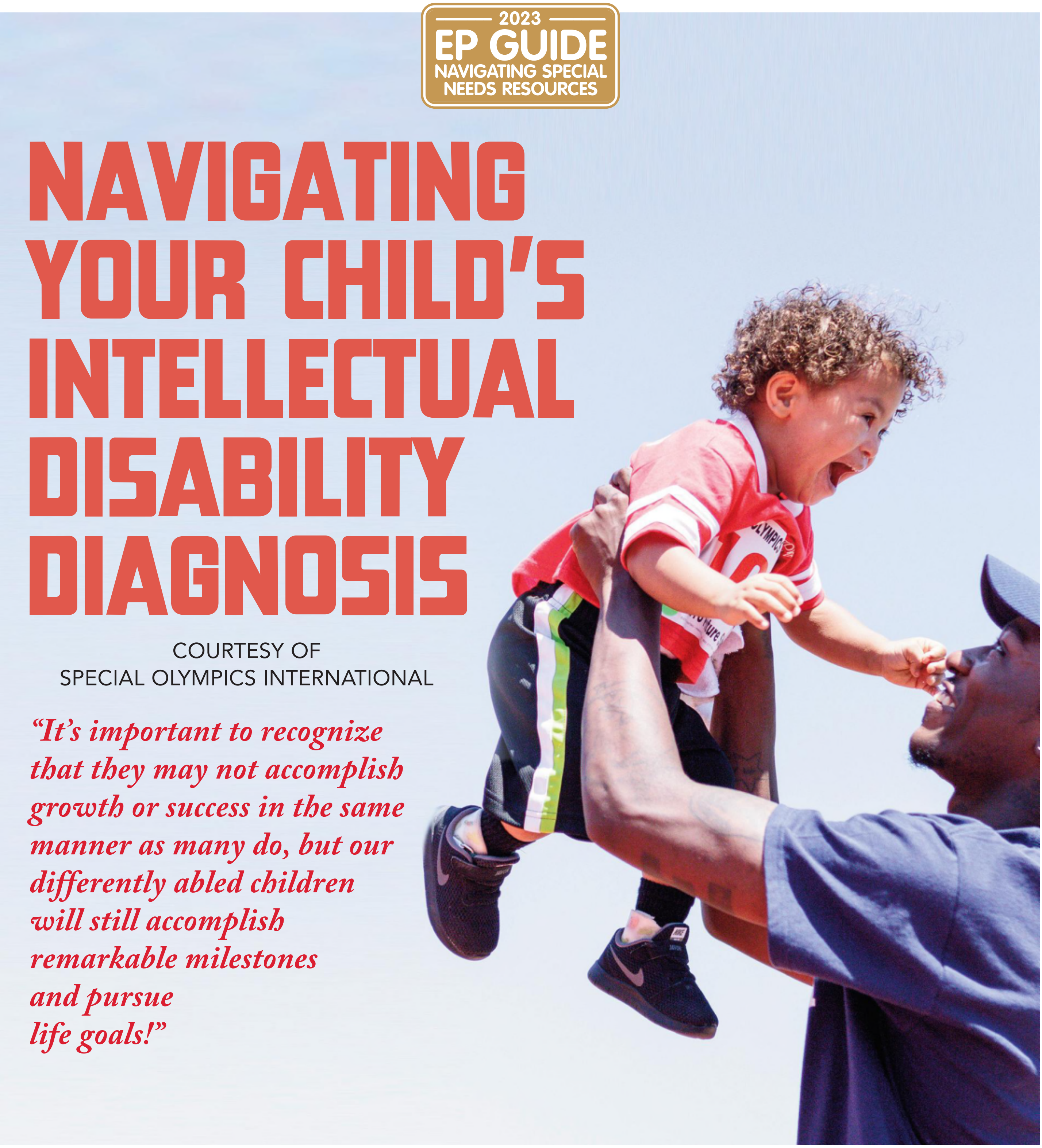
# NAVIGATING YOUR CHILD'S INTELLECTUAL DISABILITY DIAGNOSIS

COURTESY OF
SPECIAL OLYMPICS INTERNATIONAL

> *"It's important to recognize that they may not accomplish growth or success in the same manner as many do, but our differently abled children will still accomplish remarkable milestones and pursue life goals!"*



*For many families, the moment their child receives an intellectual disability diagnosis can be scary and isolating. However, access to accurate, quality information and consistent support can provide a sense of confidence and community, as they navigate this new world.*

Whether you are a new parent or caregiver of a child with intellectual disabilities (ID), or are further along in your journey, you can probably recall a time when you felt alone and in need of some advice or guidance.

Special Olympics understands this and aims to support families by providing information about intellectual disabilities, supportive opportunities within your community, and high-quality health education resources.

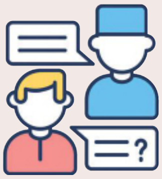
PHOTO COURTESY SPECIAL OLYMPICS NEW JERSEY

## JUST WHAT THE DOCTOR ORDERED : PROACTIVELY PARTNERING TO CREATE A SUPPORTIVE PLAN OF CARE

An important step you can take to provide support for your child with an intellectual disability or developmental delay, is to proactively partner with your child's medical and educational teams to create a supportive plan of care. Understanding your child's diagnosis and needs, takes time and is part of a continuous journey to create the most positive environment for your child to succeed. Below are some suggested strategies for how to identify and communicate with physicians, who can become key advocates for supporting your child's healthy development.

### QUALITIES OF A GOOD PHYSICIAN FOR YOUR CHILD

- *Accessible for communication outside of appointments*
- *Provides options for communication: email, messages through online medical chart, phone, real-time video chat*
- *Responds promptly to your requests*
- *Provides clear verbal and written instructions*
- *Asks for your opinion*
- *Creates a partnership in decision making*
- *Listens*
- *Supportive, compassionate, and knowledgeable*
- *Provides timely copies of evaluations, referrals, and support letters*
- *Advocates for your child*
- *Collaborates with and refers to other specialists*
- *Connects with other team members such as: teachers, therapists, or other medical providers*



### TIPS TO IMPROVE COMMUNICATION WITH YOUR CHILD'S PHYSICIAN

- *Ask questions about your child's condition*
- *Request written information about your child's condition, with specific web links, books, handouts, or other resources*
- *Clarify what you do not understand*
- *Make a follow up appointment*
- *Bring a list of questions and concerns about your child, to discuss with your healthcare providers*
- *Ask for specific recommendations and a referral for intervention*
- *Keep a copy of all medical evaluations and recommendations*
- *Create a notebook or folder with all the dates of diagnosis, treatments and contact information for providers, and bring it with you when you go to an appointment*

These strategies can be applied to all providers in your network and community who will be dedicated to your child's health and well-being.

**PEAK PERFORMANCE:** Jared Niemeyer was named Special Olympics Missouri Athlete of the Year in 2019.

"As difficult as this moment may feel for you, I can assure you that love does indeed conquer all! I can encourage you, in the most difficult moments, to simply focus on loving your child. Reveling in the day-to-day accomplishments – happy smiles, rolling over, splashing in their bathwater, learning to crawl and walk and making tiny sounds or signs – because life experiences develop one's sense of who they are. Therefore, I ask you to encourage and celebrate the many accomplishments your child achieves! Small achievements become large accomplishments as our children grow into understanding who they are. I encourage you to provide every opportunity for growth for your child. Please have high expectations of your child; in a positive, encouraging, and accountable manner. We should not expect less from our child because of their disability – it's important to recognize that they may not accomplish growth or success in the same manner as many do, but our differently abled children will still accomplish remarkable milestones and pursue life goals! In fact, our child may often work harder and more intently to accomplish milestones taken for granted by their peers."

*– Brenda Niemeyer, parent of Jared,*
*a Special Olympics Missouri athlete*

*To learn more about Special Olympics and its programs, please visit* www.specialolympics.org/what-we-do/inclusive-health

PHOTO COURTESY SPECIAL OLYMPICS NEW JERSEY

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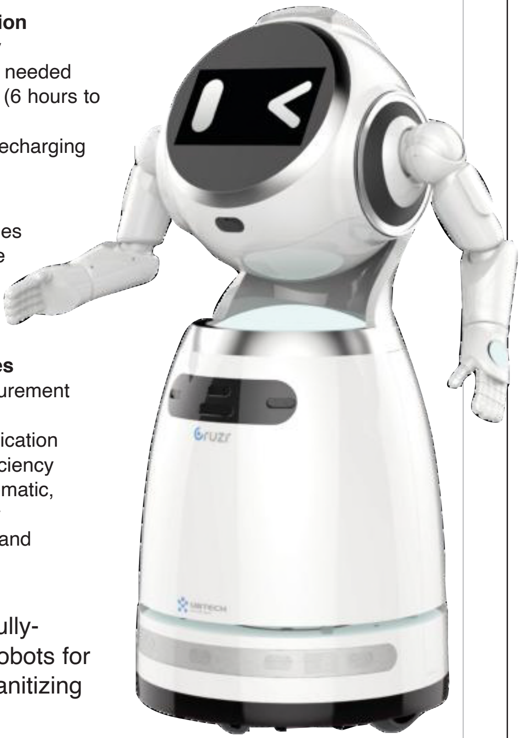

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2023
EP GUIDE
NAVIGATING SPECIAL
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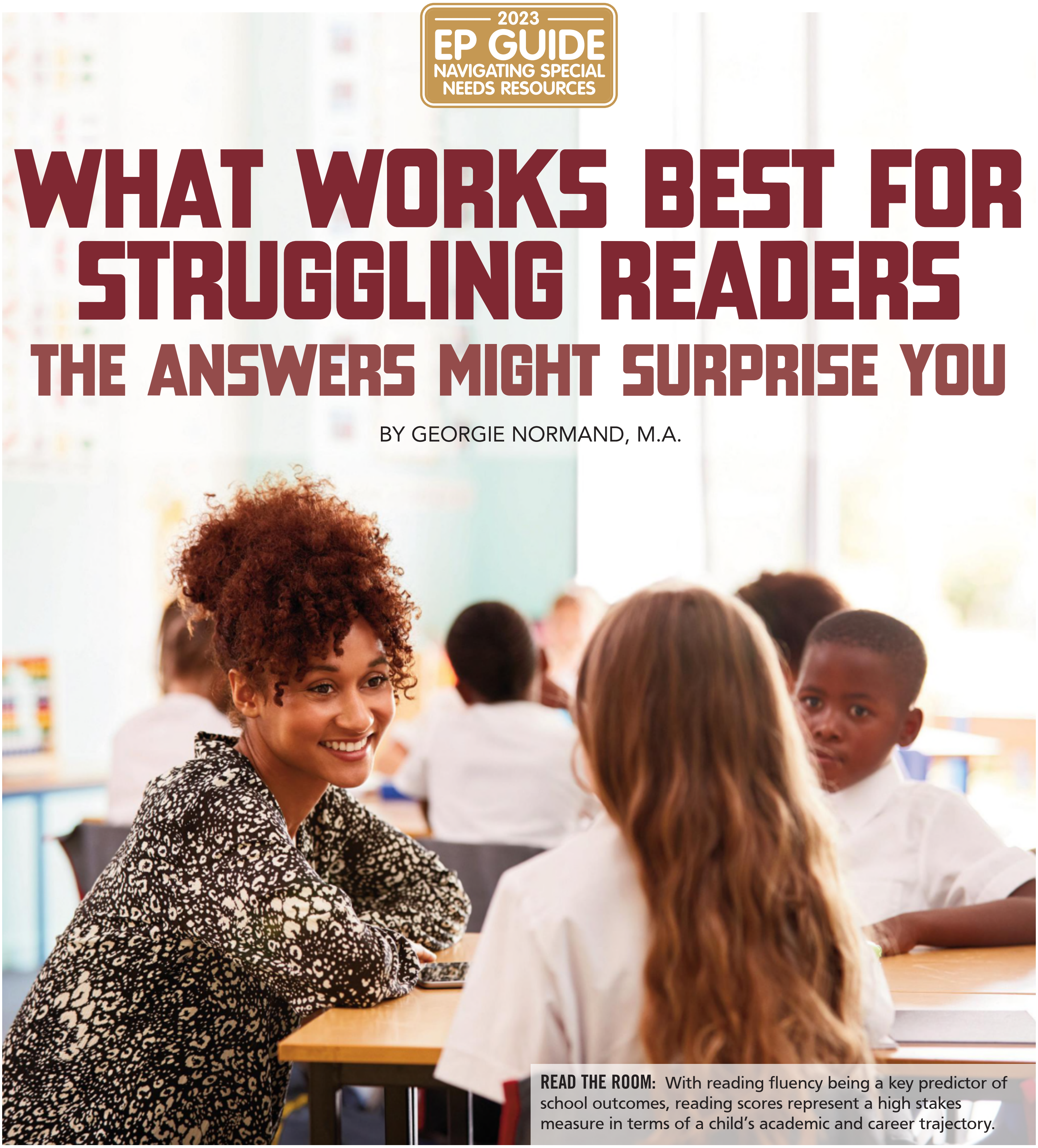
# WHAT WORKS BEST FOR STRUGGLING READERS

## THE ANSWERS MIGHT SURPRISE YOU

BY GEORGIE NORMAND, M.A.



**READ THE ROOM:** With reading fluency being a key predictor of school outcomes, reading scores represent a high stakes measure in terms of a child's academic and career trajectory.

*The recently released 2022 Nation's Report Card for Reading showed the largest drop in reading achievement since the 1980s. While the educational chaos created by the pandemic certainly impacted performance, the sad truth is that reading scores have been in the basement for a good long time.*

In pre-pandemic 2019, only 35% of fourth grade students scored in the *at or above proficiency* range. This means there are a lot of struggling readers out there. Without aggressive intervention, very few fourth graders with low reading proficiency will be able to catch up. With reading fluency being a key predictor of school outcomes, reading scores represent a high stakes measure in terms of a child's academic and career trajectory.

# WHY SO MANY STRUGGLING READERS?

## IT'S COMPLICATED...

## STUDENTS WITH DYSLEXIA

Parents who have spent years reading to their child daily are often shocked when they find out their child is struggling to learn to read. You will sometimes hear that reading to your child will either prevent or fix reading problems. Reading to your child is very beneficial in terms of building oral language skills such as vocabulary and syntax, background knowledge, critical thinking skills, and comprehension – all skills that build a great foundation for learning to read. But it will take a dyslexia-specific intervention to teach your dyslexic child to read.

Experts estimate that up to 20% of children may have some of the characteristics of dyslexia that make learning to read difficult. If a dyslexic child does not attend a school where universal dyslexia screening is implemented in kindergarten (or earlier), they will likely not receive an early intervention and will quickly fall behind their peers. Many states are mandating early screening and intervention, but implementation is lagging in many schools.

The National Reading Panel (2000) identified five critical skills that should be included in reading instruction for all students – phonemic awareness (an awareness of individual sounds or *phonemes* needed for both reading and spelling), phonics, fluency, vocabulary, and comprehension. Another key finding of the panel was that *explicit* and *systematic* phonics instruction is beneficial for all students and may even prevent reading failure in many at-risk students.

### PHONOLOGICAL SKILLS ARE NOT ENOUGH

As important as they are, phonological skills are not sufficient to produce fluent reading. Studies have found that over 60% of dyslexic students have a double deficit of both phonological awareness and rapid automatized naming (RAN or rapid naming). A deficit in RAN impacts a student's ability to become a fluent reader. This means that interventions that focus primarily on phonics and only secondarily on fluency training will not be able to help students reach grade level fluency. Fluency training has also been found to serve as a shortcut to reading acquisition, helping dyslexic students make greater gains in far less time than with a primarily phonological approach to intervention.

### HANDWRITING FLUENCY BUILDS READING FLUENCY

Fluency training activities should include extensive handwriting instruction and practice, especially timed handwriting tasks, such as timed handwriting from dictation or timed copy work. Handwriting is often minimized in dyslexia interventions, which is unfortunate because neuroimaging studies have found that even tracing letters builds the reading circuit of the brain. Handwriting fluency facilitates reading fluency. Other fluency-based activities such as repeated timed reading tasks have also been found to improve brain connectivity and fluency. In most schools, dyslexia interventions do not prioritize fluency training and the interventions are not implemented early enough to prevent reading failure. This is a tragedy, since we now know that as early as the first grade, these children are already behind their peers in reading.

### THE DILUTION PROBLEM

For dyslexic students, the explicit and systematic phonics instruction model combined with a heavy focus on fluency training should never be diluted with other reading instruction methodologies. For example, while learning to read, dyslexic students should only practice reading using *decodable* text which is based on concepts and word patterns they have been explicitly taught so far. But instead, dyslexic students are usually thrown with their peers into a *leveled* reading system that pushes them into a word-guessing habit that is very hard to break once it's established. Even non-dyslexic students can develop a guessing habit when explicit instruction isn't supported with decodable text.

The assigned levels used in leveled reading systems are based on "readability measures" rather than explicit instruction the student has received. The leveling of stories, books, and articles often relies on complex algorithms to determine reading levels. This approach to reading instruction and practice leaves dyslexic students in the dust. It is not uncommon for those in kindergarten and above to be brought to tears when they realize how far they are from reading at the levels occupied by their classmates.

There are several ways to avoid this scenario. First, dyslexia screening in early fall of PreK (or at the very least during the first few weeks of kindergarten) followed by intervention could rescue many of these students from the humiliation, embarrassment, and anxiety they begin to feel very early in their academic life.

Secondly, since leveled reading systems are especially unfair and even detrimental to the dyslexic student, they should be allowed to practice what they've learned using the antidote – decodable text. One criticism of decodable text is that even decodable books tend to be dull and contrived. But decodable text is only a temporary crutch, serving as a gateway to reading. With intensive work, dyslexic students, like most readers, will be able to read with automaticity, instantly recognizing the majority of words by sight, and the need to decode words when reading will diminish.

> "DYSLEXIA SCREENING IN EARLY FALL OF PREK FOLLOWED BY INTERVENTION COULD RESCUE MANY OF THESE STUDENTS FROM THE HUMILIATION, EMBARRASSMENT, AND ANXIETY THEY BEGIN TO FEEL VERY EARLY IN THEIR ACADEMIC LIFE."

Extensive practice with decodable text is a temporary but necessary pathway to reading proficiency for dyslexic students. Explicit instruction and practice with decodable text is beneficial for all students, but compared to their classmates, dyslexic students need even more. Because of their brain differences in neuroplasticity, connectivity, and structure, they will need a considerable amount of repetition, ongoing cumulative review, and fluency training to internalize instruction – a process that takes more time than the regular class reading block would permit. They need daily intensive one-on-one or small group intervention outside the reading block.

# OTHER STRUGGLING READERS

DYSLEXIC STUDENTS REPRESENT ONLY ONE PART OF THE MANY STRUGGLING READERS REFLECTED IN THE NATION'S REPORT CARD SCORES. WHAT IS CAUSING THE OTHERS TO STRUGGLE? THE RESEARCH HAS IDENTIFIED SEVERAL CONTRIBUTING FACTORS AND HOW TO ADDRESS THEM.

## THE DECLINE OF HANDWRITING

One study suggests that handwriting instruction and practice is being minimized in schools and is contributing to reading related disabilities. It's not uncommon for students to spend more time "filling in the blanks" rather than writing sentences and paragraphs. Since neuroimaging studies have found that handwriting builds the reading circuit, handwriting should play a greater role in the typical school day.

## ADD/ADHD

If your child struggles to read and has not been identified as at-risk in a dyslexia screening or formally diagnosed with dyslexia, there may be other factors at work. For example, ADD/ADHD can interfere with the process of learning to read. Being responsive to reading instruction requires focus and for many students the attention deficit symptoms must be addressed before reading instruction can be successful. Comprehensive assessment would be appropriate if your child has not responded to instruction and dyslexia has been ruled out.

## HOME AND SCHOOL LITERACY ENVIRONMENT

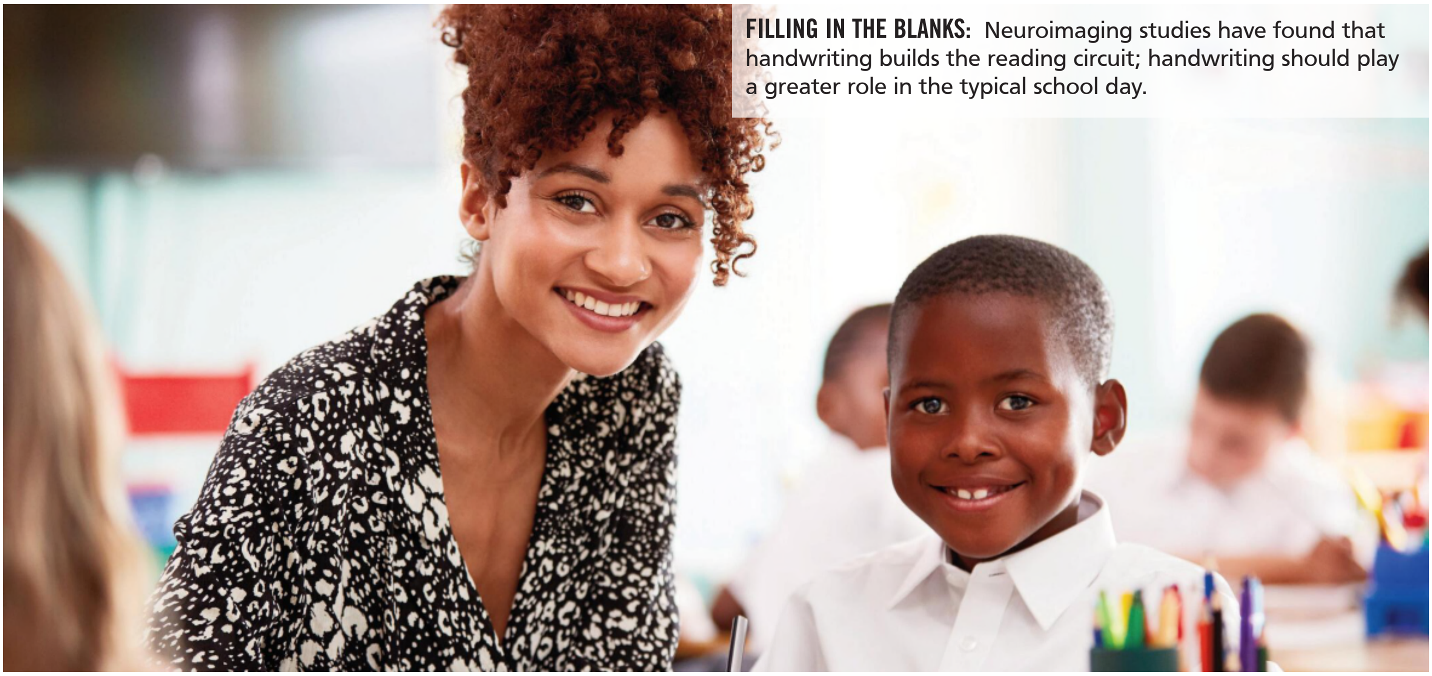
Reading acquisition can also be influenced by the home literacy environment, the child's household socioeconomic status (SES), teacher training at the university level, and the type of reading instruction offered by the school.

Students from low SES households often enter school with weaker oral language skills, especially vocabulary. Reading acquisition is harder for them. The good news is that a seven-year longitudinal study found that the same explicit instruction that works for dyslexic and other students can level the playing field for students who come from low SES households.  Although a strong home literacy background is helpful, explicit instruction can open the door to a literacy-rich academic life for those who enter school without it.

Teacher preparation programs may also be implicated in the number of students who are not reading *at or above proficiency* levels. For decades, teacher education programs have focused on everything but explicit and systematic phonics instruction. Most teachers who graduated from these programs had no idea where to begin when they entered the classroom. With no other guidance, many were forced to rely on the literacy program selected by the district for their scope and sequence for reading instruction.

These programs were often developed by curriculum publishers who followed the theories and trends prevalent in the teacher education programs, a school of thought and practice commonly referred to as *balanced literacy*. This approach minimizes the importance of explicit and systematic phonics instruction. Even after the 2000 National Reading Panel settled the question and recommended that explicit phonics instruction be included in the essential components of reading instruction, many schools continue to offer balanced literacy programs.

The rationale behind balanced literacy is that if children can just dive in and start reading books they enjoy with some guidance, they will love reading and become good readers. But this method encourages students to rely on context, pictures, and a lot of guessing to "read," without building the foundational phonics and fluency skills needed for comprehending what is being read. The Nation's Report Card scores for recent decades certainly do not provide a strong endorsement for the balanced literacy approach. Fortunately, the pendulum is finally beginning to swing away from the balanced literacy approach towards the explicit and systematic early reading instruction recommended in the body of research commonly called the Science of Reading (SoR).



**FILLING IN THE BLANKS:** Neuroimaging studies have found that handwriting builds the reading circuit; handwriting should play a greater role in the typical school day.

## THE GROWTH OF ONLINE DATA-DRIVEN READING PLATFORMS

The steady growth in the use of data-driven platforms to differentiate instruction and provide real time progress monitoring for an entire classroom offers many benefits for both students and teachers. Originally designed to support and supplement teacher-led reading instruction and track student progress in the critical reading domains, an unexpected outcome may be an over-reliance on the system and less direct instruction and monitoring by the teacher.

Even with the detailed reports these platforms generate for the teacher about student performance, they can conceal some reading proficiency issues. For example, many of these programs rely on silent reading followed by the student's response to multiple choice comprehension questions on what was read. With less teacher involvement, students can advance in reading levels with "good guessing" on the comprehension questions. Dyslexia-related reading behaviors and other reading issues are often missed in this environment. All students need immediate feedback on their oral reading and careful monitoring of their comprehension. It is so important for teachers to continuously listen to their students read aloud for authentic progress monitoring. This may be a bigger contributing factor to the Nation's Report Card scores than we are willing to admit. •

## READ ON : RESOURCES AND RECOMMENDATIONS

- Advocate for early dyslexia screening for your child or students – as early as PreK if possible. This is very important, especially if there is any family history of reading problems or a history of early language delay for the child. For children identified to be at risk, the screening should be immediately followed by a dyslexia-specific intervention that includes a special focus on fluency (handwriting fluency and reading fluency). Phonological skills are not sufficient to produce fluent reading.
- Advocate for explicit phonics instruction in your child or students' reading program to prevent reading failure.
- Advocate for fluency training to be included in your child or students' reading instruction and/or intervention. It is a key predictor of school outcomes, and is often neglected in both reading instruction and intervention. Add timed handwriting tasks to daily assignments.
- Spend as much time as possible with your child or student listening to them read aloud. Look for any unusual reading behaviors. Download our resource What Dyslexia Looks Like by Grade Level. These are not the same errors made by beginning readers.
  **www.earlyliteracysolutions.com**
- After listening to your child or student read, ask a few comprehension questions about what they have read and ask them for a retell. They need to start with the main idea if it is an information article, rather than a detail. For a story, they need to give you the big picture before launching into any details. It must be retold in the proper order, not starting in the middle of the article or story. This activity also prepares them for the writing process, which is so difficult for struggling readers.
- Make sure that there is not an overdependence on online data-driven platforms for instruction and progress monitoring. Use these programs to supplement/support the explicit instruction received.

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## ABOUT THE AUTHOR:

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

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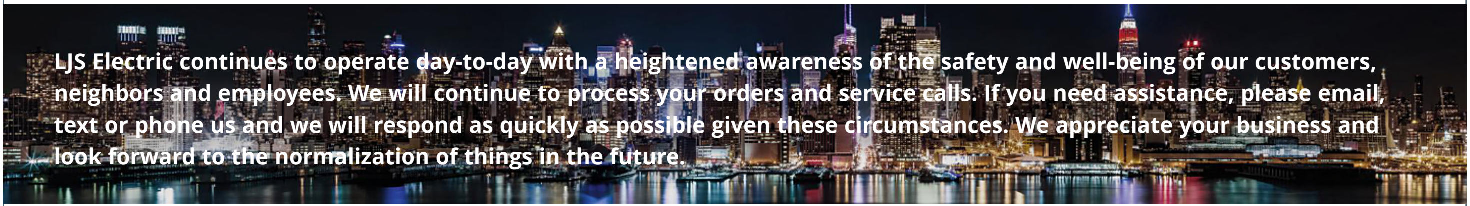

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# CONSIDERING THE GIFT OF TIME

BY RICHARD SELZNICK, PH.D.

*One of the most challenging questions parents face when it comes to their child, is whether the child is developing normally or not. Anxiety over a child's development starts early.*

A mom recently said to me, “My son is drowning in school. Do you think he has a learning disability?” What was particularly striking about this question was the fact that the child in question was only in the first half of kindergarten.

## EXPECTATIONS BY THE NUMBERS

Probably about 60 – 70% of children pass through the pre-K to kindergarten stage without difficulty. As they enter first grade, they will know all of the upper and lower case letters automatically, and can write them when asked to do so. They may also show a good understanding of the sounds associate with the letters.

These children on the “smooth road” also show early reading skills, with a capacity to read a small number of high-frequency (sight) words. On the other side are the children on a rougher road (approximately 30%).

The children on a rougher road are not developing easily, will need focused skill development in the fundamentals of letter-identification and their associated sounds. Please bear in mind that just because a child is showing difficulty in this early stage of development, does not mean that the child is necessarily dyslexic.

What it does mean, though, is the child needs to be tracked and monitored very closely. There is no gain in waiting to start doing targeted instruction, to move a child from this level to the next level of development.

## WHAT TO DO IN THE EARLIEST STAGE OF DEVELOPMENT?

The earliest stage to pay attention to, related to school, literally starts at birth and typically ends when the child leaves kindergarten.

What should you be thinking about as a parent of a child in this stage?

## COMMON CONSIDERATIONS : PRIMARY INDICATORS OF READING DIFFICULTIES

There are frequently indicators (I like to think of them as “red flags”), that may ultimately mean nothing, but are often the early predictors that there may be issues, that the child will be facing fairly early on in his/her schooling. While there are probably far too many indicators to keep in mind, some of the primary ones to consider in the preschool range include the following:

### DIFFICULTY WITH LABELLING

Labeling involves finding the words to name different things. This difficulty can be shown with a child seemingly groping to express his or herself and not having the use of basic vocabulary be easy.

### DIFFICULTY WITH VARIOUS SOUND OR RHYMING GAMES

This can show up formally or informally. Informally you may notice the child being challenged when playing different word games. More formally, the child may have difficulty identifying rhymes on worksheets or in classroom activities.

### EXHIBITING CHALLENGES WITH PLAY THAT IS NOT OPPOSITIONAL IN NATURE

When children have trouble playing games, it may not be that they are being difficult or oppositional, but that they are legitimately confused. A mom recently told me about her four-year old who was having meltdowns when playing Candyland, largely because the girl was confused and frustrated because she did not understand how to play the game. This was compounded by the family having fun, when she was having trouble playing the game.

### DIFFICULTY UNDERSTANDING OR FOLLOWING DIRECTIONS

Following directions is often immediately attributable to issues with attention. This is often a too fast “go to” done by professionals. Following directions may be a highly significant indicator of language-based confusion, that will typically later emerge with early first grade level academic activities.

### SHOWING AVERSION TO ANY EARLY READING ACTIVITIES

Similar to what was noted above, often we mistakenly assume certain things that may or may not be the case. Rather than assume that the child is being difficult or oppositional by avoiding early reading activities, it could well be the case that the child is intuitively avoiding the activities because they are simply too challenging.

### SLOW IN RECOGNIZING LETTERS AND THEIR ASSOCIATED SOUNDS

Children who have difficulty learning letters and their associated sounds need to be watched very closely, as it is one of the more important predictors of later reading disability (dyslexia).

I will state it simply – *bombard the child with language.*

Please don't misinterpret that to mean to talk the kid to death, as you will start being tuned out pretty quickly with incessant eye-rolling. (Yes, eye-rolling starts early too.)

**“PLAYING DIFFERENT GAMES EMPHASIZING RHYMES ARE FUN, AND GREAT FOR PROMOTING PARENT/CHILD BONDING, WHILE MOVING LANGUAGE ALONG AND CONTRIBUTING TO EARLY READING DEVELOPMENT.”**

Read bedtime stories to the toddler and preschooler. Read stories throughout the day. Playing different games emphasizing rhymes are fun, and great for promoting parent/child bonding, while moving language along and contributing to early reading development. Rhyming games can even be played in the car on the way to and from school or errands.

Back in the dark ages (the 1960s) There was a song called “The Name Game,” which played with names and rhyming nonsense words (for example: “Shannon Shannon Bo Bannon, Banana Fanna Fo Fannon, Fee Fi Fo Fannon, Shannon.”)

Also, from another era, a seemingly forgotten author who was brilliant with language was Dr. Seuss. Just listen to the rhymes and the rhythmic beats of *The Cat in the Hat Comes Back* or *One Fish, Two Fish, Red Fish, Blue Fish* as you read them to your child. The rhymes and rhythm will be internalized for later use when more formal reading instruction takes place.

One can do a lot worse (in fact many do, by gluing their child’s attention to an iPad) than playing the “Name Game” over and over or reading *The Cat in the Hat* to your young toddler or preschooler.

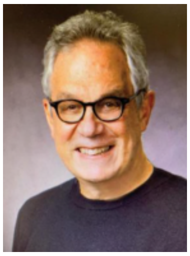
## THE GIFT OF TIME

Children who show these early “red flags” may later be diagnosed as having a learning disability or some type of attention deficit. For the preschool school, it may be wise to simply view them (at least for a certain period of time) as “immature.” This may go contrary to much current theory, but this may help parents view the child as possibly needing more time, rather than assume the child has a disorder or disability. The parents can then keep close tabs on how the child progresses, to determine whether there is, in fact, a learning disorder of some kind.

For such children delaying their entry into kindergarten or first grade, can be enormously beneficial. This delay has the effect of allowing the child to have greater time to develop and mature, while having certain skill areas targeted.

Many schools discourage giving the child such a “gift,” but for the child who is showing a number of indicators, it is something that should be strongly considered.

### ABOUT THE AUTHOR:



Dr. Richard Selznick is a psychologist and the director of the Cooper Learning Center, Department of Pediatrics, Cooper University Health Care. The author of *The Shut-Down Learner: Helping Your Academically Discouraged Child,* as well as *What to Do about Dyslexia: 25 Essential Points for Parents,* and three other related books, he can be contacted through email: **selznickr@cooperhealth.edu**. To learn more about his books, blogs and podcasts, go to **www.shutdownlearner.com** and **www.cooperlearningcenter.org**

2023
EP GUIDE
NAVIGATING SPECIAL NEEDS RESOURCES

# DIAGNOSIS AND TREATMENT OF PANDAS AND PANS

## USEFUL RESOURCES FOR FAMILIES

BY KARA JOLLIFF GOULD, PH.D.

*While the terms PANDAS and PANS are used more commonly now than in recent years, many families are not familiar with the terms and may not realize their child is exhibiting symptoms. Obsessive-compulsive disorder, often accompanied by severely restricted eating and/or tics, or new problems with academics or motor skills can often be attributed to other causes.*

But when onset of such symptoms is sudden, or when such symptoms regularly occur and resolve only to recur repeatedly, parents should consider having their child evaluated for PANS or PANDAS.

PANS and PANDAS are acronyms that stand for "pediatric acute-onset neuropsychiatric syndrome" and "pediatric autoimmune neuropsychiatric disorders associated with streptococcal infections." PANDAS is thought to be caused specifically by a strep infection, while PANS is an umbrella term that includes PANDAS as well as instances in which the syndrome is caused by infections other than strep.

## INVOLUNTARY EXPERTS : A PANDAS/PANS RESOURCE GUIDE

### INFORMATIONAL WEBSITES

ASPIRE
www.aspire.care

NEW ENGLAND PANS/PANDAS ASSOCIATION
www.nepans.org

NEUROIMMUNE FOUNDATION
www.neuroimmune.org

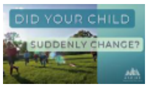
NIMH National Institute of Mental Health
www.nimh.nih.gov/health/publications/pandas

PANDAS NETWORK
www.pandasnetwork.org

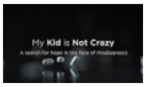
PANDAS PHYSICIANS NETWORK
PPN
A DIVISION OF THE FOUNDATION FOR BRAIN SCIENCE AND IMMUNOLOGY
www.pandasppn.org

PANDAS/PANS CONSULTATION PROGRAM
www.pansconsult.com

### ONLINE VIDEOS



About PANS and PANDAS:
www.youtube.com/watch?v=3qt5wnmRsRI



My Kid is Not Crazy
www.youtube.com/watch?v=WJQT9-cQwIw&t=574s

Stolen Childhood
www.youtube.com/watch?v=Cprp-zhkDCM

What is PANS?
www.youtube.com/watch?v=IDmD78znv_o

### PICURE BOOKS FOR CHILDREN

*In a Pickle Over PANDAS*
by Melanie S. Weiss

*Super Sam and the Battle Against PANS/PANDAS*
by Lindsey Wells

### BOOKS

*A Parent's Guide to PANDAS, PANS, and Related Neuroimmune Disorders*
by Patricia Rice Doran, et al.

*Brain Inflamed*
by Kenneth Bock

*Brain Under Attack: A Resource for Parents and Caregivers of Children with PANS, PANDAS and Autoimmune Encephalitis*
by Roseann Capann-Hodge, et al.

*Childhood Interrupted: The Complete Guide to PANDAS and PANS*
by Beth Alison Maloney

*Demystifying PANS/PANDAS*
by Nancy O'Hara

*My Kid is not Crazy*
by Tim Sorel

*PANDAS and PANS in School Settings*
by Patricia Rice Doran

*PANS, CANS, and Automobiles*
by Jamie Candelaria Greene

*The Parent's Survival Guide to PANDAS/PANS*
by Deborah Marcus

*Somewhere in There: Families Living with PANS & PANDAS Share Their Journeys*
by Melissa Nolan

*What Happened to My Child?*
by Heather Korbmacher

According to The Heartwood Program in Bethesda, MD, if a child's symptoms cannot be explained by a known disorder such as Sydenham chorea, Tourette syndrome, etc., then sudden-onset OCD or severe food restrictions plus symptoms from two of the following categories warrants evaluation for PANDAS or PANS:

***1)Anxiety***
***2)Extreme mood swings and/or depression***
***3)Irritability or severely oppositional behaviors***
***4)Developmental regression***
***5)Worsening school performance***
***6)Sensory or motor abnormalities***
***7)Sleep disturbances, bedwetting, etc.***

Because PANS and PANDAS were identified relatively recently*, many parents, educators and even medical providers may not be familiar with the associated symptoms. Sadly, responses often include disciplinary actions or inappropriate medical or psychological treatments, when specific medical interventions for PANS or PANDAS may be needed.

PANDAS parents are often compelled to do their own research to determine how best to help their child. Parent Doris O'Meara recognizes the need for more readily available information. "I wish there were more knowledge and resources," she said. "So many doctors aren't familiar with PANS/PANDAS. It's taken us years to get to where we are [with treatment], and we just started on the road to healing." Another parent explains, "I recently heard someone refer to PANDAS parents like us as 'involuntary experts.' I thought that was such as good way of describing it." These parents are among many who have benefitted from Facebook groups formed for parents of children with PANS and PANDAS to share information and support each other in their quest to help their children.

> **"PANDAS PARENTS ARE OFTEN COMPELLED TO DO THEIR OWN RESEARCH TO DETERMINE HOW BEST TO HELP THEIR CHILD."**

This resource guide, while not exhaustive, is designed to help parents and educators learn more about PANDAS and PANS and to determine the best way to help children suffering from such autoimmune disorders. The websites, videos, books and social media sites listed below include information about symptoms, treatments, specialty physicians, nurse practitioners and treatment clinics, as well as supportive words from parents and children who readily share their experiences with PANDAS and PANS. •

### ABOUT THE AUTHOR:

Kara Jolliff Gould, Ph.D., is Assistant Professor of Journalism at the School of Journalism and Strategic Media at the University of Arkansas. Previously, she has taught at colleges such as Weber State, John Brown University and Pepperdine. She has worked professionally in journalism and electronic media in Chicago and Salt Lake City and holds degrees from Wheaton College (IL) and the University of Utah. She is acquainted with the needs of students with disabilities, both as a professor and as a parent.

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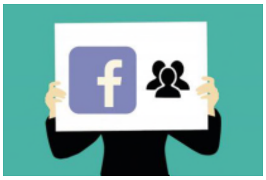
* PANDAS was identified in 1998 by Dr. Susan Swedo of the National Institute of Mental Health; the term PANS was coined later.

## U.S. STATES WITH LAWS THAT REQUIRE INSURANCE COVERAGE FOR PANDAS/PANS TREATMENT*

Arkansas
Delaware
Illinois
Indiana
Maryland
Minnesota
New Hampshire

*Source: https://www.cga.ct.gov/2022/rpt/pdf/2022-R-0104.pdf

## LINKS TO FACEBOOK SUPPORT GROUPS



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www.facebook.com/groups/P.A.N.D.A.S.International/
www.facebook.com/neuroimmune
www.facebook.com/groups/PAS.care
www.facebook.com/groups/pandasparents
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www.facebook.com/groups/PANDASVirginia
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www.facebook.com/groups/pandasaustin
www.facebook.com/groups/AtlantaPandasPansSupport
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www.facebook.com/groups/MarylandPANDASSupport
www.facebook.com/groups/pandaspansontario
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www.facebook.com/groups/125726187584259
www.facebook.com/groups/504811019560963
www.facebook.com/pandasnetwork

## SPECIALTY CLINIC WEBSITES

Banner Health.

www.bannerhealth.com/locations/mesa/banner-childrens-specialists-postinfectious-autoimmune-encephalopathy-clinic-dobson

Greater Regional HEALTH

www.greaterregional.org/pans

MassGeneral Hospital for Children

www.massgeneral.org/children/pediatric-neuropsychiatry-and-immunology

Stanford MEDICINE

med.stanford.edu/pans.html

Children's Postinfectious Autoimmune Encephalopathy Center

https://peds.arizona.edu/cpae

UAMS Health

https://uamshealth.com/location/arkansas-childrens/cpae-clinic/

UWHealth

https://uwhealth.org/locations/american-family-childrens-hospital-169/pediatric-acute-onset-neuropsychiatric-syndrome-pans-clinic-1292

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**CONTACT: Faye Simon at fsimon@epmagazine.com**

*EPMAGAZINE.COM:* AN ALL-INCLUSIVE DIGITAL HOME FOR THE SPECIAL NEEDS COMMUNITY

# WHEN HEARING LOSS IS DIAGNOSED: NAVIGATING RESOURCES

BY GAYLA H. GUIGNARD, M.A., CCC-A/SLP, LSLS CERT. AVT AND LISA A. GOLDSTEIN

*Thirty-three babies are born with hearing loss each day in the United States, yet this is unexpected news for most parents of the children who are found to be deaf or hard of hearing.*

With the advent of technology, very young babies can be accurately screened and tested for hearing loss. Hearing technology can be fitted in the early weeks and months of infancy, and children and their parents can begin early intervention services right away. Not all children are identified with hearing loss in the early months of life. For a variety of reasons some children may be diagnosed later on. In some cases, it is due to missed earlier hearing screening/testing opportunities through the Universal Newborn Hearing Screening [UNHS] program, (which is available in all U.S. states and territories). Sometimes it is a misdiagnosis (which is rare) or it could be the onset of hearing loss following the newborn period. In any case, parents experience a multitude of feelings as they embark on their family's journey with hearing loss.

## TOPICS FOR PARENTS BY CHILD'S AGE OR GRADE

When new to hearing loss, parents need guidance on the topic areas on which to focus. Over time, the need to gain new information will continue as the child grows and has new experiences. Parents will likely find it much easier to help their child if they educate themselves and look for opportunities to be educated, that may be provided by their school, state, or national organizations.

Children, ages birth to three, are typically eligible for enrollment in the early intervention program offered through their State or Territory's Early Intervention System. Families may choose to use that service and/or opt for private services. Some of the topics families of children in this age range need to learn about include: hearing technology options, early intervention and family support services, communication strategies/options, partnering with professionals to reach the desired outcomes for the child, speech/language and other developmental milestones, and the scope and sequence of goals to reach those desired outcomes, home (and daycare) carryover goals, and suggestions on how to work on those goals, and transition to preschool services.

Children who are deaf or hard of hearing, ages three to kindergarten, may be found eligible for preschool services through their local school district. Each state's Early Intervention System has a role in helping families connect with their local education agency (LEA) and the appropriate school district personnel, to start the transition process from early intervention to preschool eligibility and possible services no later than 2 ½ years of age. The recommended referral age varies by state. Testing that is conducted by the school (and sometimes by early intervention personnel) is used to help determine the need and eligibility for preschool services. A primary focus of parents should be helping their child adjust to preschool, working on continued speech/language development at home, sending their child to school with well-functioning hearing technology, monitoring their child for progress, and communicating back and forth with the school about their child on all of these topics. Even if knowledgeable school personnel are on staff, parents may need to assist the school with their understanding of what may be needed to help their young child hear optimally at school. Making sure that your child has access to what is being taught in the school environment will need to be monitored across time.

For children enrolled in kindergarten or higher grades, much of the focus is making sure that your child has the same opportunities for learning as all children. Parents will find themselves in the role of advocate, and will share the role increasingly with their child, as the child grows. For children who are deaf or hard of hearing and who have any academic delays, or who are at risk for academic delay, will benefit from having an Individualized Education Program (IEP), which is outlined on a legal document called the Individualized Education Plan. Among other IEP components, a child's goals, accommodations (including hearing technology that allows the child to hear clearly), modifications, and placement for each coming school year, should be listed. Children who are performing at or above grade level often have a 504 Plan rather than an IEP. Every child's situation, levels of function and needs for support vary, thus the plan for that child should be individualized as well. Parents and their children who are deaf or hard of hearing have legal rights at every juncture of their early intervention and school experience, and may need to exercise those rights to make sure the child has a free and appropriate public education.

> “MORE THAN 90 PERCENT OF PARENTS HAVE NO EXPERIENCE WITH HEARING LOSS IN THEIR FAMILY. THIS CAN MAKE A FAMILY FEEL ALONE, BUT THE GOOD NEWS IS, THERE ARE MANY GOOD RESOURCES AND MUCH CAN BE DONE TO HELP A CHILD WITH HEARING LOSS GROW AND THRIVE.”

### LOTS OF QUESTIONS

Understandably, parents have many questions. More than 90 percent of parents have no experience with hearing loss in their family. This can make a family feel alone, but the good news is, there are many good resources and much can be done to help a child with hearing loss grow and thrive. Because there is so much available information, parents will find it helpful to ask some of the following questions as they sort through the many resources.

Once engaged in their search for information and related services, parents may find that some individuals around them have very strong opinions, particularly related to communication strategies. These strong opinions can feel like validation when they are in line with parental plans, but when not, may cause anxiety and cause a parent to question their decisions. Parents are the only people in a child's life who have the right, role, and responsibility to make decisions for their child/children. While others' opinions might be helpful, as a parent gathers information, and will help in their decision-making process, ultimately these decisions belong to the child's parents. This make sense, as parents know their child better than others and are in the best position to make decisions for their child. Parents should feel free to talk with as many people as they wish, and to connect with any and all resources as they learn about and live with hearing loss. As individuals, we process information in a variety of ways, and so there is no one best way for all parents to sort through the information and come to important decisions for their children. As parents receive and review information for a decision that needs to be made now or to tuck away for later, they will want to evaluate the quality of the information. For that purpose, the following questions might be helpful:

1) *What or who is the source of this written or spoken information?*

2) *Does the source have professional or personal expertise about hearing loss? If professional, do they have specialized, deep knowledge, skills and experience related to childhood hearing loss in particular? If personal expertise, does this individual's story relate to my child and family, and if so, what takeaways are there? Remember that one person's story is one person's story. A child who is deaf or hard of hearing and born in 2023 generally has different (usually better) access to intervention resources than a child born in 1985.*

3) *Is the information sourced from opinions or facts? Would the author or speaker be willing and able to share their sources (if not already available)? Anything stated as fact should have evidence (data, research) that backs up that statement.*

4) *Is the information shared by the professional directly related to interaction with or testing on my child and their performance, progress or skill levels gained by working with them, versus a blanket statement about all children who are deaf or hard of hearing?*

5) *Does the information appear to have a bias? If so, does the author openly disclose that bias in some way? For example, there are organizations in the field of hearing loss that focus on one particular communication strategy, versus all available communication strategies. Organizations often have a primary focus to allow for more specialization and provide deeper knowledge and resources to the public. Biased resources can be helpful, but parents will need to review other resources as well to make sure they are "getting the whole picture" related to childhood hearing loss, especially for children who have the same type and degree of hearing loss as their own child.*

6) *Last, but often most important, parents should do a gut check as they receive and process new information, by asking themselves questions such as, "Does this statement ring true?" "Does this information make sense?" "Do I feel funny or ill at ease about this information or source?" "Does the statement made or opinion shared about my child seem like a good fit?"*

### A GOOD PLACE TO START: ONE PARENT'S STORY

There are many quality resources available for families. A mother, Chelsea (name changed), shared this story with AG Bell, "On Veteran's Day 2020, I felt depressed after learning that my daughter had a hearing loss just three weeks earlier. Angry and blaming myself for both her hearing loss and delayed diagnosis, I was in research mode to get her the help she needed. After reaching out to AG Bell for support and getting involved in their Parent Chats, I began to feel encouraged and able to get my daughter the services and support she needed."

## OTHER PLACES TO START

Parents typically begin to seek answers and help immediately following their child's hearing loss diagnosis. Finding the right resources are crucial. For example, when it comes to hearing technology and speech and language development, when navigating the world of hearing loss. Hearing First (**www.hearingfirst.org**) provides a quick and clear place to start for families. Their resource, Starts Hear (**www.hearingfirst.org/starts-hear-awareness-campaign**), also helps families understand the importance of getting help and starting on their family's journey with hearing loss right away.

The Alexander Graham Bell Association for the Deaf and Hard of Hearing (AG Bell) is a great resource for families who wish to use Listening and Spoken Language (LSL) with their child who is deaf or hard of hearing. AG Bell Listen-Learn-Link Parent Support Line (**www.agbell.org/Families/Listen-Learn-Link-Parent-Support-Line**) allows parents, caregivers, and guardians of children with hearing loss to connect with AG Bell's Early Intervention Parent Consultant, who speaks both English and Spanish, and is a parent of a now-adult deaf son who uses listening and spoken language. In addition to inviting parents to participate in AG Bell online Parent Chats and one of AG Bell's local Chapters (**www.agbell.org/Connect/Local-Chapters**), she directs parents to professional resources (LSL Professionals: **www.agbell.org/locateLSLS**) and other national and local resources and services. AG Bell recognizes that every family is unique and every family has the potential to create a beautiful story, one that is their own and that works for their family.

The Centers for Disease Control (CDC) provides links to several resources: Parent Resources (**www.cdc.gov/ncbddd/hearingloss**). The CDC's materials on Parent Guidance (**www.cdc.gov/ncbddd/hearingloss/parentsguide/index.html**), help parents think about what questions they need to ask as they embark on their family's journey, and the Decision Guide related to Communication Options (**www.cdc.gov/ncbddd/hearingloss/parentsguide/decision/index.html**) is a valuable resource that can help a family sort through some of their next steps.

## RESOURCES RELATED TO COMMUNICATION AND FAMILY SUPPORT

In many cases, families may find that local professionals who know their child (e.g. pediatric audiologist, certified listening and spoken language specialist, educator and/or speech-language pathologist who specialize in hearing loss, and their pediatrician, family physician, and otolaryngologist) are in a better position to provide informed opinions, and connect families to the local services that will help them reach the outcomes that they wish for their child to achieve.

A good team, with the parent and child at the center is priceless, and should be the norm for every family of a child who is deaf or hard of hearing, but often it isn't. Many families benefit from both the quality resources and connections to others who know about hearing loss provided through national organizations. •

## HEAR THIS : DEAF AND HARD OF HEARING RESOURCES

The vast number of written resources collectively available through the below organizations, while designed for parents, are not meant to be navigated alone. Parents can reach out to these organizations to connect directly with a knowledgeable person through email links on their websites.

**AG BELL**
Provides family support through its
Learn-Listen-Link Parent Support, Parent Chats, online
resources, chapter network and programming
**www.agbell.org**

**HEARING FIRST**
Provides a family community and many other resources on how to learn Listening and Spoken Language (LSL) as part of its online digital community
**www.hearingfirst.org**

**THE JOHN TRACY CENTER**
Provides parent training modules in English and Spanish related to Listening and Spoken Language (LSL) that parents can complete at home
**www.jtc.org**

**HANDS & VOICES**
Provides family-to-family support across communication choices through their state chapters and programs
**www.handsandvoices.org**

**THE NATIONAL CUED SPEECH ASSOCIATION**
Provides information and education on how to learn Cued Speech
**https://cuedspeech.org**

**AMERICAN SOCIETY FOR DEAF CHILDREN**
American Society for Deaf Children provides information and education on how to learn American Sign Language (ASL).
**https://deafchildren.org**

### ABOUT THE AUTHORS:

Gayla H. Guignard, M.A., CCC-A/SLP, LSLS Cert. AVT has served as AG Bell's Chief Strategy & Programs Officer since September, 2015. By training, she is an audiologist, speech-language pathologist and Listening and Spoken Language Specialist Certified Auditory-Verbal Therapist. In addition to clinical practice with children and families, she has led state programs in Indiana, including EHDI, and is focused on systems that help improve outcomes for children who are deaf or hard of hearing, including the preparation of professionals in the field.

Lisa A. Goldstein is a deaf journalist and Officer of the Pennsylvania Chapter of The Alexander Graham Bell Association for the Deaf and Hard of Hearing. She has been a member of AG Bell since 1982. She was born profoundly deaf, diagnosed at 14 months, learned to lipread and speak, and now listens through a cochlear implant and digital hearing aid. Lisa has a master's degree in journalism from UC Berkeley and works as a freelance journalist in Pittsburgh, where she lives with her husband and two children.

HOW A MONTCLAIR STATE UNIVERSITY PROGRAM PROVIDES A MODEL OF EXCELLENCE IN EARLY INTERVENTION.

# SETTING A STANDARD FOR EARLY CARE AND EDUCATION

COURTESY OF MONTCLAIR STATE UNIVERSITY

*Support for our young children is a community effort, and at Montclair State University, the Ben Samuels Children's Center goes above and beyond for families, through its early care and early intervention services, like the Jeffrey Dworkin Early Intervention Program (JDEIP).*

**FINDING A WAY:** The JDEIP program promotes collaborative partnerships that strengthen and enhance family competence to develop and use lasting networks of natural support.

The program is a comprehensive Essex County agency within the New Jersey Early Intervention System (NJEIS), designed to enhance the capacity of families to meet the developmental and health-related needs of children from birth to age three, who have delays or disabilities.

## WHAT IT OFFERS

A support team of consultants in the JDEIP program provides a variety of services reflecting the current best practices in the field of early intervention: developmental intervention, occupational therapy, physical therapy, speech/language therapy, social work/family training and support, and bilingual services or translation for non-English speaking families.

These quality therapeutic services are provided in the most natural and comfortable occurring environments - familial homes, childcare settings, community classes, etc. Therapists and practitioners work within the typical routines of families, respect family-centeredness, and advocate for and within consultative transdisciplinary practices.

The program promotes collaborative partnerships among families, the community, health care providers, and schools/child care programs, that strengthen and enhance family competence to develop and use lasting networks of natural support. It also fosters opportunities for the development of peer relationships with children without disabilities.

Practitioners and therapists working in Early Intervention and providing services at the Ben Samuels Children's Center, work on childrens' individualized outcomes and strategies, which have been developed for each child by the therapists, classroom team, and family. The outcomes are addressed within developmentally appropriate routines and play activities, that may also include "Floor Time™" and semi-structured activities in the context of the inclusive routines during the school day.

## ABOUT BEN SAMUELS CHILDREN'S CENTER

The Ben Samuels Children's Center at Montclair State University is a model of excellence in the inclusive early care and education of children from 3 months through 5 years. Some children who are enrolled at the Ben Samuels Children's Center also receive early intervention services.

Through NJEIS, therapists partner with service coordinators, families, and teachers, and are committed to examining and implementing the best practices of teaching and learning in a nurturing environment, where neuroatypical children, children with special needs, or diagnosed disabilities can learn, play, and grow alongside their same-age peers.

## FOR MORE INFORMATION

Families who may have concerns about their child(ren)'s development, if they are under the age of three, can contact the New Jersey Early Intervention System (NJEIS) statewide referral service at 888-653-4463.•

*Individuals interested in learning more about the programming or enrollment at the Ben Samuels Children's Center may call 973-655-7177 to speak with the enrollment coordinator or send a message to* childrenscnt@mail.montclair.edu

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2023

EP GUIDE

NAVIGATING SPECIAL NEEDS RESOURCES

# SPECIAL NEEDS NEW YEAR'S RESOLUTIONS

BY BETH C. MANES, ESQ.

*We all tend to make unrealistic New Year's resolutions that are never fulfilled. Let this year be different, you owe it to your child and yourself. Below are some tips to help you set manageable goals for 2023:*

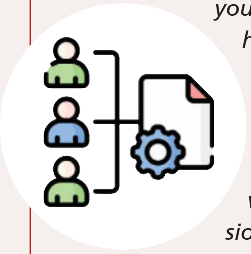
## SPECIAL EDUCATION : PREPARING FOR THE IEP REVIEW SEASON

Breaking down the larger projects of IEP review into smaller tasks and manageable goals should set you up for success in 2023.

Once the calendar flips to the new year, we seem to move at breakneck speed toward June. Therefore, we suggest you start preparing for IEP review season now. Although, most annual review meetings occur later in the spring, there are things you can do now, so you do not find yourself running out of time to iron out details for ESY (extended school year), or to have next year's program and placement finalized before school staff and administration are off for the summer. Here are the first steps to take:

- *Begin by getting organized. Create a 3-ring notebook for your child's documents. Get dividers to separate the binder into 504 Plans/IEPs, testing/evaluations/reports from your school and specialists, report cards, IEP progress reports, and communications between you and school staff members. We recommend filing the documents by date within each section, with the most recent on top. If any of those documents are missing, ask for them.*
- *Next, review your child's 504 Plan and/or IEP. Make note of any services that are not being provided at the frequency set forth in the IEP. Compare the goals and objectives with the progress reports to be sure that everything is being tracked, and if progress is being made as anticipated.*
- *If your child is 14 or older, transition planning should be addressed in the IEP. Make a note if it is not, and be sure to raise it in your annual review meeting. Transition planning serves to prepare your child for college or a career. This section of the IEP should have its own set of goals and activities, with time frames for achievement. This is one area of the IEP where input from your child is vital; their life plans should be taken into account when developing a transition plan.*

- *If your child is in 12th grade, be sure that you and the District are on the same page with respect to graduation. You do not want to be caught off-guard and discover late in the school year that the District intends to graduate your child, thereby terminating all services. A student who is not graduating may still walk in the graduation ceremony and participate in other end-of-senior year activities, if they wish to do so. If you believe your child is not ready to graduate and the District believes otherwise, it is essential that you file for mediation or due process.*
- *If your child has turned 18 since the IEP went into effect, be aware that education decisions have now transferred to your child. This should be noted in the IEP. If your child is not capable of making their own education decisions, there are steps you can take to ensure that you continue to make those decisions, like having your child authorize you in writing to make them, or, if your child does not have the capacity to understand such authorization, you can seek guardianship of your child (whereby the court will grant you authority to make decisions for your child). If you believe you will require guardianship of your adult child, be aware that it may take several months for a guardianship to be heard by a judge.*



- *You should also review the most recent evaluations. Be sure all of your child's needs, as noted in the evaluations, are being addressed in the IEP. Remember, your child should be evaluated every three years. If your child is due within the next 6 months, ask that evaluations begin now. Given the length of time these evaluations take, it would be best to have them completed prior to the annual review meeting.*

**PIECE BY PIECE:** Breaking down IEP review and estate planning into smaller, more manageable tasks makes these seemingly overwhelming projects much more feasible.

## ESTATE PLANNING : REVIEWING AND UPDATING

Making manageable goals for estate planning tasks should make 2023 a successful year.

Estate planning is something that often remains at the bottom of the list of things to do. However, it is essential to protect your family, especially your children with special needs, by doing a quick review and update. We recommend you start by pulling out your old documents to review them. Things to look for include:

- *When did you last update or review your documents? If it has been more than 5 years, or if your family has experienced significant changes since the documents were signed (i.e., birth of more children, change in your marital status), we recommend sitting with your attorney to review and advise if any changes are needed.*
- *Have you indicated your selection of guardians for minors as well as adult disabled children?*
- *If you have disabled children, have you directed their inheritance into a Special Needs Trust in order to protect their eligibility for means-tested government benefits?*
- *Do your estate planning documents include a Last Will and Testament, a Durable Power of Attorney, a Healthcare Directive and a Funeral Disposition Representative Document?*

There are other things to consider that are not addressed within your Will. For example:

- *You should also review the beneficiary designations of your retirement plans and other accounts, to confirm that nothing is going directly to a beneficiary who is, or will be, receiving government benefits or is a minor beneficiary. A disabled beneficiary's share should go into a Special Needs Trust, and a minor's share should go into another protective trust.*
- *If your child with special needs is age 17 or older, you should consider guardianship or another protective arrangement.*
- *If your child with special needs is age 18 or older, you should apply for Supplemental Security Income (SSI) and Medicaid on that child's behalf.*

Breaking down the larger projects of "IEP review" and "estate planning" into smaller, more manageable tasks should set you up for success in 2023. It also makes these seemingly overwhelming tasks much more feasible. In the end, you will appreciate the peace of mind you will give yourself when you can cross these off of your mental or actual "to do" list. Most importantly in 2023, take time for yourself. You deserve it! •

*If you have questions about preparing for your annual IEP review, or your estate plan, please contact Manes & Weinberg, LLC, to discuss your family's needs and options.* *(973) 376-7733* **kathy@manesweinberg.com** **www.manesweinberg.com**

### ABOUT THE AUTHOR:

Beth C. Manes, Esq., is a founding member of Manes & Weinberg, Special Needs Lawyers of New Jersey, LLC. She is licensed to practice law in New Jersey, where she has been practicing for over 25 years. Her practice concentrates in Special Education Law, Special Needs Planning, Guardianships and Estate Planning. Beth is also active in her community, raising puppies for the Seeing Eye of Morristown, and serving as a member of her synagogue's Accessibility and Inclusion Task Force. Beth resides in Essex County with her husband, several dogs, and whichever adult children are home at the time. Beth loves to travel; her favorite vacations are on a bicycle, in a tent, or observing animals not typically found in New Jersey. Beth started her career in corporate law but did not like the impersonal nature of the practice and decided to change direction. After a few more turns in her career path, Beth searched for the field of law where she could have the most impact and discovered a love for special needs advocacy and planning.

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# HEALTH-RELATED RESOURCES

## FOR PEOPLE WITH IDD AND THEIR SUPPORTERS

BY CRAIG ESCUDE, MD, FAAFP, FAADM

*With significant health disparities noted in people with IDD, it is important that people with intellectual and developmental disabilities (IDD), their supporters, and healthcare providers educate themselves on the different health risks that are more commonly seen in people with IDD and about what can be done to prevent serious complications.*

Supporters and healthcare providers are often challenged in finding helpful information related to healthcare for people with IDD. As a physician who started practicing in this field in the 1990s, finding clinically relevant information about healthcare for people with IDD was challenging. Fortunately, over the past several years, more resources have been developed that relate specifically to healthcare issues and improving health equity for people with IDD. In this article, you'll find a listing of websites, tools, and training available to provide information and guidance to you, whether a family member, paid supporter, healthcare provider, or person with IDD.

### BOOKS

*Clinical Pearls in IDD Healthcare* (**https://replacingrisk.com/product/clinical-pearls**) provides easy-to-understand and clinically relevant information to clinicians and supporters of people with IDD. The book is centered on "clinical pearls," which are small bits of free-standing, clinically relevant information based on experience or observation. They are part of the vast domain of experience-based medicine, and can be helpful in dealing with clinical problems for which controlled data does not exist.

You will find 1-2 page documents covering 55 health-related conditions commonly seen in people with IDD. Topics include: medical causes of adverse behavior, sexuality, quality of life, end-of-life care, dental care, polypharmacy, common preventable cause of illness, aging with IDD, and much more. The guide is used by physicians, supporters, nurses, and family members to gain an understanding of the many health issues that are more common in people with IDD. For family members, it can be helpful for self-education but also as a means to provide concise information to physicians, who may appreciate additional clinical details related to IDD healthcare.

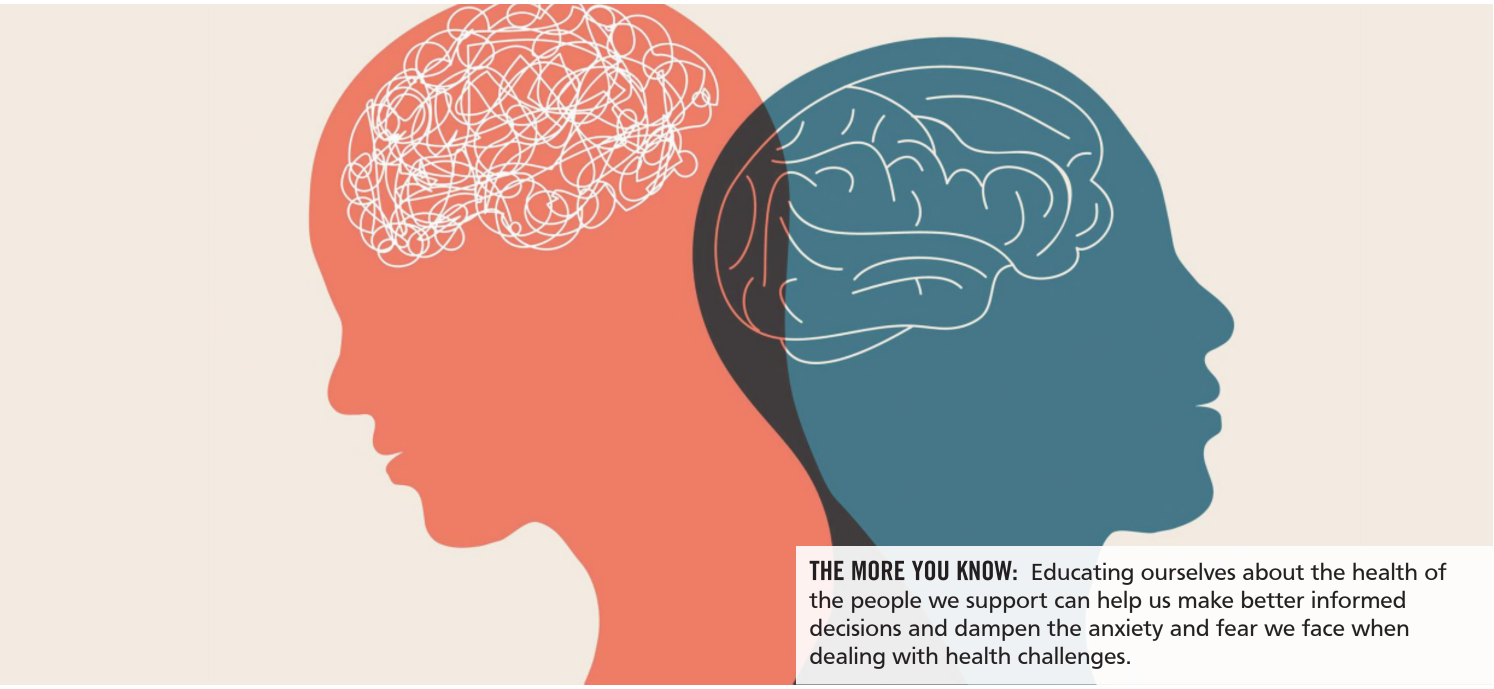
### ELECTRONIC LEARNING COURSES

For clinicians looking to receive additional training in IDD Healthcare, the Curriculum in IDD Healthcare (**https://replacingrisk.com/curriculum-in-idd-healthcare-elearn**) is a web-based Continuing Medical Education-approved eLearning course that teaches the fundamentals of IDD healthcare that were likely not taught in clinical training programs. It's a 6 module, self-paced course that has been studied and shown to significantly improve clinicians' clinical confidence in providing healthcare to people with IDD. It's currently used in medical and nursing schools, and by practicing clinicians throughout the United States.

The Fatal Five (**https://replacingrisk.com/store**) eLearning courses are excellent programs that teach learners about the top preventable causes of illness and death in people with IDD. The specific topics covered in these 7-module courses include discussions about aspiration, dehydration, seizures, bowel obstruction, sepsis, and gastroesophageal reflux, as well as a discussion on knowing when to act to avoid serious complications. The *Fatal Five Fundamentals* is geared to teach direct support professionals and family members about these topics. The *Fatal Five Advanced* course teaches about the same conditions at a more clinical level, which is great for nurses.

### WEBSITES

Special Olympics (**https://resources.specialolympics.org/health?locale=en**) has a webpage dedicated to health resources for people with IDD. Topics include Health Promotion, Fitness, Health Smiles (dentistry), and many other health and wellness resources.



**THE MORE YOU KNOW:** Educating ourselves about the health of the people we support can help us make better informed decisions and dampen the anxiety and fear we face when dealing with health challenges.

The Eunice Kennedy Shriver National Institute of Child Health and Human Development (**www.nichd.nih.gov/health/topics/idds/more_information/resources**) has an extensive list of IDD health resources for patients, healthcare providers, and researchers. You'll find general and condition-specific information, including links to related entities such as the Association for University Centers on Disabilities (**www.aucd.org/template/index.cfm**).

The Vanderbilt Kennedy IDD Toolkit (**https://iddtoolkit.vkcsites.org**) is an excellent resource guide for clinicians and others relating to several common genetic conditions often associated with IDD. In addition to general guidance, there is specific guidance for health screening about conditions like Autism, Down syndrome, Fragile X, Prader-Willi, and other conditions, as well as a number of valuable resources relating to topics such as informed consent, communication, and behavioral health.

## ORGANIZATIONS

There are two organizations for healthcare providers that offer resources online and provide educational opportunities at their annual conferences. The American Academy of Developmental Medicine and Dentistry (**www.aadmd.org**) focuses on physicians and dentists, and the Developmental Disabilities Nurses Association (**www.ddna.org**) for nurses. Both organizations are excellent resources where providers can enhance their skills and knowledge in providing IDD healthcare and collaborate with others in the field.

Several organizations provide valuable information about specific genetic conditions and syndromes, including the Prader-Willi Syndrome Association (**www.pwsausa.org/what-is-prader-willi-syndrome**), the National Association for Down Syndrome (**www.nads.org**), the National Autism Association (**www.nationalautismassociation.org**), the Autism Society of America (**www.autismsociety.org**), the National Fragile X Foundation (**www.fragilex.org**), the Angelman Syndrome Foundation (**www.angelman.org**), and others. Many of these societies have information tailored to supporters, family members, healthcare providers, and researchers relating to their specific syndrome.

## FINDING ADDITIONAL RESOURCES

The internet is filled with resources, but not all are what I'd call "good." And some contain misinformation or are more based on people's opinions, rather than what is generally considered acceptable and reliable health-related information. When looking for resources, I'd recommend going to websites that are from known entities, such as well-known hospital systems, governmental agencies like the CDC and the NIH, or official websites for whatever you are looking for. I also recommend reaching out to people you know in your community to see what resources they recommend. Talk to trusted physicians and nurses, or call your local hospital to see if there might recommend a particular resource.

## FINAL THOUGHTS

I'm sure that there are many excellent resources I have left out. But hopefully, the ones listed here will be useful to many. Educating ourselves about our health and the health of the people we support can help us make better informed decisions, which can dampen the anxiety and fear we might face when dealing with health challenges. •

### 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.

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# What Roles Need to Be Filled in My Estate and Care Plan?

THIRD OF A THREE-PART SERIES

BY JOSHUA FISHKIND, J.D., MBA

*Building a plan that will protect your loved one beyond your lifetime is not just about drafting documents, or even ensuring that there are sufficient funds to supplement benefits. A team needs to be assembled to fill various roles in your estate plan, any trusts created, and to ensure care needs will be met. Below are some common appointments that you may be asked to make during the planning process, and some tips on who you may want to consider.*

## BUILDING YOUR TEAM : TRUST ROLES

There are two trust structures that you may choose for your plan. A delegated trust, which is more common, appoints a trustee or trustees who are each responsible for all aspects of trust administration. Whether there is one trustee, or multiple co-trustees, each are responsible for each other's decisions. In a delegated trust, you may be asked to appoint:

### TRUSTEE

The trustee is the person or entity who manages all aspects of a trust. They are responsible for all investment management and distribution decisions, filing tax returns, and ensuring that expenses are compliant with any government benefits regulations.

### CO-TRUSTEE

An additional trustee, with all the same rights, responsibilities, and liabilities of the trustee.

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The second trust structure, a directed trust, appoints multiple professionals or individuals to manage the trust. Commonly called bifurcation (2 roles) or trifurcation (3 roles), a directed trust allows for different persons or professionals to serve only in their area of expertise. Below are the roles you may consider in a trifurcated directed trust:

### ADMINISTRATIVE TRUSTEE

Responsibilities include filing taxes, accountings, and record keeping.

### INVESTMENT ADVISOR

Manages the money and investment management decisions.

### DISTRIBUTION ADVISOR

Makes distributions to the beneficiary and is responsible to ensure that benefits eligibility is not compromised.

Unique to the directed trust, trustees are not liable for each other's decision making. This means, for example, that an error by the distribution advisor does not trigger risk or liability for the investment advisor, and vice versa. Often, using this structure can reduce fees for trust administration and allows you to work with advisors, who otherwise, may be wary of serving as trustee.

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When drafting either a directed or delegated trust, two additional questions will arise: "Who can oversee the trustee?" and "Where do excess trust assets go after the beneficiary's demise?"

### TRUST PROTECTOR

Perhaps the most important and underutilized role in special needs trust planning is a trust protector. Three of the most common questions families raise when creating their plans can all be answered by building a trust protector into the plan:

1. *What happens if the trustee (individual or corporate) is doing a bad job?*
2. *What is the right role for a sibling or family member who shouldn't bear all the responsibility of serving as trustee, but should be involved?*
3. *How do we ensure that family-level thoughts and concerns are communicated to a corporate trustee?*

Trust protectors can solve all these concerns. A trust protector is a customizable role, built into your trust document, that generally grants an individual the power to remove or replace trustees. They are not fiduciaries (in most cases), have no daily responsibility or liability, but simply have the power to fire anyone doing a bad job and hire their replacement. With this authority, they have a voice in how the trust is administered, as they can move it to another institution, or to another trustee, but don't need to do all of the work of actually administering the trust. This is often the best role for family members – oversight, without daily work or risk.

### REMAINDERPERSONS

After the beneficiary passes, remainderpersons (remaindermen) will receive any assets remaining in the trust. This isn't a job, just the named recipient(s) of your gift. In a third-party trust, this will be any remaining assets. In a first-party trust, this will be the assets remaining after the repayment of any Medicaid liens. Note: with pooled trusts, special rules may apply where the trust retains excess assets. Check with your pooled trust company, as there is substantial variation in policies between pools.

Also, consider whether your plan puts your remainderpersons in a conflicted position – if they are also a trustee, will they still distribute money as freely to the beneficiary? Remember, everything that is spent, would otherwise be passed to the remainderpersons upon the beneficiary's demise.

## BUILDING YOUR TEAM : ESTATE ROLES (PLAN FOR 2 GENERATIONS)

When creating your estate plan, consider who is best to fill these roles both at the parent level, and for the individual with special needs. Doing this planning for the individual with disabilities now can prevent very complicated issues from arising in the future, when parents may not be available to assist.

### EXECUTOR

Who will settle any open bills or accounts, gather all your assets, and distribute them as directed by your will? Professionals can fulfill this role, but often this is a very responsible friend or family member who is entrusted to execute your wishes.

### POWER OF ATTORNEY

Who can make legal decisions on your behalf? Two types of POAs that you may wish to consider: durable and springing. For you, the parent, in most cases, a springing power of attorney is used. The springing POA "springs" into action only if you cannot make legal decisions. (e.g., If you developed dementia, the springing POA would trigger and your designee could pay bills, access your accounts, and manage financial and legal affairs.)

A durable power of attorney offers the same powers, but takes effect immediately and those powers last until revoked. This is less common for estate planning purposes as it relates to parents, but is often part of planning for the individual with special needs.

Power of attorneys can be broad or narrowly tailored and you should discuss with your attorney what is most appropriate for your goals. Often, this role is filled by a spouse, competent child, or sibling.

### HEALTHCARE PROXY

Who can make medical decisions on your behalf if you cannot do so? Again, appointments should be considered for both generations. What will happen if you or your spouse can't make a medical decision, and for your child if they are incapacitated. Note, this doesn't require that your child lose their ability to make decisions now, but what if they are not able to make such decisions in the future.

Healthcare proxies are generally family members or very close friends, and you can assign successors in case someone isn't available or is deceased. For you child, for example, parents may serve as healthcare proxies during their lifetimes, then a sibling upon the demise of the parents.

**LOOKING DOWN THE ROAD:** Consider who is best to fill these roles both at the parent level, and for the individual with special needs. Doing this planning for the individual with disabilities now can prevent very complicated issues from arising in the future.

**PROCEED WITH CAUTION:** Before rushing to appoint a guardian, however, consider the full impact of placing someone under guardianship.

## BUILDING YOUR TEAM : CARE ROLES

Terminology here is very state dependent. Some states use the term conservator and guardian interchangeably, others use the term conservator only with regard to assets. It is essential that you speak with local counsel to ensure that your plan uses the right terminology and will comply with state law. That said, the duties are largely the same, even if the local naming conventions differ.

### GUARDIANS & CONSERVATORS

If your loved one is under guardianship, consider who will succeed the parent in that role. If they are not under guardianship, should they be? Often parents can avoid dealing with a formal guardianship, because as parents, despite lacking legal infrastructure to make certain decisions, they continue to do so out of practical necessity. This freedom will not exist for non-parent successors, so parents often must consider whether appointing a guardian is right for their loved one.

Before rushing to appoint a guardian, however, consider the full impact of placing someone under guardianship. In the simplest terms, a guardianship makes your loved one a legal child, ward of the guardian, and the guardian is like the parent. Guardians can tell (not ask) the beneficiary where they will live, who they can date, if they can vote, whether they can drive, and will be the intermediary between the trust and the beneficiary. When needed, this can provide a great deal of protection and support for a person with substantially limited capacity. However, this should be a last resort, and only utilized when there is not a less restrictive means of providing the necessary supports and protections.

Depending on local statutes, the role of guardian can be broken into two parts: monetary and personal guardianship.

### GUARDIANS OF ASSETS

Sometimes called a Conservator, the Guardian of Assets is responsible only for financial matters, but not personal issues. Thus, they can access bank or investment accounts, pay bills, or file taxes, but they do not make personal decisions.

### GUARDIANS OF PERSON

A Guardian of the Person makes all personal decisions on behalf of an incapacitated person. Medical, daily living, personal, romantic, housing decisions, and more, will all be handled by the guardian on behalf of, and critically, in the best interest of the beneficiary, as determined by the guardian's discretion. Again, it is rare that this is the best option, but, if necessary, this can offer substantial protection for an individual who cannot safely make such decisions themselves, even with supported decision making.

### SUPPORTED DECISION MAKING (SDM)

More recently, supported decision making teams have become the preferred tool for ensuring that an individual with special needs retains as much control as possible over their own life and decisions, with an infrastructure for guidance and support. In the same way persons without disabilities rely on advisors, such as a financial advisor when planning their retirement, a supported decision-making team can appoint different individuals to roles where they can advise on each type of issue. A member of the SDM may provide medical support, while another focuses on employment. SDM involves documentation and creating a legal infrastructure to support, what in many cases, is already, a natural part of the decision-making process. With the SDM infrastructure in place, hospitals, doctors, lawyers, and others who may want to ensure that the person they are working with understands the decisions that are being made, will be less likely to require that a formal guardianship be in place, as the SDM team will be able to show structured support for the decision.

**MAKING THE DREAM WORK:** Taking small steps, building the right team of advisors, and ensuring your team members are in frequent communication, will yield the best result.

## BUILDING YOUR TEAM : PROFESSIONAL SERVICES TO CONSIDER

### REPRESENTATIVE PAYEE

If your loved one is receiving money from Social Security, but cannot manage the funds themselves, a representative payee (Rep-Payee) can be appointed to handle benefits on their behalf. This role is separate from the trustee, who only manages funds within the trust. Often a family member or guardian serves as Rep-Payee, but there are organizations in every state who can serve as well.

### CARE MANAGER

If your loved one requires additional care and support to live independently, has complex medical needs, or you want there to be oversight of a residential facility or group home, consider engaging a care manager. Protocols can be established to check in weekly, monthly, or quarterly. Where needed, home healthcare services can be arranged and paid for by the trust. This role is filled by a professional and will work with your trustee to make sure that appropriate services and support are provided.

### GROUP HOME

This is a hard topic for many families, where providing daily in-home support to a loved one has become a way of life. Often parents and families are concerned about the quality of care in group homes, or that they are abdicating their role as caregiver by encouraging a loved one to move to a group home. Despite gut instincts to the contrary, a group home can provide a loved one with the most stability and freedom of any housing option. While nothing can replace mom and dad's care, giving your loved one the opportunity to live semi-independently, with peers, in a setting designed to ensure their safety, may be the best plan. Moreover, making this transition during the parents' lifetime, allows for insights to be shared with group home staff, and for parents to oversee the operation of the residence, to ensure it is a good fit.

Making this difficult choice earlier gives you the opportunity to be selective about your loved one's living situation, rather than having to find housing in a crisis, when parents aren't there to assist, and options may be limited. It allows your loved one to adapt, while you are there for support, and ensure a smooth transition.

## YES, YOU DO NEED TO PLAN:

Hopefully, throughout this three-part series, some of the mystery, stress, and anxiety around planning for your loved one has been alleviated. Taking small steps, building the right team of advisors, and ensuring your team members are in frequent communication, will yield the best result.

Honest discussion with family members about what roles they want in the future, and how much responsibility is appropriate for them given their own obligations, will help determine where professionals will be needed. Working with legal and financial advisors experienced in serving the special needs community will greatly reduce the stress of creating a plan that works. Tying all this together into a comprehensive care plan, that will guide future caregivers and trustees in how best to support your loved one, will crystalize your hopes and lifetime of experience into an action plan. Let's get planning! •

### ABOUT THE AUTHOR:

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

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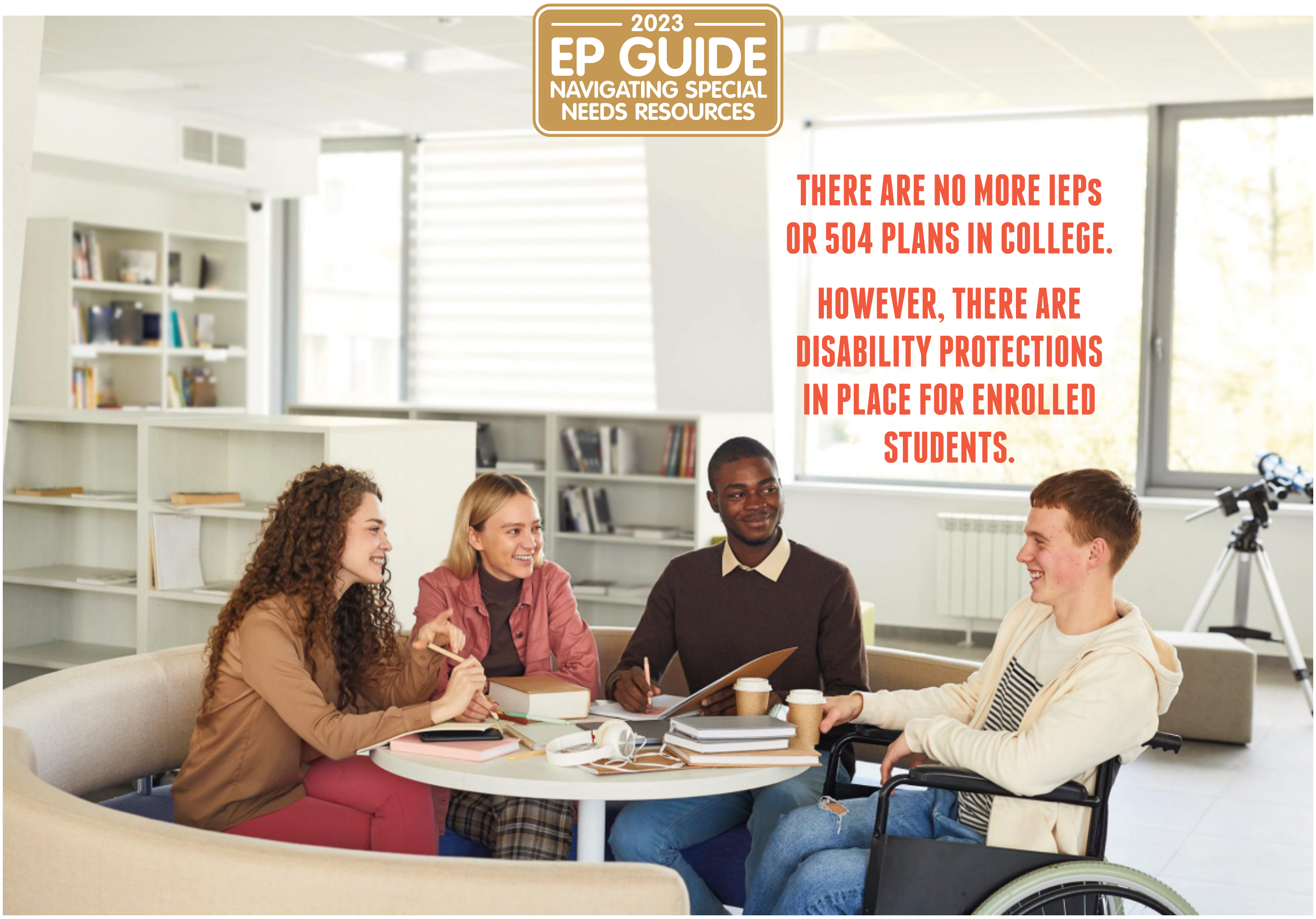

THERE ARE NO MORE IEPs OR 504 PLANS IN COLLEGE.

HOWEVER, THERE ARE DISABILITY PROTECTIONS IN PLACE FOR ENROLLED STUDENTS.

# WHAT STUDENTS WITH DISABILITIES NEED TO SUCCEED IN COLLEGE

BY LAUREN AGORATUS, M.A.

## RIGHTS OF STUDENTS WITH DISABILITIES IN POST-SECONDARY EDUCATION

There are mandates to prevent discrimination under the Americans with Disabilities Act (ADA) and Section 504 of the Rehabilitation Act that all colleges must follow. Although students do not have to disclose their disability, if they need supports they can contact the college special services department to discuss accommodations.

## WHAT ACCOMMODATIONS CAN BE PROVIDED IN COLLEGE?

Some examples of accommodations that can be given include: using a calculator, testing free of distraction, extra time, recording rather than writing class notes, typing rather than writing notes and homework, etc. Accommodations are based on what each individual student needs. High schools can help prepare students, and a detailed list of how to help students ask for accommodations is available at Edutopia *(see Resources)*.

## PREPARING FOR COLLEGE

Parent Centers funded under the Individuals with Disabilities Education Act (IDEA) can help families with transition IEPs during high school. Centers for Independent Living can help students during high school and beyond with independent living skills. Think College has resources to prepare students with disabilities for college. The National Technical Assistance Center on Transition and the National RAISE (Resources for Access, Independence, Self-determination and Employment) Transition TA Center have a plethora of resources for families and professionals on effective transition services, scholarships for youth with disabilities, mental health on college campuses, post-school outcomes, and much more. Transition TN has a college prep checklist for students. They also have a family tip sheet on accessing accommodations.

## STUDENTS WITH DISABILITIES IN COLLEGE

There is a federally funded National Center for College Students with Disabilities. Here families and self-advocates will find information on finding a school, paying for college, and problem-solving during matriculation. Best Colleges issued the “College Guide for Students with Disabilities.” This guide includes knowing your rights and considerations, while choosing a college to attend. The Campus Disability Resource Database is searchable by state and by specific services, such as tutoring. Some programs have peer mentors to provide tutoring, help the new student takes notes, or help them adjust to being in school. Think College has resources and tools for students with intellectual disabilities, including daily living skills.

There are many resources for families and self-advocates to assist them in the college enrollment process. Students with disabilities can get needed accommodations and supports to be successful during their college experience. •

## 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 2 academic journals (**https://pubmed.ncbi.nlm.nih.gov/?term=agoratus+l**). Lauren was recently named a Hero Advocate by *Exceptional Parent Magazine* (**https://reader.mediawiremobile.com/epmagazine/issues/207207/viewer?page=18**).

## WAY TO GO : COLLEGE ENROLLMENT, ACCOMMODATIONS AND SUPPORT RESOURCES FOR FAMILIES AND INDIVIDUALS

**EDUTOPIA**
Helping Students with Disabilities
Understand Accommodations in College
**www.edutopia.org/article/helping-students-disabilities-understand-accommodations-college**

**CENTER FOR PARENT INFORMATION AND RESOURCES**
**www.parentcenterhub.org/find-your-center**

**CENTERS FOR INDEPENDENT LIVING**
**www.ncil.org**

**THINK COLLEGE**
**https://thinkcollege.net**

Tools to Help Manage Daily Life for College Students with Intellectual Disabilities.
**https://thinkcollege.net/ta-training/video-library?wchannelid=o80csx46wu&wmediaid=9lh8dm45zc**

**TRANSITION TENNESSEE**
College Readiness Checklist for
Inclusive Higher Education Programs
**https://transitiontn.org/downloadable/college-readiness-checklist-for-inclusive-higher-education-programs**

What Should I Know About Getting Accommodations in College?
**https://transitiontn.org/wp-content/uploads/2022/07/Parent-Tip-Sheet_College_Accommodations_07-2022.pdf**

**RAISE**
National RAISE Transition TA Center
**https://raisecenter.org**

Post-secondary Education/Training Programs Resources
**https://raisecenter.org/partner-pti-youth-family-resources/postsecondary-education-training-programs-resources**

Post-secondary education newsletter
**https://myemail.constantcontact.com/RAISE-The-Standard-June-2022.html?soid=1115638112245&aid=-nLsNN6XGL0**

**NATIONAL TECHNICAL ASSISTANCE CENTER ON TRANSITION**
**http://transitionta.org**

**NATIONAL CENTER FOR COLLEGE STUDENTS WITH DISABILITIES**
**www.nccsdonline.org**

**BEST COLLEGES**
College Guide for Students with Disabilities
**www.bestcolleges.com/resources/students-with-disabilities**

**CAMPUS DISABILITY RESOURCE DATABASE**
**www.cedardatabase.org**

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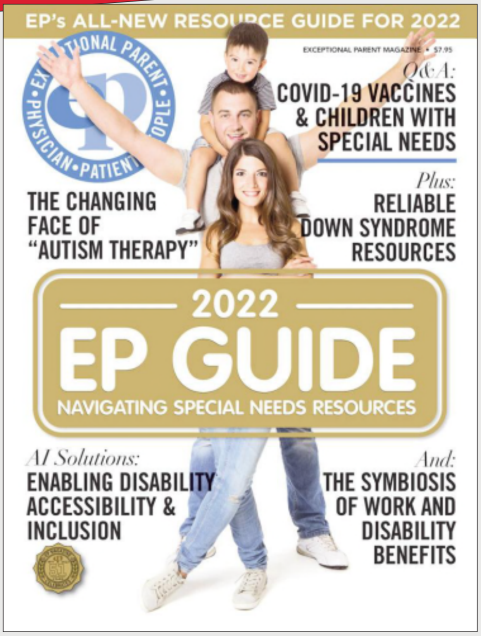
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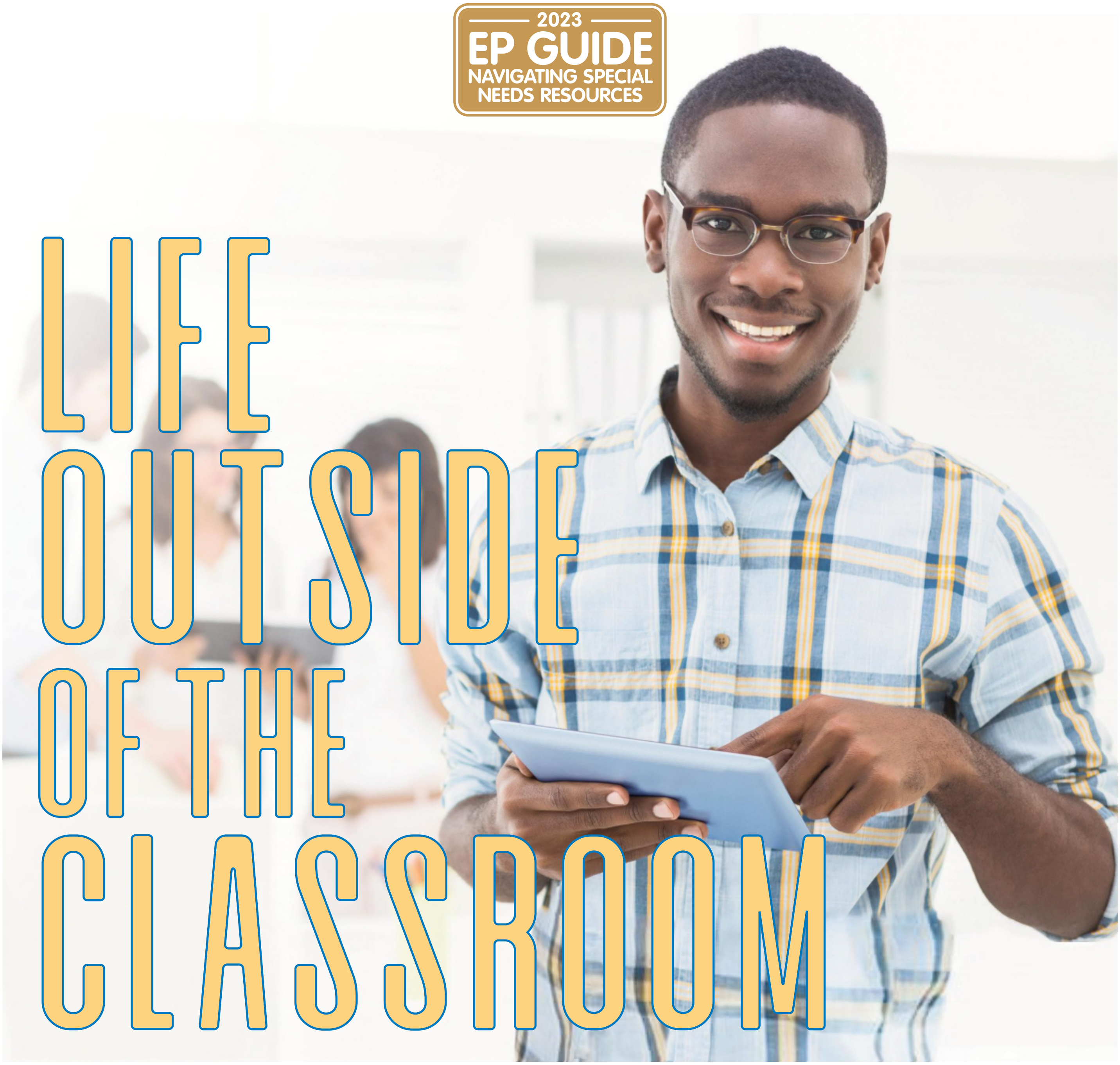

# LIFE OUTSIDE OF THE CLASSROOM

## FINDING THE RESOURCES THAT WILL PREPARE YOUR CHILD WITH AUTISM FOR INDEPENDENCE

BY LISA MARIE CLINTON

*We all use mobile technology to assist us with our daily life, and individuals with disabilities can further excel with technology, especially when that technology is adapted and created with their needs in mind. Over the last decade, there has been a significant increase in digital resources for individuals with autism spectrum disorder (ASD) and other intellectual and developmental disabilities (IDDs).*

Many of these advancements relate to in-home support tools and communication tools, specifically created to assist individuals in an academic setting. Of course, setting up your child for success in the classroom is paramount, but they will continue to need support, and should have continued learning opportunities, once they graduate high school.

After working with individuals with autism and other IDDs for over a decade, I understand that for both the individuals and the family, transitioning from school to adulthood is daunting – and for a good reason. For young adults with ASD and their parents, graduating high school means leaving a steadfast support system. Many young adults with autism fall victim to the "services cliff," following

## SUCCESS AND CONFIDENCE : ACQUIRING THE CORRECT DIGITAL ASSISTIVE TECHNOLOGIES

Connecting with the correct digital support tools to prepare your child for their next phase of life begins with asking future-oriented questions and then understanding your child's current needs.

### ASKING FUTURE-ORIENTED QUESTIONS

Digital assistive technologies are designed to support the functional capabilities through a strength-based approach, and overcome any limitations that individuals with disabilities, like autism and other intellectual and developmental disabilities, may face. Tools like memory aids, text-to-speech systems, sensors, reminder notifications, note taking software, and mobile devices with specialized apps can all help your child, as they transition into adulthood.

To prevent decision fatigue and ensure that you set your child up for success, ask yourself the following questions when exploring the available assistive tools for your child:

1. *What are my child's immediate needs and short-term goals?*
2. *What are their strengths and limitations, and how can I find a solution to address these?*
3. *What are both my and my child's goals ten years from now, relating to employment and independent living?*
4. *How can I augment the services and programs my child currently receives through technology?*
5. *What tools is my child already comfortable with?*
6. *Is there a tool my child is already using that can transition from school-based assistance to workplace assistance?*
7. *Does this tool enable independence and help instill confidence in my child?*

Answering these questions can help identify the tools that will enable your child to find success and confidence after graduating from high school.

### UNDERSTANDING YOUR CHILD'S CURRENT NEEDS

It can be difficult to understand your child's future needs, without the measurable or concrete academic assessments and goals put in place by their support network. When selecting the most appropriate tools, there are three main categories to consider: your child's communication skills, social skills, and life skills. Digital assistive technologies used to aid in these skills will play a vital role, once an individual has left the classroom.

Ideally, you want to find digital assistive technologies that transfer seamlessly from the workplace to home, to make it easier for your child to learn and benefit from its use. Technologies that work offline are especially useful when it comes to utilizing a resource routine.

#### COMMUNICATION SKILLS

People with autism spectrum disorder may experience a wide variety of communication difficulties while at their first job or in the community. Your child could be anywhere on the spectrum, from non-verbal to having difficulties understanding social cues or appropriate conversation topics. Speech-generating devices are hand-held electronic devices that play words or phrases when the user touches a picture on a screen or presses buttons or keys. Tablets, laptops or other common devices can also provide speech-generating apps or functions.

#### SOCIAL SKILLS

Social skills do not always come as easily to people on the spectrum, and can cause insecurities in the workforce, as well as in a person's social life. Individuals with ASD or other IDDs, or their caregivers, may develop and hone those social skills by utilizing technology that can help people recognize facial and behavioral cues which assist in social interactions. Video modeling, augmented environments, and script training all aid individuals in learning prosocial behaviors based on imitation. These tools can increase an individual's confidence and improve their relationships with co-workers and friends.

#### LIFE SKILLS

Understanding and learning basic life skills to complete more complex tasks, like paying bills on time or basic household maintenance, is an important hallmark in any young adult's quest for independence. Specialized software and mobile device solutions that support executive functioning (the skills and mental processes that enable us to plan, focus attention, remember instructions, and juggle multiple tasks successfully) are excellent tools to help individuals excel in their workplace, as well as with independent living. Tools which offer support in sequencing and repetition are also extremely useful in assisting individuals with tasks in the workplace.

**GEARING UP:** Transitioning from school to adulthood is daunting; by considering your child's unique needs, parents, providers and caregivers can choose the right digital assistive tools that will enable them to enter adulthood with the resources they require.

high school, losing access to valuable services, like teaching support and behavior management. A Drexel University study (**https://drexel.edu/autismoutcomes/blog/overview/2015/August/falling-off-the-services-cliff**) found that 70 percent of families with a child with autism reported that “some'' or “great effort” was needed to access services following high school, and more than 25 percent of individuals on the autism spectrum receive no services, once they reach early adulthood.

Digital assistive technologies provide effective support and continuous learning as your child transitions into adulthood. Resources like the Center for Assistive Technology Act Data Assistance (**https://catada.info**) or the State Assistive Technology Programs (**https://at3center.net/state-at-programs**) equip caregivers with helpful state-specific information on the available assistive technology programs, resources, and funding available to get connected to these resources. However, due to a lack of formal guidance, understanding digital programs within the disability space, can be overwhelming. Connecting with the correct digital support tools to prepare your child for their next phase of life begins with asking future-oriented questions and then understanding your child’s current needs.

## FINDING MORE SUPPORT

Accessing support for individuals with ASD or other IDDs is not always easy and, unfortunately, the responsibility most often falls on parents and caregivers to ensure their children are well-equipped for success outside of the classroom.

If you’re seeking more support for your adult child with ASD or other IDDs to help select the right assistive technologies, or for moral support, I recommend organizations like Parent to Parent USA (**www.p2pusa.org**) or the Pacer Center (**www.pacer.org/about**), and recommend looking into assistive technology libraries. Finding funding for assistive technologies can often feel daunting, which is why I recommend parents and caregivers explore the ABLE National Resource Center (**www.ablenrc.org**), which provides information on the state-run savings program for individuals with disabilities in the U.S., the National Disabilities Institute (**www.nationaldisabilityinstitute.org**) which provides helpful resources on how to introduce finances and fiscal responsibility to your child with autism or other IDDs, or Benefits.gov (**www.benefits.gov**) which is the official benefits website of the United States federal government, which helps millions assess their eligibility for various resources. For resources involving pre-employment transition services, the WINTAC (**www.wintac.org/topic-areas/pre-employment-transition-services**) provides training and universal, targeted, and intensive technical assistance to State Vocational Rehabilitation Agencies (SVRAs) and related agencies and rehabilitation professionals and service providers.

By considering your child's unique needs, parents, providers and caregivers can choose the right digital assistive tools that will enable them to enter adulthood with the confidence and resources they require, to live successfully outside of the classroom. •

### ABOUT THE AUTHOR:

Lisa Marie Clinton is the Director of avail Support at CentralReach. She has 15 years of in-depth, hands-on experience in the field of education and skills development for individuals with Intellectual / Developmental Disabilities (I/DD). While working in education, employment and directly with many families in their home environment, she witnessed the challenges in developing and obtaining the right support for individuals. Fueled with her passion, drive and vast real-life expertise, Lisa Marie set about creating a revolutionary digital program to promote lifelong learning, focusing and enabling young adults to live an independent and fulfilled life. Through further study in a Masters and Dissertation, Lisa Marie researched the underpinning data for avail® in 2015, which was launched in 2017. Since then, as Founder and CEO she has continued to research and develop avail® into the revolutionary program expanding therapy, 1:1 support and addressing waiting lists while achieving incredible outcomes for both end users and their providers: Schools, Employment Agencies, State bodies and Service Providers across Europe and North America. In 2021, Lisa Marie and the Avail Support team joined forces with CentralReach to accelerate reach and further program delivery across the neurodiverse population.

2023
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NAVIGATING SPECIAL
NEEDS RESOURCES

### PHYSICAL THERAPY SAFETY TIP SERIES • PART TWO

# SAFETY FOR THE ELDERLY POPULATION: RESOURCES FOR CAREGIVERS OF THE ELDERLY

BY HILLARY SUSSMAN, MSPT

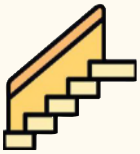
**Last month's article shared how to assess your home or your relative's home in order to address safety and fall prevention. To reiterate a few important points, it is crucial to observe the home and step outside the box in order to implement fall prevention strategies and to create a safer environment.**

So how does a caregiver do this? This article, will dive deeper into some helpful resources aimed to improve the safety and mobility of your loved one. Contacting your local durable medical equipment provider is always a great place to start. It can get tricky, as some items are covered by insurance, and others may not be. In some instances, a more reasonable option may be to purchase an item on Amazon, or to go to the local Goodwill store, drug store, or ask family and friends if they have any extra equipment.

**The MOST important thing to remember is that new equipment is safest when you are trained by a professional on how to use it properly and safely.** This article provides insight into resources, but it is important that when introducing something new to an elderly person, the client or the caregiver must be trained to use the equipment properly, in order to reduce the chance of unwanted falls.

## SAFE AT HOME : SIMPLE TIPS FOR GENERAL HOME SAFETY

Some items discussed below can be purchased and used immediately without risk, but most would be safer with a professional consultation from a home physical or occupational therapist. This is especially true if your family member is going home after being in the hospital or rehab and has a change in functioning or cognition. It is always better to err on the side of caution and have a professional complete a home safety assessment. You will need a referral from your family member's physician or the treating physician in the hospital or rehab. These discussions should be initiated prior to your loved one being discharged to go home. Typically you would be in contact with the social worker for these conversations.



### STAIRS

☐ A stair glide can be a great option.

- A stair glide serves as a great option for a senior to move between the floors of their house with greater ease.
- This is especially true if there is no bathroom on the first floor, and if they still like to sleep on the second floor.
- There are width restrictions that need to be taken into consideration to see if it is feasible to install.
- There are several options if you research online. Some can be rented, instead of purchased.
- It is important to have a representative from a stair glide company come out and do a home assessment, measurement, and review options.

### COMMODE VERSUS RAISED TOILET SEAT

(Should be trained by a professional)

You may want to consider one of these options if your loved one:

☐ Just returned from the hospital or rehab.
☐ Struggles getting on and off the toilet.
☐ Has any surgical precautions.
☐ Has a far distance from bed to bathroom.
☐ Has to go to the bathroom in the middle of night.
☐ Has a very low toilet.
☐ Has had a medical or cognitive decline.

*Remember, a general rule of thumb is that is it much easier for a person to get up from a higher surface, as long as their feet safely touch the ground.*

☐ *Commode*

- Typically covered by insurance
- Great option to be placed next to the bed. The bucket underneath can be emptied by a caregiver.
- It is a safer option if your loved one gets up in the middle of the night to use the bathroom.
- It can be placed over the toilet. The bucket is removed and the frame can provide an elevated height and arm rests for easier getting on and off the toilet.

☐ *Raised Toilet Seat*

- It can just be a "donut" or can have handles.
- It is typically not covered by insurance, and can be purchased at a drug store. It is best to get one with handles for safer getting on and off the toilet.

### LIFE ALERT

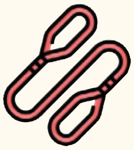
(Instructions provided upon installation)

☐ Life alert is a very important component of fall prevention, especially if your loved one lives alone.

☐ There are many different plans out there, so you may have to do some research. Most companies charge you a monthly fee, but it is so important to have the peace of mind to know that if your loved one has fallen and is not near a phone, the life alert can be activated and emergency services can come to help. There are too many stories of elderly people falling and lying on the floor for hours prior to receiving assistance.

*Make sure your loved one wears the life alert at all times and understands how it works.*

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



### LEG LIFTER STRAP

(May be helpful to have a therapist provide instructions)

- It can be ordered online. It is used to help someone bring their leg in and out of the bed, if this is a struggle.
- Some examples are post-stroke, post-surgery, swollen/weak leg. Typically, it runs $9-$11.

### HOSPITAL BED

(May be helpful to have a therapist provide instructions)

A hospital bed is a great option for anyone who just returned from the hospital and is unable to perform steps to access their second-floor bedroom. It can be adjustable, and can help with pain, swelling, pulmonary, cardiac, and other issues.

- It reduces the chance of injury for the caregiver.
- It helps elevate legs to reduce swelling.
- It helps with pressure relief.
- You typically need a letter from a primary care physician and can sometimes be difficult to get covered by insurance.
- It can be a safer option if your loved one is at risk for falling out of bed.
- Only a few diagnoses qualify a person to get it covered, so ask a medical professional or therapist.
- There are several types: fully electric, partial electric, bariatric, and manual

### TRANSFER BOARD

(A therapist should provide training)

- Also called sliding board, it is typically made of wood or plastic
- It serves as a bridge that allows a person to move from one surface to another, ie. from a bed to wheelchair, or a bed to a commode.
- It allows a person to move from one surface to another without using their legs.
- It can be very helpful for a caregiver to reduce fall risk when getting a client from point A to point B.
- Check with a medical supply company to see if it is covered by insurance.

### PRESSURE RELIEF

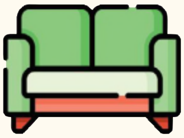
(For Wheelchair or Hospital Bed)

☐ A cushion or pad can be placed on the wheelchair seat or over the mattress on a hospital bed.

☐ Typically, it is used if the loved one has a wound, or is at risk for skin breakdown, and is unable to walk or spends most of the time in bed or in a wheelchair.

☐ Remember the golden rule is to change positions every two hours to displace pressure on bony prominences and reduce the risk of developing a pressure sore.

☐ While in bed, it may be necessary to have your family member elevate his/her heels to reduce pressure; as this is a typical place where skin breakdown can occur.



### COUCHES

(It is helpful to have a therapist work with your loved one to problem solve.)

If your loved one spends a lot of time on the couch, and struggles getting up and down due to the couch being low or soft:

- Place a pillow underneath the cushion to elevate the height of the sitting surface.
- Make sure you provide proper sequencing instructions when getting up (*see below*).

### CHAIRS WITH ARM RESTS, ELECTRIC SEAT LIFT, POWER LIFT RECLINER

Seating is an important topic for seniors. There are several options, and caregivers may find this overwhelming. Again, speaking to a professional, typically a therapist, can provide insight into the right equipment.

☐ *Arm Rests:* as mentioned the in previous article, it is best to have a senior sit in chairs that have arm rests, to provide ease of transfer in and out of the chair.

### HOW TO PERFORM A TRANSFER

A transfer is defined as moving from one place to another. Here are a few simple instructions for your elderly loved one to use when getting up from any surface safely.

☐ Scoot forward

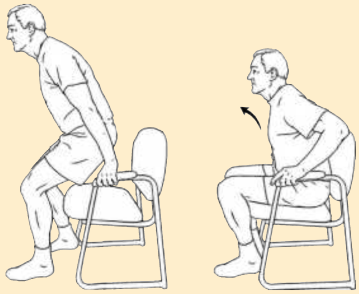
☐ Put your weight forward, “nose over toes”

☐ You may need to use a little momentum, by rocking back and forth “one, two, three”

☐ Put hands on couch/chair

☐ PUSH UP Only pull up if there is something very secure, like a well installed grab bar

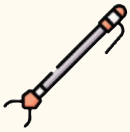
☐ When getting up from a chair to a walker, push-up, using the arms of the chair, and then reach for the walker, do not use the handles of the walker to pull yourself up. NEVER put your hands on the walker to pull up.



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

☐ *Electric Seat Lift:* (uplift seat cushion) is best placed on a firm surface to provide a mechanical assist to standing up from a chair or surface. This should not be purchased or used without professional input.

☐ *Power Lift Recliner:* It is very typical for the elderly population to not only use these chairs, but to sleep in them as well, especially if stairs become too difficult to negotiate. In some instances, insurance may provide some reimbursement, it is best to speak with a trained medical professional prior to ordering. Some benefits of this type of recliner:
  - Elevates legs for management of swelling.
  - Elevates height of chair to provide ease of getting up/down independently and safely.
  - Very comfortable.



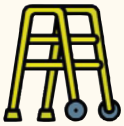
## REACHER/GRABBER

(Typically part of OT training, but can attempt at home with family)

Be careful if loved one has any hip precautions, and bending restrictions.

☐ A great item to retrieve items out of reach which can reduce fall risk, if your loved one needs to pick up objects off the floor, but has limited flexibility or just had surgery and has precautions.

☐ They are typically found online, and run around $13 to $30.

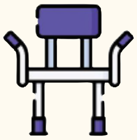


## ROLLING WALKER, ROLLATOR

(Safest if taught to use by therapist)

☐ *Rolling Walker:* Has two wheels in front and is a great choice to provide more support when walking.
  - They are typically covered by insurance, but you will not be able to get a new one covered for 5 years.
  - Placing tennis balls or "skis" on the back two legs can reduce the scraping of wooden floors and also make it a smoother experience.
  - It can help reduce the energy used during walking.

☐ *Rollator:* Has four wheels and a compartment for storage/seat. Rollators are a great option to:
  - Provide ease for turns.
  - Store portable oxygen canisters, phones, tissues, necessities, etc.
  - Provide a place to sit and rest if your loved one has compromised endurance.
  - They are also the preferred choice for someone with cardiac or pulmonary issues, as walkers can be locked and utilized as a place to sit and rest when needed. It is important to have a therapist, properly train and teach your loved one how to do this, otherwise it can create an increased fall risk.



## SHOWER CHAIR, STOOLS, BENCHES

(Safest if trained how to use by therapist)

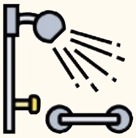
If your loved one takes showers, he/she may need a device to provide a safer environment while doing so. Please make sure that your loved one is not showering alone if it is unsafe. None of these are covered by insurance, unfortunately, so you might want to shop for the best deal. Consult with an occupational therapist to see which is the right choice. (They can range from $40 to $100).

☐ *Bath Seat:* Typically has armrests, a great choice to provide stability and safety during bathing. Sits inside the shower or in the tub.

☐ *Bathtub Stool:* Less safe, small and narrow, really for a much higher-level person.

☐ *Tub Bench:* Extends from outside to inside the tub, your loved one sits on the bench and then scoots over the side of the tub and swings legs inside. If your loved one needs a tub bench, it may be best to have another person present while bathing.

All three can be adjusted to the appropriate height. Remember to raise it as high as possible until the feet still touch the floor.



## GRAB BARS

(Can get them installed, also helpful if a therapist can provide input)

- You can order online and pay someone to install it. If your loved one lives in a facility, the maintenance person should be able to install it, and often will provide them as well.
- They range from $15 to $30 each and in varying lengths, (12 inch, 16 inch, 24 inch).
- You can choose from different finishes
- It is best if it is installed by a professional , typically it is used next to the toilet and in shower area.
- If you have a prefab wall, you probably need to use a bar with suction cups, which is much less sturdy and much less safe - not recommended. You can get someone knowledgeable about construction to see if there is a way to safely and securely attach a grab bar.
- It is typically an out of pocket expense.
- Please advise your family member NEVER to use a towel rack for support, as they will rip right out of the wall.

## WHEELCHAIR

(Prior to ordering, it is best to get your family member properly measured)

☐ *Standard Wheelchair:* Typically used in the home, if your loved one has

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

limited mobility, and spends most of the day in the chair. Please consider getting some sort of gel cushion to prevent skin breakdown.

- Make sure that your loved one is properly assessed/measured prior to ordering, as wheelchairs come in different widths and with many options, such as: removable arm rests and leg rests, etc
- Look at Bariatric for heavier people.
- Check out the pediatric size wheelchair for a very small, elderly family member. Measuring is key!

☐ *Transport Wheelchair:* May be an out of pocket expense (check with Medicare).

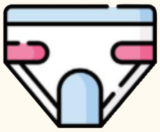
- If it is not covered, you can rent and pay monthly, and pay towards ownership as an option.
- It is a great option for taking a loved one to the doctor and you can leave it in your car.
- It is lightweight, but NOT meant for your loved one to self propel. It is strictly for caregiver transportation.

*Electric Wheelchair:* An entirely different category, and this discussion is best started with a therapist or wheelchair specialist.

### SWELLING

(If this is an issue, talking to a skilled nurse is a great place to start)

Typically, swelling is called edema. If your loved one has swelling in his/her legs, it is important to initiate a way to elevate the legs during the day.



### HYGIENE

☐ *Pull ups:* Can provide added support and protection from incontinent episodes. It is best to discuss toileting schedules and liquid consumption. If your loved one lives alone and gets up in the middle of the night, you may want to encourage him/her to sleep in a pullup, to avoid having to get up alone and use the bathroom.

☐ *Flushable Wipes:* Can be helpful with elderly population, providing improved perineal hygiene.

### CANES

(Therapist training for proper sequencing)

Typically, a cane is not covered by insurance, but if it is, Medicare may only pay for 1 device. If so, it is always better to purchase a cane out of pocket, and use insurance for more expensive devices.

☐ *Quad Cane:* Can be a little more challenging for an elderly person to negotiate, especially if he/she has not previously used a cane. A narrow-based cane is easier to manage, compared to a wide-based quad cane. The reason to choose a quad cane would be for added support.

☐ *Single Point Cane:* Provides support, helping reduce falls and provide support when negotiating steps.

### IN HOME CAREGIVERS

There are agencies that will provide a caregiver in your home for varying costs, whether you need two hours per day or 24 hour care, As stated below, home health aides can be covered when your family member gets a referral to receive home health care, but this may be for limited time.

### HOME CARE SERVICES

A very important option for your elderly loved one if there are any health, cognitive, or safety concerns. Referrals from primary care physicians can be sent to home care agencies to start the process and check insurance. You may want to consider home health services if any of these apply:

☐ It is too difficult to get your loved one out of the house to see a physician.
☐ Recent fall or recent discharge from hospital or rehab.
☐ Demonstrates any type of decline physically or cognitively.
☐ Services can include skilled nursing, social work, physical therapist, occupational therapist, speech therapist and home health aide.

In Summary, DME (Durable Medical Equipment) is a whole new world to navigate for caregivers and may feel overwhelming. If you are concerned about your elderly loved one living alone or worried about his/her safety, it may be time to assess some of these items with a trained medical professional, to see what help your loved one needs to be safe.

### ABOUT THE AUTHOR:

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

“Working lets me...

keep contributing.”

earn a living.”

be there for the team.”

provide for my family.”

## 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.

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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

# VA | Family member

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

## Did You Know...

- You may qualify for monthly payments that are tax-free and not counted as income.
- You may be entitled to comprehensive health care benefits and affordable dental coverage through the VA dental insurance program.
- You may be eligible for education and training assistance to earn a degree or professional certificate, become an apprentice, or learn on the job.

## VA Serves Veterans

In gratitude for their honorable service to our nation, VA provides benefits to help Veterans take care of their family; buy, retain, or modify a home; earn a degree; start a career; stay healthy; and do so much more in their life after the military.

VA also recognizes the family members who support Veterans and service members. Explore these VA benefits that may be available to spouses, dependents, and survivors:

- **Monthly payments.** Under the Dependency and Indemnity Compensation program, VA provides income to certain surviving loved ones of deceased Veterans and service members. Annual payments average about $15,500 to spouses and $7,000 to children. Spouses or children of service members who died while on duty or survivors of Veterans who died from their service-connected disabilities may qualify. Parents may also benefit.
- **Health coverage.** Under the Civilian Health and Medical Program of VA, the medical expenses of spouses and children of Veterans may be covered in whole or in part. To qualify, the Veteran must either be rated permanently and totally disabled due to service or have died while rated as such or as a result of service or a service-connected disability.
- **Education, pension, home loan, and other benefits.** You or your children may have earned education benefits to pay for college or training. Survivors of Veterans who are of limited means may qualify for VA pensions. As a surviving spouse, you might qualify for a VA home loan. In addition, you or your children may receive burial benefits and many other services.

## Find Out How You Can Benefit

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

/VeteransAffairs
@DeptVetAffairs

EXPLORE VA BENEFITS AT
**VA.gov**

Choose VA

FROM OUR FAMILIES… TO YOUR FAMILIES

# MILITARY SECTION

# MILITARY LIFE

# WOUNDED, ILL OR INJURED, AND THEIR CAREGIVERS: BENEFITS

*Access to quality care and valuable services does not end when wounded, ill or injured service members leave a military treatment facility. In many ways, the help is just beginning. Military members who have combat injuries or are battling serious illness because of their service are eligible for a host of benefits. While Military OneSource does not provide health care services, it does offer non-medical counseling and information about health care services and benefits.*

## MILITARY ONESOURCE WOUNDED WARRIOR SPECIALTY CONSULTATIONS

Military OneSource provides specialty consultation services to help eligible wounded, ill or injured service members, veterans, their families and caregivers get immediate assistance for issues related to health care, resources, facilities and benefits. Consultants are available to help with support for transportation needs, respite care, reporting problems with military facilities and getting additional support. Learn more about wounded warrior specialty consultations.

## MILITARY WOUNDED WARRIOR PROGRAMS

Each service branch operates a wounded warrior program to help service members and their families with non-medical issues associated with transitioning back to duty or civilian life.

**Army Recovery Care Program:** www.arcp.army.mil

**USMC Wounded Warrior Regiment:** www.woundedwarrior.marines.mil

**Navy Wounded Warrior:** www.navywoundedwarrior.com

**Air Force Wounded Warrior Program:** www.woundedwarrior.af.mil

## DISABILITY BENEFITS

**Disability severance pay:** You may be entitled to disability severance pay, which is a one-time lump payment equaling two months of basic pay for each year of service, which includes active service and inactive duty points. Find out more at the Defense Finance and Accounting Service (www.dfas.mil).

**Social Security Disability:** Service members can receive expedited processing of disability claims from Social Security. Benefits through the Social Security Administration – such as the Social Security Disability Insurance Program and the Supplemental Security Income Program – are different than those from the Department of Veterans Affairs and require a separate application. Visit the administration's Disability Benefits for Wounded Warriors (www.ssa.gov/people/veterans/ww.html).

**Servicemembers' Group Life Insurance Traumatic Injury Protection Program:** This provides for payment up to $100,000 if you incur a qualifying loss as the result of a traumatic injury (www.va.gov/life-insurance/options-eligibility/tsgli)

**Special Monthly Compensation:** This is an additional tax-free benefit that can be distributed to veterans, their spouses and parents to assist with special circumstances, such as the need for aid or caregiving or because of a specific disability, such as the loss of a hand or leg (www.va.gov/disability/compensation-rates).

## FINANCIAL BENEFITS

**Federal Thrift Savings Plan:** The TSP is a government-sponsored retirement savings and investment plan that is similar to the benefits private corporations offer their employees under 401K plans (www.tsp.gov/index.html).

**VA Home Loans:** Veterans and family members are eligible for home loan guaranty benefits and other programs that assist with buying, building, repairing, retaining or adapting a home (www.benefits.va.gov/homeloans/index.asp).

Military OneSource offers **financial counseling** (www.militaryonesource.mil/confidential-help/interactive-tools-services/financial-counseling/financial-counseling-services-for-a-secure-future) in person, by phone or via video chat. If you live on or near your military installation, you can reach out to the installation Personal Financial Management Program (https://installations.militaryonesource.mil/?looking-for-a=program), which offers workshops and classes in addition to individual financial counseling.

## HEALTH CARE BENEFITS

**TRICARE home health benefits:** Care for wounded warriors depends on your current military status. Visit the TRICARE site to discover what's available to you (www.tricare.mil/injuredonAD).

**Medicare and Medicaid programs:** If you meet eligibility requirements for Medicare or Medicaid, coverage may be available for medical costs, transportation, respite care, home modifications and equipment expenses (www.cms.gov).

**WELL DESERVED BENEFITS:** Military members who have combat injuries or are battling serious illness because of their service are eligible for a host of benefits. Access to quality care and valuable services does not end when wounded, ill or injured service members leave a military treatment facility.

## EDUCATION AND EMPLOYMENT BENEFITS

**Subsistence Allowance Rates:** Some veterans participating in vocational rehabilitation and education programs may be eligible to receive an allowance while they pursue an educational or training program (www.benefits.va.gov/vocrehab/subsistence_allowance_rates.asp).

If a veteran qualifies for the GI Bill, he or she may be eligible to receive the **Basic Allowance for Housing rate** for subsistence (www.defensetravel.dod.mil).

The **VA's Vocational Readiness and Employment Program** helps veterans with service-related disabilities find and keep employment. The program helps veterans prepare for employment and provides counseling and independent living services for disabled veterans who are unable to work (www.benefits.va.gov/vocrehab/index.asp).

The **VA's VetSuccess On Campus Program** helps veterans, service members and their dependents complete their education and prepares them to enter the workplace through on-campus benefits assistance and counseling (www.benefits.va.gov/vocrehab/vsoc.asp).

The Department of Defense **Transition Assistance Program** is an outcome-based program that bolsters opportunities, services and training for transitioning service members in their preparation to meet post-military goals (www.dodtap.mil).

## MILITARY RELIEF ORGANIZATIONS

Each service has a private, nonprofit organization that assists families in times of need. Assistance may include emergency transportation; help with medical bills, child care expenses, food, rent, utilities and other household bills; vehicle repair and family emergency assistance. For more information on relief societies, contact Army Emergency Relief (www.armyemergencyrelief.org), the Navy-Marine Corps Relief Society (www.nmcrs.org) or the Air Force Aid Society (www.afas.org).

## SEMPER FI FUND

The Semper Fi Fund provides immediate financial assistance and lifetime support to post-9/11 wounded, critically ill and injured service members and their families, ensuring that they have the resources they need during their recovery and transition back to their communities (thefund.org).

## MILITARY HEROES FUND EMERGENCY FINANCIAL ASSISTANCE

The Military Heroes Fund, an initiative of the PenFed Foundation (https://penfedfoundation.org), provides wounded veterans, military families and caregivers with financial assistance and support that cannot be supported by government agencies. The MHF has two components:

**Emergency Financial Assistance** for Operation Iraqi Freedom/Operation Enduring Freedom wounded warriors and their families facing short-term financial difficulties.

**Family and Caregiver Transition Support** including child care support for families of wounded OIF/OEF veterans while receiving outpatient care; short-term training or education expenses for job certification, licensure requirements and course materials; and in-home health care for injured veterans to support caregiver respite needs.

**The DOD Wounded, Ill, and/or Injured Compensation and Benefits Handbook for Service Members of the Armed Forces** provides military members and their support network with an extensive list of military support services and resources to assist through the complexities of recovery (https://health.mil/Military-Health-Topics/Access-Cost-Quality-and-Safety/Warrior-Care/DoD-Compensation-and-Benefits-Handbook)

**RESTING EASIER:** Military OneSource provides specialty consultation services to help eligible wounded, ill or injured service members, veterans, their families and caregivers get immediate assistance for issues related to health care, resources, facilities and benefits.

**USA Cares Warrior Treatment Today** pays essential household bills while a wounded service member or veteran is attending residential treatment for a traumatic brain injury or PTSD (https://usacares.org).

**Project Valour-IT** provides voice-controlled laptops and personal GPS systems to service members recovering from hand wounds and other severe injuries including TBI and PTSD (https://soldiersangels.org/valor-it-helps-wounded-heros-recover).

## MOBILITY ASSISTANCE

Sometimes a major injury or illness can affect mobility. If you or your loved one are facing new physical challenges, be sure to check out these resources:

**Office of Disability Employment Policy:** Access all of the federal government's disability-related information and resources (www.dol.gov/agencies/odep/topics).

**VA Home Loans:** These loans and grants are available to adapt the homes of disabled veterans or help them buy accessible homes (www.benefits.va.gov/HOMELOANS)

**Homes for Our Troops, Inc.:** This privately-funded nonprofit builds specially adapted homes for severely injured veterans nationwide (www.hfotusa.org).

**Coalition to Salute America's Heroes:** This site helps wheelchair-bound or blind veterans can receive financial assistance to buy homes that accommodate their disabilities (www.saluteheroes.org).

**National Resource Center on Supportive Housing and Home Modification:** This nonprofit provides helpful advice and links, including state-by-state information (www.saluteheroes.org).

## ASSISTIVE DEVICES

There are many illness-specific assistive devices and tools available through organizations such as Paralyzed Veterans of America (www.pva.org) and the Amputee Coalition.

For computer-assistive technology, consult the TRICARE Computer/Electronic Accommodations Program (www.cap.mil).

## CAREGIVER BENEFITS

Caregivers of wounded warriors can get additional support from Military OneSource beyond specialty consultations including: Personalized Experiences, Engagement and Resources – or PEER – forums, as well as webinars, caregiver-related events and specialized resources.

**In-Person Military Caregiver PEER forums:** Caregivers can support each other and share knowledge, experience and resources at these monthly forums held on military installations nationwide (https://warriorcare.dodlive.mil/Caregiver-Resources/Military-Caregiver-PEER-Forums-Find-Your-Location/).

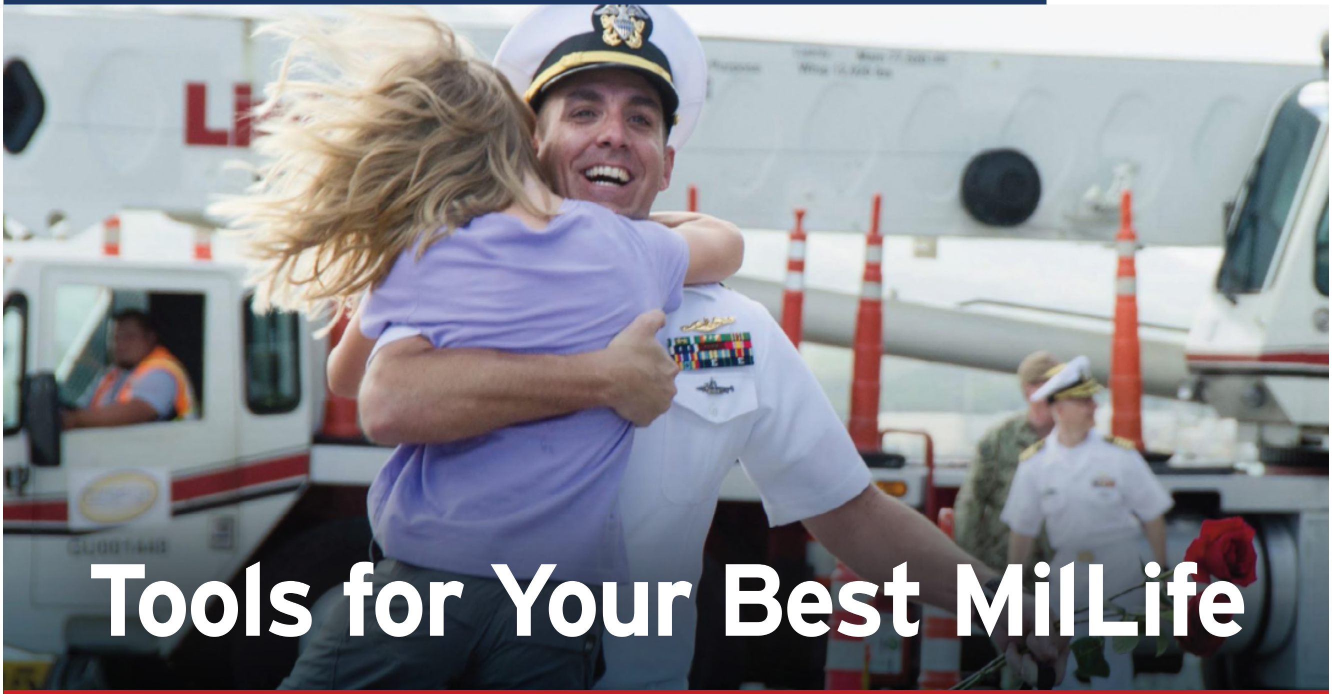
**Virtual PEER forums:** These monthly virtual forums are available for caregivers who can't attend in person (https://warriorcare.dodlive.mil/caregiver-resources).

**Online caregiver webinars:** These include military caregiving (https://oneop.org/military-caregiving) and wounded warrior webinars (www.militaryonesource.mil/training-resources/webinars/what-is-a-wounded-warrior-resources-specialty-consultation). Learn more about being a caregiver through Military OneSource and OneOp.

*Still have questions or need help locating resources? Military OneSource consultants are available 24/7/365 to connect you with the resources you need to live your best MilLife. Call 800-342-9647, use international calling options (*www.militaryonesource.mil/international-calling-options*), or schedule a live chat (*https://livechat.militaryonesource-connect.org/chat*).*

*– Military OneSource*

MILITARY ONESOURCE



# Tools for Your Best MilLife

## Need financial or tax guidance? Want to talk about managing stress or family challenges? What about a health and wellness coach?

Military OneSource is your 24/7 connection to information, answers and support for your best MilLife. Contact us anytime to arrange free Military OneSource services including: confidential counseling, specialty consultations, financial and language services.

### Access Confidential Non-medical Counseling

Just need to talk? Get non-medical counseling from experts trained in military life.

- Private, not reported to command
- Up to 12 sessions per issue
- Counseling from licensed mental health clinicians
- Phone, in-person, video conference or online chat

### Schedule Specialty Consultations

- Health and Wellness Coaching
- Spouse Relocation and Transition
- Wounded Warrior Assistance
- Peer-to-Peer Support
- Building Healthy Relationships
- Transitioning Veterans
- New MilParent
- Special Needs
- Adoption
- Elder Care
- Education

### Take Command of Your Taxes With MilTax

- Easy-to-use, tax preparation and e-filing software
- Prepare and file federal and up to three state returns for free
- Trained tax experts to help by phone

### Master Your Money With a Financial Counselor

- Talk to accredited counselors by phone, video or in-person
- Manage and eliminate debt
- Budgeting, retirement, tuition planning

### Bridge Barriers With Language Services

- Language interpretation services
- Document translation
- 150 languages

Military OneSource is a Defense Department-funded program for service members and military families.

**For resources, tools and more information, contact:**
www.MilitaryOneSource.mil | 800-342-9647

U.S. Department *of* Defense

U.S. MILITARY ★ BOOK EXCERPT 2ND OF A SERIES

# THE RESILIENT WARRIOR

## KEEP THE BEST AND LEAVE THE REST

BY VANESSA JACOBY, PHD, ABPP ADVISOR WITH CLARITY CHILD GUIDANCE CENTER

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

*Evaluate the situation and create a lifestyle strategy that best fits your circumstances, utilizing what works and removing what doesn't.*

For many, being a military service member is not just a job. Military service is surrounded by unique culture, values, and lifestyle. Some service members embrace their military culture and training and bring those values home to their families. Others try to intentionally separate themselves from the "soldier" at work and the "parent and spouse" at home.

There is no specific "right" way to do things and different strategies work for different families. However, in working with military families, I have noticed that the families who are struggling tend to take an extreme approach at either end of this spectrum – the "All or None" approach.

Most things in life are not black and white. "All or nothing" thinking is a common yet unhelpful thinking pattern that can cause problems in our lives. This is true for bringing your military training and values into your home, as well. On the one hand, many military values may have great benefits and are meant to create strong and resilient people. Who doesn't want their family to be strong and resilient? Likewise, completely isolating your family from military life can lead your family to feel left out on top of missing out on the unique strengths that come with being in a military family. On the other hand, the military has a specific purpose, and they train people to behave in order to fulfill that purpose. That means that not all aspects of military training and values, rigidly followed, make sense in the context of raising children. Here are key military values that are great to bring into the family (with moderation) plus a couple of additional values that are essential to good child development.

### THE HACK UNPACKED

So, what to keep, and what to toss?

**High expectations:** The military famously "breaks you down to build you back up." They test your limits, push you to the max. They need you to be not just good, but great. This is because service members often encounter life-threatening

**KEEPING THE BEST:** USMC Veteran Sarah Plummer Taylor with her husband and two daughters; when raising children, it is our job as parents to teach our children to identify and appropriately express our full range of emotions. Sarah wrote the afterword to *The Resileint Warrior.*

situations, and a service member being unskilled could have life or death consequences for themselves or others. It is the nature of the job.

When it comes to our family, it is important to consider the difference in context between training for a warzone and parenting. Setting high expectations communicates to your children that you believe in them and that they can accomplish great things. However, it is especially important that the expectations placed upon them are developmentally and individually appropriate.

Consider your children's age, as well as their unique strengths and struggles while keeping in mind that no one can be great at everything. When you set expectations unrealistically high, you are setting your child up for failure which could have negative consequences on their self-esteem.

**Teamwork:** The military is composed of many teams. Missions can only be successfully completed through effective teamwork. Teamwork means that each person on a team (or in a family) is important and makes meaningful contributions. When one member of the team is successful, we all celebrate that success. When one member of the team is struggling, we rally around to support them.

Teaching children to work together as a team can set them up for success in school, with peers, and in adulthood. Building teamwork in families works best when parents can balance this value with also spending time and showing affection for each of their children individually. Give it your all.

Military training teaches you that when you set out to accomplish a goal, you give it your all – you do not do things halfway. In a military mission, a service member may go as far as injuring themselves to complete the mission for the sake of the team. This goes back to teamwork – each member of the team is important. On military missions, one person not completing a task can have dire consequences for others.

Like high expectations, it is important to keep the context of the environment in mind when teaching perseverance to your children. There is an important difference between completing a task at war and, for example, not dropping an AP class or finishing a soccer game.

Teaching integrity can help a child build self-esteem and strength as they accomplish difficult goals and are praised for "putting in their all." Yet, when it comes to children's developing minds and bodies, it is important to recognize that it is possible to push a child too hard, leading to injury (for a physical task) and unhelpful, distressing anxiety or self-criticism.

**Vigilance:** It's common military saying: "Stay alert, stay alive." In combat, vigilance is essential. Service members live in extremely dangerous environments in which an enemy is out to harm them. There are, of course, dangers that children

PHOTO COURTESY NICK BENAS

should be aware of. Traffic, bullies and even child predators. However, when teaching children to be vigilant, it is important to use developmentally appropriate language. Three-year-olds and thirteen-year-olds understand the concept of danger very differently, and conversations around safety should reflect that. Also, remember that difference in context.

While dangers clearly exist in this world, our children are not fighting an enemy and so the dangers are less probable. When discussing safety with your children, be sure to differentiate between "situational awareness" and hypervigilance or paranoia. While the first can help our children stay safe, the second can lead to phobias, chronic worry, and anxiety.

**Self-Control:** In the military, self-control and inner strength are essential, and are often represented by training service members to maintain a sense of stoicism. While strength and self-control are wonderful values to teach our children, the best way to teach children is not the same as how it is trained in service members.

> **"GIVING CHILDREN DEVELOPMENTALLY APPROPRIATE INFORMATION AND ALLOWING THEM OPPORTUNITIES TO PROVIDE INPUT ABOUT FAMILY EXPERIENCES, TRANSITIONS, AND DECISIONS IS ESSENTIAL FOR CHILDREN TO MAKE MEANING OF AND EXPERIENCE SOME SENSE OF CONTROL IN THE WORLD."**

To understand this, it is important to consider children's development and context in which stoicism is used. In war, you are expected to see and experience incredibly difficult and even traumatic events. There may be times that you must push through them or "drink water, drive on" to survive. In contrast, our goal in raising children is to provide a nurturing, safe, and predictable environment. Therefore, the context of the environment is completely different than at war. In fact, when raising children, it is our job as parents to teach our children to identify and appropriately express our full range of emotions. This means teaching our children to regulate the expression of emotions (which is where self-control comes in), but not to ignore or hide them.

## AND WHAT SHOULD YOU ADD?

Military training and values have the potential to provide so much for service members and their families. And yet, because of the context and purpose of the military, they cannot provide all that is needed to raise children. Below are a few things to consider intentionally adding to your parenting toolbox. I want to stress here that the principles below are in no way incongruent with military culture. In fact, I would argue that they fit right in and many service members who are successful and satisfied in their jobs use these tools.

**Two-way communication:** For important reasons, the military is structured in strict hierarchies. While there are individual differences in leadership styles, much information is communicated in one direction, on a "need to know" basis, and service members can be punished for questioning leadership authority.

Hierarchy is important in families as well. Parents are largely the decision makers and children should not be given all of the information all of the time. Yet, as our children develop, so should our communication with them. Giving children developmentally appropriate information and allowing them opportunities to provide input about family experiences, transitions, and decisions is essential for children to make meaning of and experience some sense of control in the world. In contrast, keeping children in the dark because "they are just children" can be frustrating, confusing, and scary.

**Emotional connection:** You can think of this as the flip side of stoicism. Our children need to know that we are there for them not only physically, but also emotionally. This means providing an environment that makes it safe to appropriately express any emotions (by appropriately, I mean saying "I'm angry" vs. hitting your sister), and that you appropriately share your emotions with the family as well.

This doesn't mean sharing all emotions you have all the time. However, it does mean sharing enough that your family can understand your actions. This emotional connection is vital for your children to build a strong and healthy attachment to you and your spouse.

**Finding your balance:** All families are unique. What works for one family may not work for another, and it may take some trial and error to find the right balance of how much to incorporate (or not) military values into your family. If you work to keep in mind the context and intention of these values, as well as how to incorporate them in developmentally appropriate ways for your children, be confident. That balance will come.•

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

### ABOUT THE AUTHOR:

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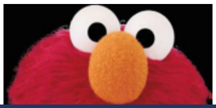
PHOTO COURTESY OF BUZZ BRYAN

MILITARY ONESOURCE

# 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**

SESAME STREET

**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.

# Tiramisu of Events

## In life, a lot of little things that add stress and slowly add weight can become layers like tiramisu. In other words, life can be a "tiramisu of crap."

It's not just one event that can throw you over the edge. It can be a lot of minor events that over a period of time, can slowly break you down. Caretakers of children with special needs understand this concept extremely well. It may not be just one thing. It may be a string of events that when compiled with the added stressors of life, becomes difficult to handle. Raising children with unique needs builds a foundation that encompasses long-term stress. We are ensuring our child's medical needs are met, as well as respite care and educational needs, or are faced with an incomplete plan for their care once we, as parents, can no longer care for our children. Stressors, such as these, never go away.

Years ago, a wise counselor told my husband to picture in his mind a speedometer. The minor inconveniences of life may keep you at lower RPM's. As long as you can keep operating at lower RPM's, you have the ability to process and handle anything that comes your way. Are you a few minutes late for an appointment? No problem, just call ahead and let them know. Did your puppy chew up a pillow? Maybe it was an old pillow anyway, and it was time to replace it. These experiences alone are fairly manageable, until they aren't anymore.

**PRACTICE MAKES PERFECT:** "This is Broden learning how to drink without a straw! You can see how it was going by looking at his shirt. He improved the more we practiced!"

What if added stressors in our lives drive our RPM's to the point that we are operating daily, just under the red zone? The red zone meaning that it's difficult to hold it together. If that is the case, then just one or two things that normally wouldn't be that big of a deal, become just that. So, many parents raising children with disabilities operate in this zone every day and they walk among others that do not have that foundation of added daily stressors.

Granted, it may not be one large impactful event. It could be a series of small mundane events that occur over time. I picture in my mind these small and mundane events as layers, small and light layers, if they occur independently. Over time, as each small event happens, things can build. They will lay over on top of one another and can get heavier and heavier. I picture in my mind a scrumptious piece of tiramisu. Tiramisu is a delicious treat that is comprised of individual layers of coffee-soaked ladyfingers, custard, and whipped cream. Each layer doing its part to provide you with an unforgettable edible experience. One thing I connect with tiramisu is that it is heavy. Each layer doing its part adds weight and once the dessert is complete, it can be surprisingly heavier than expected.

In life, a lot of little things that add stress and slowly add weight can become layers like tiramisu. In other words, life can be a "tiramisu of crap." The other day I had to pick up Broden to take him

PHOTO COURTESY SHELLY HUHTANEN

to his oral surgeon, because it is time for him to have his wisdom teeth extracted. For a child with severe autism, this is not an easy process. After months of finding an oral surgeon willing to work with us to create a plan for Broden, the time had finally come to meet him at his office for a consult. With my typical son, it was a piece of cake. His oral surgeon took our dental insurance. It inconvenienced our typical son for a few days, and then he was off again living his life.

> "It was time for Broden to have his wisdom teeth extracted. For a child with severe autism, this is not an easy process. After months of finding an oral surgeon willing to work with us to create a plan for Broden, the time had finally come to meet him at his office for a consult."

For Broden, this was going to be different. This hasn't been an easy process. Before I looked for an oral surgeon, we needed to work with the dental hygienist to get some good x-rays to get a look inside. Then, I needed to work with his BCBA (Behavioral Therapist) to get him used to drinking out of a cup, since he only drinks with a straw. Mark and I slowly introduced more water into his diet, because he mostly drinks his high calorie formula on ice, to maintain his weight. Another layer of stress was looking at his diet. What will he eat that meets the criteria for something safe for him to consume after the surgery?

After pulling him out of therapy and taking him to the oral surgeon's office, I was handed a stack of paperwork to fill out, while we waited. After five minutes, Broden turned to me, "Mom, ready to go." Not only am I thinking about how to care for him after surgery, and thinking about how we are going to get him prepped for the procedure, I'm also trying to figure out how I am going to fill out the paperwork for this appointment. After 30 minutes of Broden pacing around the waiting room and asking to leave, I head up to the receptionist, "Here is my cell number. Call me when it's Broden's turn. Remember, he has autism. We're going to wait in the car and listen to music until it's time." Looking confused, she took my number, and I grabbed the book of paperwork with Broden, and headed to the car.

Another layer of stress was that Mark was stuck in meetings that day. I was doing this myself. I thought, "It would be helpful to have Mark here. He could be walking Broden around and keeping him entertained, while I fill out his paperwork." I grab the paperwork and notice there isn't an option to state that he has autism, so at the top in big letters I write, "SEVERE AUTISM!" I wrote it in angry handwriting. By that time, these individual layers of stress were getting heavier.

Finally, I received a text from the office. They were ready for us, so I promised Broden that we would be in and out very quickly. After this appointment, we would be home. He could rip his pants off and put on his "papaw pants." All would be well with the world, and I could shed off some of this stressful weight that I was holding. By this time, an hour had passed.

After sitting in the doctor's office and listening to the oral surgeon talking to a patient next door, we finally meet him. I'm sitting in the dental chair and Broden is sitting in the corner, looking very suspicious. The oral surgeon jokes, "Mom, are we taking your teeth out!?" I wasn't in a joking mood, "No, it's for him. We've been here for over an hour. Let's get this over with, so I can take him home." He checks his mouth and grabs a scale to weigh him, "Let's see if we can do this in the office. We might not have to go to the hospital." After the sudden change of plans, that was it. That was all the weight that I could seem to hold at that moment. After he left the room to grab Broden's x-rays, since the office couldn't seem to locate them earlier, I reached into my purse and grabbed a beta blocker and shoved it into my mouth.

Parenting a special needs child comes with stressors and sometimes, I need some help to manage, especially when there are added layers of events that unexpectedly add extra weight. The doctor came back into the room and saw my face, "I think we can do this. Let's try to do it in the office. Are you ok?" I leaned forward in the chair, "I just took a beta blocker, so I think I can manage this plan. I'll talk to Mark and I want to see if we can get some blood drawn for a full blood work up, since he'll have an IV for this procedure." He agreed to the plan and then asked, "Was the beta blocker for me or Broden?" I answered honestly, "The beta blocker was actually for you. Your change of plans for Broden's wisdom teeth extraction, was the last thing I could deal with today, but let's do it."

Each experience does not happen in a vacuum. At times it's difficult to compartmentalize, especially when you are caring for a child that will most likely need care for the rest of his life. The tiramisu of crap can build and it can get heavy. The first step is recognizing it, and when it gets heavy, slow down and take a deep breath. It will still be there waiting when you can pick it up and start moving again. •

### PUZZLES & CAMO

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

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