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MAGAZINE
SEPTEMBER 2021
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EP's ANNUAL EDUCATION ISSUE:

AMERICAN RESCUE PLAN FUNDS *and* STUDENTS WITH DISABILITIES

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"READING MAKES MY BRAIN HURT"

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INSOMNIA IN AUTISM *and* RELATED DISABILITIES

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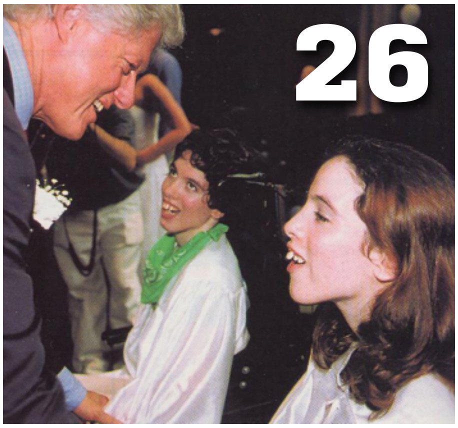
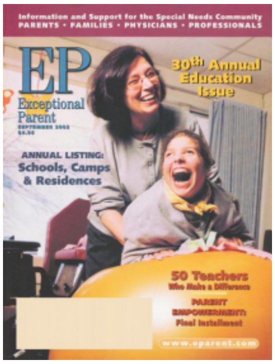


ANNUAL EDUCATION ISSUE



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ON OUR COVER

EP's Annual Education Issue explores scaffolding supports in IEPs, innovative reading solutions, and the effect of the American Rescue Plan on students with disabilites, plus Part IV of our Advocate Hero Honorees and much more. *Coverage begins on page 14.*

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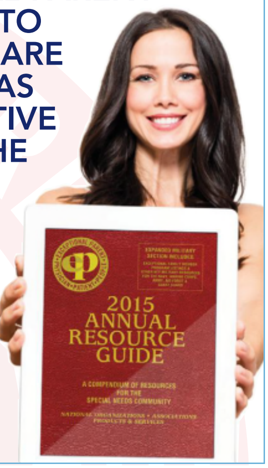

Information and Support for the Special Needs Community

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Note from the Editor-in-chief: EP World, Inc. advocates for the dignity of all citizens with disabilities including the use of "people first language" where possible. We do not normally edit articles and submissions that do not reflect this language, therefore, at times, readers might see alternative nomenclature.
— Rick Rader, MD

EP **magazine neither endorses nor guarantees** any of the products or services advertised in the magazine. We strongly recommend that readers thoroughly investigate the companies and products being considered for purchase, and, where appropriate, we encourage them to consult a physician or other credentialed health professional before use and purchase.

ANCORA IMPARO RICK RADER, MD ▪ EDITOR-IN-CHIEF

FORGET ME NOT: People were amazed that Jane Goodall was able to recognize one chimpanzee from another. She reported that their facial features were as unique and novel as those of humans.

PHOTO MICHAEL NEUGEBAUER/@JANEGOODALLINST

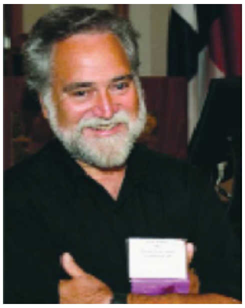
Unforgettable

Humans remember, recall and recognize faces more than any other physical characteristic. It's no wonder that police ask victims or eye witnesses, "What did he look like?" "Could you recognize her?" or "How would you describe them?"

Typically, when I am driving to work, I listen to the news. I like to know what's going on, what kind of peril we are facing that day and how many new species human kind has forced into extinction. The other day, the news was full of doom and gloom and it appeared there was little I could do about it. Then I realized there was something I could do about it, so I switched to a station that played oldies. In several seconds I was transformed from listening to plummeting stock prices, startling pandemic statistics, and political stalemates, to Nat King Cole.

It was my favorite of his songs. "Unforgettable" was a popular song written by Irving Gordon. The song's original working title was "Uncomparable." The music publishing company asked Gordon to change it to "Unforgettable." The song was published in 1951 and was inducted into the Grammy Hall of Fame in 2000.

I suspect it is the hope of every human that one day, they would meet someone who is indeed, unforgettable. Of course, the ultimate icing on the cake would be that the person would think the same of you. And so Nat King Cole lays it out with…



Unforgettable, that's what you are
Unforgettable though near or far
Like a song of love that clings to me
How the thought of you does things to me
Never before has someone been more

Unforgettable in every way
And forever more, that's how you'll stay
That's why, darling, it's incredible
That someone so unforgettable
Thinks that I am unforgettable too.

Typically, meeting someone who becomes "unforgettable" begins when you see their face for the first time. Thoughts range from, "wow," "OMG," "what eyes," "now those are lips," to "chiseled cheeks for real."

It has been proved, that facial symmetry is one of the criteria, by which we perceive attractiveness of a face. According to research, there are certain acknowledged features that are universally considered to be key components of a potentially "unforgettable" face. Based on surveys, there are eight elements of a perfect face: perfect forehead, eyebrows, twinkling eyes, pointed nose tip, high cheek bones, full lips, a tapering chin and flawless skin. It's no coincidence that these are the features that are requested by most people seeking plastic surgery consults.

Humans remember, recall and recognize faces more than any other physical characteristic. It's no wonder that police ask victims or eye witnesses, "What did he look like?" "Could you recognize her?" or "How would you describe them?"

When anthropologist Jane Goodall decided to live with the chimpanzees in their natural surroundings, people were amazed that she was able to recognize one from another. She reported that their facial features were as unique and novel as those of humans and thus, she was able to recognize Flint, Goliath, Passion, Frodo and Fifi from each other. It was also obvious, based on observing the chimps, that they were able to identify each other from their facial features.

Chimps are our closest cousins in the animal kingdom, sharing nearly 99% of our DNA. Beyond our genetic makeup, we share several other traits with the chimps. Chimpanzees laugh when tickled. Like us, the first five years of chimp's life are spent playing, socializing and developing a strong infant-mother bond. While our brains are larger, it is structurally identical to a chimpanzee's. According to writer Anna Muir, "They are capable of reasoned thought, abstraction and generalization. They can even recognize themselves in a mirror – most other animals cannot!" Their bodies are very similar to ours, sharing the same bones, muscles, nervous system and the same number of fingers and toes. Chimps are taught to share their food and tools. They kiss, hug, pat each other on the back, hold hands and shake their fists. Chimps demonstrate a range of emotions including joy, sadness, fear and even empathy. The human fascination with chimpanzees has historically been framed in terms of how good chimps are at doing things we humans do.

Watching chimps swing from three limbs reminds us that there are things they can do that we can't. Until recently, there was one trait that we never considered as unique to chimps that somehow has escaped our skills and abilities; and that is their ability to recognize one chimp from another by their butts.

> "Parents of children with special needs recognize many things about them that may elude others."

According to researcher Mariska Kret, "It is important for social animals to be able to recognize one another quickly. Humans are able to recognize each other immediately from their faces. Faces are also important for chimpanzees, but we now know that (at least with chimps) buttocks also play a role."

The chimps appear to be able to recognize rear ends as efficiently as we process faces.

In something called the "inversion effect" our abilities to recognize features are reduced when the images of faces are turned upside down. Chimps, as well as humans, are prone to this diminished recognition… except in the case of the backside. Much of this is attributed to the evolutionary changes to the physical features of butts when we began walking upright. According to the study, it was determined that bottoms and faces "are both symmetrical; and interpreting what about a butt is saying is crucial to chimpanzees' reproductive success, just as interpreting facial messaging is important to human mating."

Parents of children with special needs recognize many things about their children that may elude others. They can recognize the significance of a smile, a whimper, a whisper and a sigh. They can recognize signs of joy, frustration, elation, fear and pleasure.

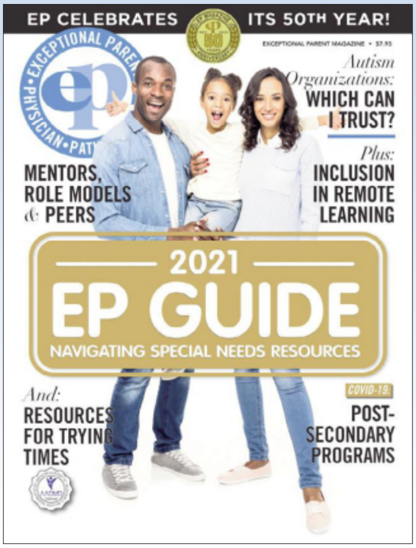
They also subscribe to the suggestion of Serbian philosopher Dejan Stojanovic, "For a moment at least, be a smile on someone else's face."

Somehow, it's just not the same, listening to Cole's "Unforgettable." Sometimes, reading research can do those things.•

ANCORA IMPARO

In his 87th year, the artist Michelangelo (1475 -1564) is believed to have said "Ancora imparo" (I am still learning). Hence, the name for my monthly observations and comments.

— Rick Rader, MD, Editor-in-Chief, EP Magazine
Director, Morton J. Kent Habilitation Center
Orange Grove Center, Chattanooga, TN



FROM THE PUBLISHER'S DESK

Dear Loyal Readers,

When I took over as the Publisher several years ago, my mission was to create a website where *EP Magazine* was available free to all who could benefit from the content, including archived issues. That was accomplished, thanks to the advertisers who support our magazine, because they have a product or service appropriate for our readers.

COVID-19 damaged our advertiser base and proved to be a financial challenge. I am hopeful that some of our readers would be able to help us by referring companies they are connected to, that would benefit from having a presence in our magazine and on our website.

If any of you are able to provide referrals or introductions, it would be greatly appreciated. Please send all such communications to Faye Simon, our VP of Marketing, at FSimon@epmagazine.com

Rest assured that EP will continue to provide, promote and share the best information that impacts the disability community.

Thanks for taking the time read this message and I wish you all good health and happiness.

Sincerely,

Len Harac, PhD
Publisher, *EP Magazine*

LEN HARAC, PHD • PUBLISHER, EP MAGAZINE • lharac@epmagazine.com

WHAT'S HAPPENING

BREAKTHROUGH SUMMIT 2021: THE MOST IMPORTANT RARE DISEASE CONFERENCE OF THE YEAR

Registration is now open for the NORD Rare Diseases and Orphan Products Breakthrough Summit.®

The NORD Summit, one of the largest global events in rare disease, brings together experts and leaders from patient advocacy groups, government, industry, and academia to discuss the current and critical topics in rare diseases and orphan products.

Key learnings announced include Designing Trials for Inclusivity, Equity and Engagement, which will focus on what's being done and what needs to be done to increase inclusivity, equity, and engagement in clinical trials; as well as a session highlighting Project Baby Bear as a case study into how one state (California) demonstrated healthcare system savings through access to genetic testing.

Expert speakers announced include:

- John Whyte, MD, Chief Medical Officer, WebMD
- Michelle McMurry-Heath, MD, PhD, President & CEO, Biotechnology Innovation Organization (BIO)
- Phillip L. Pearl, MD, Director, Epilepsy and Clinical Neurophysiology, Boston Children's Hospital; William G. Lennox Chair of Neurology, Harvard Medical School; President, Child Neurology Society; Member, NORD Board of Directors
- RADM Richardae Araojo, PharmD, MS, Associate Commissioner for Minority Health, US Food and Drug Administration (FDA)
- Quita Highsmith, Vice President and Chief Diversity Officer, Genentech
- Brian Maienschein, Assemblyman, 77th District, State of California
- Patrizia Cavazzoni, MD, Director FDA Center for Drug Evaluation and Research (CDER)
- Peter Marks, MD, PhD, Director FDA Center for Biologics Evaluation and Research (CBER)
- Jeffrey Shuren, MD, JD, Director, FDA Center for Devices and Radiological Health (CDRH)
- David Dimmock, MD, Chief Medical Officer, Rady Children's Institute

There are a select number of complimentary passes available to member organization leaders, Rare Action Network state leaders and medical professional students. To learn more, visit **nordsummit.org**.

The National Organization for Rare Disorders (NORD) is the leading independent advocacy organization representing all patients and families affected by rare diseases in the United States. NORD began as a small group of patient advocates that formed a coalition to unify and mobilize support to pass the Orphan Drug Act of 1983. Since then, the organization has led the way in voicing the needs of the rare disease community.

THE ARC'S NATIONAL CONVENTION : REGISTER TODAY

The Arc's National Convention is an unmatched opportunity to connect and learn with advocates, professionals, people with intellectual and developmental disabilities, and their families. If you are interested in employment, education, advocacy, housing, criminal justice, and more – our sessions are sure to challenge, inspire, and motivate! Visit **https://convention.thearc.org**

If you haven't registered for The Arc's upcoming National Convention in September, it's not too late – and, there are no travel arrangements required. While the Arc is sad not to be gathering in person, they continue to be dedicated to delivering an exceptional program that includes sessions on strategic crisis response, remote supports, mental health struggles, and diversity and inclusion. The event will be held on the same dates (September 27-29), now with updated pricing!

With the start of a new year approaching, there's no better time to reconnect, build on your knowledge and skills, and prepare for what lies ahead in the fight for disability rights.

FULL EVENT	ONE DAY
Member: $315	Member: $165
Non-member: $435	Non-member: $210
Self-Advocate, Personal Care Attendant, Direct Support Professional: $195	Self-Advocate, Personal Care Attendant, Direct Support Professional: $120

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HELPING YOU COMBAT COVID-19
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www.bantec.store

WHAT'S HAPPENING

AUTISM SPEAKS OPENS APPLICATIONS FOR NORMA AND MALCOM BAKER RECREATION GRANTS

Autism Speaks – the global non-profit dedicated to promoting solutions, across the spectrum and throughout the life span, for the needs of people with autism and their families – recently announced the opening of applications for the final cycle of Norma and Malcom Baker Recreation Grants.

Since 2018, the Autism Speaks Baker Grant program has awarded over $607,000 to 123 organizations across the country and served tens of thousands of people with autism, their caregivers and families, teachers, therapists and neurotypical peers.

Autism Speaks' Baker Grants offer funding for programs that provide autistic people of all ages with social and educational experiences that have a true, measurable impact on their lives. The program accepts applications from both for-profit and non-profit organizations for grant awards of $5,000.

GOING SWIMMINGLY: Autism Speaks Local Impact Grants support programs demonstrating the ability to have true, measurable impact on the lives of those who participate and their loved ones.

Baker Grant applicants must grow and replicate best practices with other partners in their community, state or region within one of the following categories of service delivery:

- **Summer Camp Programs:** including day and overnight programs that provide a safe and nurturing environment where people with autism can enjoy a variety of therapeutic activities and sports, and arts and technology programs that help them reach their full potential during the summer.
- **Adult Service Programs:** including recreation and respite programs specifically for adults. These programs may also teach life skills, health and community living skills.
- **Adult Employment Programs:** including programs that are dedicated to helping individuals with autism find and maintain meaningful employment by teaching them the skills needed to succeed in the workplace.
- **Physical Fitness and Sports Programs:** including a wide range of athletic activities and team sports, as well as health and wellness programs, both in school and after school, which aim to ensure people with autism are learning how to engage in physical activities that they can share with their peers.
- **Swimming and Water Safety:** including programs that provide qualified swimming and water safety lessons specifically for individuals with autism.

Service providers are encouraged to apply. Applications will close on October 22, 2021, and funding will be disbursed starting January 15, 2022.

The 2021 schedule is as follows:

- September 7: *Application process opens*
- October 22: *Final date for applications*
- October 26 - November 9: *Review committees meet and make decisions on recommendations*
- November 10: *Recommendations are reviewed and grants approved*
- November 22: *All applicants notified and announcements made on social media*
- Starting January 15: *Funds disbursed upon receipt of contracts*
- End December 2022: *Final Report from recipients due to Autism Speaks*

For more information, email grants@autismspeaks.org. •

AMERICAN ACADEMY OF DEVELOPMENTAL MEDICINE & DENTISTRY

How is it possible that people abuse children (and adults) with disabilities?

BY H. BARRY WALDMAN, DDS, MPH, PHD, STEVEN P. PERLMAN, DDS, MSCD, DHL (HON), AND NORA J. BALADERIAN, PH.D.

"About 1,750 children die from abuse and neglect in the U.S. every year, according to federal data." [1]

"Nearly 700,000 children are abused in the U.S annually." [2]

"There are reports… that ***children with disabilities are 4 to 10 times more likely to be abused than children without disabilities."*** [3] (emphasis added)

"Unfortunately, the 'dirty secret' about abuse of children with disabilities is all too true." [4] *"…Children with disabilities may be perceived as less valuable than other children."* [5]

87% of the perpetrators of child abuse are parents or family relatives, compared to less than one percent of perpetrators who are child care providers or residential facility staff members.

There is a significant relationship between parental substance abuse and child abuse. There is a particular increase in cases of abuse of youngsters in the month of January. Limited funds are available after spending monies for the holidays.

Native American children and African American children have the highest rate of victimization. Asian-Pacific islander children have the lowest rate.

More boys with disabilities are physically abused and neglected, but more girls with disabilities are sexually abused. [3,4,6]

"Physical abuse of children has become so common place that it is only when the death of child occurs that the news media may carry the story and then only when it is gruesome." [7]

AMERICAN ACADEMY OF DEVELOPMENTAL MEDICINE AND DENTISTRY

The American Academy of Developmental Medicine and Dentistry (AADMD) was organized in 2002 to provide a forum for healthcare professionals who provide clinical care to people with neurodevelopmental disorders and intellectual disabilities (ND/ID). The mission of the organization is to improve the quality and assure the parity of healthcare for individuals with neurodevelopmental disorders and intellectual disabilities throughout the lifespan.

Child abuse isn't something that only happens to little children: 32 percent of 14 to17 year-olds in the United States are abused or neglected in their lifetimes, and 28 percent are sexually victimized. [8]

In 2015, the rate of violent victimization (including rape, robbery and aggravated assault) against persons with disabilities (12 years or older, except for persons 65 years or older) was **more than 3 times higher** than the rate for persons without disiabities. For each race and ethnic group reported by the U.S. Department of Justice, persons with disabilities had higher violent victimization rates than persons without disabilities.

- *Persons with cognitive disabilities had the highest victim rates of violent crime. Children with autism had a lower risk.*
- *Children with Down syndrome or cerebral palsy had the same risk as children without disability.*
- *Persons with hearing disabilities had the lowest rates of violent victimization.*
- *Compared to individuals with a single disability, a greater proportion of persons with multiple disabilities were subjected to violent crime; particularly, rape and sexual assault.*
- *A higher percentage of violence against persons with disabilities was committed by persons the victims knew well or were casual acquaintances, compared to persons without disabilities.* [9,10]

STOP THE VIOLENCE: In 2015, the rate of violent victimization against persons with disabilities was more than 3 times higher than the rate for persons without disiabities. More boys with disabilities are physically abused and neglected, but more girls with disabilities are sexually abused.

WHAT ARE THE SIGNS OF CHILD ABUSE AND NEGLECT?

In younger children:

- *Unexplained bruises, cuts, burns, or other injuries*
- *Poor personal hygiene and clothing that is ill-fitting, dirty, or inappropriate to the weather*
- *Reluctance or fear of going home, and excessive fear or anxiety about doing something wrong*
- *Extreme behaviors, such as being unusually passive or aggressive*
- *Acting either inappropriately as an adult (taking care of other children) or inappropriately infantile (rocking, thumb-sucking, tantrums)*
- *Displaying more knowledge or interest in sexual acts than is normal, including acting out sexually explicit behavior*
- *Often late or absent from school*

In older youth:

- *Changes in eating or sleeping habits*
- *Aggressive or inappropriate behavior*
- *Depression, anxiety, or mood swings*
- *Attention-seeking behavior*
- *Increased risk-taking*
- *Difficulty concentrating*
- *Declining school performance or absences*
- *Withdrawal from friends*
- *Physical distress (e.g., recurring headaches or stomaches)*
- *Running away*
- *Sexual promiscuity* [8]

AN INTERNATIONAL "EPIDEMIC"

Abuse of children (and adults) with disabilities is not just a U.S. heartbreaking dilemma. The United Nation Secretary General's Report on Violence Against Children with Disabilities details the international reality that, "violence against children with disabilities occurs at annual rates at least 1.7 times greater than their non-disabled peers… 90% of individuals with intellectual impairments will experience sexual abuse at some point in their life." [11]

ENOUGH ABOUT NUMBERS AND PROPORTIONS! WHY ABUSE?

Abuse among children with disabilities are the same rates as those found in the general population of single parents, teen parents and others with various levels of stress. However, families with children with disabilities can experience additional stressors, including:

- *Feeling unprepared to handle the care of a disabled child, including acceptance of that child as being "different."*
- *Having financial or time limits stretched as additional medical/educational activities are suggested.*
- *Lacking necessary social supports or networks to work through the many concerns and situations that arise in providing care for this child and the rest of the family.*[7]

UN Report: "Throughout history many – although not all – societies have dealt poorly with disability. Cultural, religious and popular social beliefs often assume that a child is born with a disability or becomes disabled after birth as the result of a curse, 'bad blood', an incestuous relationship, a sin committed in a previous incarnation or a sin committed by that child's parents or other family members.

(Children with disabilities) are far less likely than their non-disabled peers to be included in the social, economic and cultural life of their communities; only a small percentage of these children will ever attend school; a third of all street children are disabled children. Disabled children living in remote and rural areas may be at increased risk.”[11]

- *In societies where there is stigma against those with disabilities, some parents respond with violence because of the shame the child had brought on the family or respond with violence because a lack of social support leads to intense stress within the family.*
- *Children with disabilities may be killed, either immediately at birth or at some point after birth. The rationale for such killings is either: 1) the belief that the child is evil or will bring misfortunate to the family or the community, or 2) the belief that the child is suffering or will suffer and is better off dead. In ‘mercy killings’ a parent or caretaker justifies withholding basic life sustaining supports (usually food, water and/or medication).*
- *When a child with a disability lives in a violent setting, his or her disability often serves to compound and intensify the nature and extent of the abuse.*
- *Neglect can be a precursor to violence. Parents may respond to the stress of caring for a child with a disability with neglect, rather than active violence. However, when this neglect involves denial of food, medicine and other life sustaining services, it must be considered a form of violence.*
- *Physical, sexual, verbal and emotional abuse may be carried out by caregivers without the parent’s knowledge or while the parent is away.*[11]

HOW DO YOU PREVENT ABUSE TO CHILDREN WITH DISABILITIES?

In 2005, two of the authors reported (in *EP Magazine*) the tragedy of the abuse of children with disabilities.[4] Almost a generation later, we now recite the continuing misery of the abuse of children (and the not so young) with disabilities. However, now, we also must include the consequences of the plague of increasing drug abuse in families; potentially by those providing the care of children with disabilities.

Repeated research reports emphasize the family’s stress, as well as the financial demands associated with the efforts to provide the additional care and supervision for children with disabilities.

- *Child welfare professionals should emphasize to parents or caregivers the importance of attending to their personal physical and mental health needs, as well as the needs of their children.*
- *A limited ability to connect with other parents and social isolation in general may leave these parents unaware that their children are at increased risk of maltreatment, and they may be unprepared to identify and protect their children from risky situations.*[12]

The Centers for Disease Control and Prevention (CDC) provides an extended internet library regarding the needs of families raising children with disabilities into adult years and beyond.[13] *But these efforts can succeed only with a cultural transformed understanding that children (and adults) with disabilities are not some kind of retribution for evil parental (or other family members) past actions and therefore not equal to their counterparts with no disabilities.* ***Otherwise, they are fair game for the warped minds of their abusers!***

Remember: Although this bleak picture is true, there are increasing supports for parents of children with disabilities as well as their children. These programs include support by the Arc organizations around the country. It is well recognized that when identified, trauma treatment for child abuse victims can begin a healing process after they are removed from contact with the abusers. **It is important to recognize that parents are generally not informed that their child with a disability is more vulnerable to abuse than children without a disability. They should be not only informed, but supported in creating plans to reduce the risk of abuse for their child with a disability.** Knowledge is power, and acting on effective methods to reduce the risk of abuse to their child is important. Having such a plan in place has been found to reduce the impact of abuse when it happens. Empowering parents is one important first step to reduce abuse. Another is to empower health providers to whom the parents turn when changes in their child occur (without any known cause). All health providers should be provided the information on the high incidence of abuse of children with disabilities. During patient visits, they should inquire into the possibility of abuse being the cause of the significant.•

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2021 Advance Child Tax Credit Payments

Payments start July 15

Filed already?

You don't need to take any action now if you've filed a 2020 tax return.

Haven't filed yet?

File your tax return as soon as possible. For people not required to file a tax return and who didn't file in 2019 or 2020, quickly register using the IRS **Non-filer Sign-up Tool**. You may qualify for the Child Tax Credit and Economic Impact Payments.

- Eligible families can receive advance payments of **up to $300 per month** for each child under age 6 and **up to $250 per month** for each child age 6 and above.
- Payments begin July 15 and will be sent monthly through December 15 without any further action required.
- You can benefit from the credit even if you don't have earned income or don't owe any income taxes.
- The tax credit includes advance payments for 2021 only.

The American Rescue Plan Act Advance Child Tax Credit provisions include:

- The maximum Child Tax Credit increased to $3,600 for children under the age of 6 and to $3,000 per child for children between ages 6 and 17.
- The credit includes children who turn age 17 in 2021.
- Taxpayers may receive part of their credit in 2021 before filing their 2021 tax return.

Eligible taxpayers who don't want to receive advance payment of the 2021 Child Tax Credit will have the opportunity to unenroll from receiving the payments.

IRS.gov/childtaxcredit2021

Students with disabilities were impacted the most during the pandemic.

The American Rescue Plan can help them get back on track.

HOW THE AMERICAN RESCUE PLAN FUNDS CAN HELP STUDENTS WITH DISABILITIES

BY TATSIANA DAGROSA AND LAUREN AGORATUS, M.A.

The federal American Rescue Plan (ARP), signed into law in March of 2021, provides an unprecedented investment in education, giving states and school districts access to funds to help safely reopen and sustain the safe operation of schools. In addition, this funding is intended to address the impact of the COVID-19 pandemic on the needs of students more strategically.

This article offers specific strategies so that schools, educators, families, parent groups, and community stakeholders can better advocate for systemic changes that intentionally target the education of students with the greatest needs, including students with disabilities.

HOW MUCH OF THE ARP FUNDING IS AVAILABLE?

The Elementary/Secondary School Emergency Relief (ESSER) Fund under the ARP provides almost $122-billion to States and school districts. While the state education agency can retain up to 10% of the amount, at least 90% will be allocated directly to school districts "to help meet a wide range of needs arising from the coronavirus pandemic, including reopening schools safely, sustaining their safe operation, and addressing students' social, emotional, mental health, and academic needs resulting from the pandemic" *(See ARP Factsheet in Resources).*

HOW CAN THE ARP FUNDING BE SPENT BY THE DOE AND DISTRICTS?

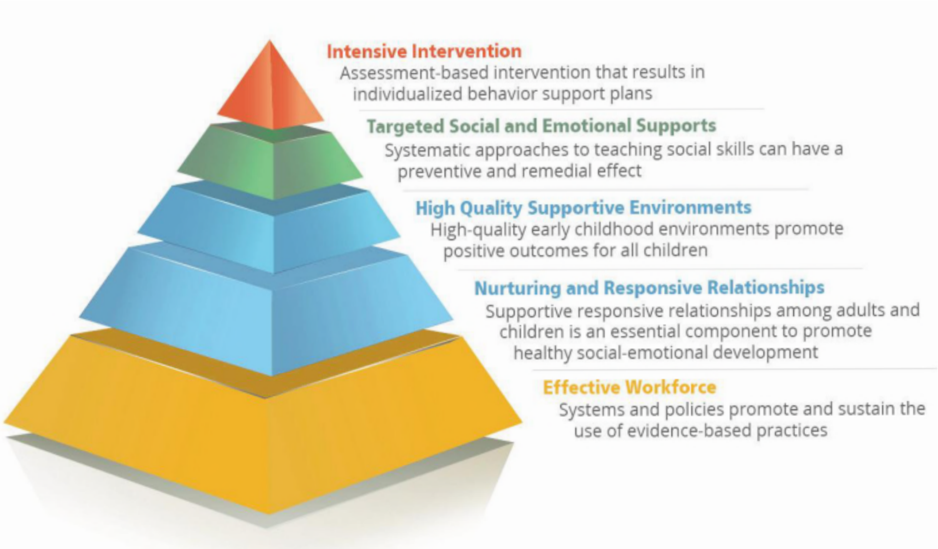
The State must use 5% of retained funds to address learning loss, 1% for summer enrichment programs, and 1% for comprehensive after-school programs. While each State must abide by the Individuals with Disabilities Education Act (IDEA) restrictions and requirements when spending the funds specifically reserved for special education, the bulk of district funding comes with much more flexibility *(See state plans in Resources).*

Districts must use at least 20% of the ARP funds on evidence-based interventions to address learning loss. In addition, districts must ensure that the programs and interventions respond to students' academic, social, and emotional needs and address the disproportionate impact of COVID-19 on students living in poverty, English learners, racial and ethnic minorities, and students with disabilities. The remaining 80% of funds may be spent on any activities authorized under all federal education laws, including IDEA, and may also include expenses related to professional learning for educators, access to and purchase of educational technology, and certain types of facilities improvements. District activities may also – and should – address family engagement in all aspects of their work, including in developing and implementing district spending plans and in other areas. For example, districts may spend funds to provide training to families around providing positive behavior and/or social-emotional supports at home consistent with the programs that are implemented at school.

PRIORITY AREAS FOR STUDENTS WITH DISABILITIES

School Operations

Ensure building modifications are guided by universal design principles, allowing facilities to be accessible to all. Learning strategies can also follow the principles of Uniform Design for Learning (UDL) (see Resources).



TRIANGULATING SUCCESS: The Pyramid Model for Supporting Social Emotional Competence in Infants and Young Children; Social-emotional learning (SEL) is the process of developing the self-awareness, self-control, and interpersonal skills that are vital for school, work, and life success. Students with strong social-emotional skills are better able to cope with everyday challenges and benefit academically and socially.

Screening, Assessments, and Special Education:

- *Assessments conducted as a part of the special education evaluation process provide valuable data to IEP teams, including parents, as they determine eligibility for services and, if eligible, a baseline for present levels of academic achievement and functional performance levels.*
- *Review testing materials and ensure they reflect best practices in assessing culturally and linguistically diverse students.*
- *Implement robust multi-tiered system of supports to ensure that high-quality interventions for all tiers are available to students, whether they are attending school in person, virtually, or through hybrid model.*
- *Address the inadequate provision of related services and supports. Create a multidisciplinary team, including Child Study Team members and families, to review student data to develop a clear understanding of who needs which services.*

Trauma, Mental Health, and Social Emotional Supports

- *Provide ongoing training to all staff to build their capacity around the impact of trauma and early detection techniques in anticipation of an uptick in behaviors stemming from trauma, social isolation, etc.*
- *Refine protocols, data systems, and interventions to ensure alignment to trauma-informed practices.*
- *Ensure school-wide practices and strategies are trauma-informed and support the whole child and social emotional skills-building rather than punitive discipline.*
- *Examine and improve policies and practices to prevent and reduce the use of exclusionary discipline, especially the restraint, seclusion, referral to law enforcement, suspension, and expulsion of students of color and with disabilities.*
- *Invest in training and coaching for staff on understanding the functions underlying challenging behaviors, positive behavior supports, self-awareness, and implicit bias.*

Impact on Learning and Opportunities

- *Identify opportunities to expand learning time, such as summer school, after-school, and extended school year programs, to provide students with critically needed increase in time with instructional staff.*
- *Ensure such programs are not offered in place of extended school year (ESY) services, which typically address skill regression after the summer break for students with disabilities and are decided on by each student's IEP team.*
- *Schedule time for general and special education staff to work together to*

AMERICAN RESCUE PLAN STRATEGIES : AN UNPRECEDENTED INVESTMENT IN EDUCATION

AMERICAN RESCUE PLAN ACT FACT SHEET
https://oese.ed.gov/files/2021/03/FINAL_ARP-ESSER-FACT-SHEET.pdf

STATE ESSR PLANS
https://oese.ed.gov/offices/american-rescue-plan/american-rescue-plan-elementary-and-secondary-school-emergency-relief/stateplans

ED COVID-19 HANDBOOK, VOLUME 1
Strategies for Safely Reopening Elementary and Secondary Schools
www2.ed.gov/documents/coronavirus/reopening.pdf

ED COVID-19 HANDBOOK, VOLUME 2
Roadmap to Reopening Safely and Meeting All Students' Needs
www2.ed.gov/documents/coronavirus/reopening-2.pdf

TIERED SYSTEMS OF SUPPORTS
https://ccrs.osepideasthatwork.org/teachers-academic/tiered-support

EARLY CHILDHOOD REOPENING COLLECTION
www.parentcenterhub.org/early-childhood-reopening-resource-collection

KEY POINTS TO RAISE FROM ED'S REOPENING SCHOOLS
https://www.parentcenterhub.org/reopening-schools-key-points-to-share/

KEY QUESTIONS TO ASK BEFORE SCHOOLS REOPEN
https://spanadvocacy.org/wp-content/uploads/2020/08/START_Roadback_Quick_Guide_8.pdf
https://spanadvocacy.org/wp-content/uploads/2020/08/START_oadback_Quick_Guide_8_spa.pdf (Spanish)

SOCIAL-EMOTIONAL SUPPORTS

CENTER ON THE SOCIAL EMOTIONAL FOUNDATIONS OF EARLY LEARNING
http://csefel.vanderbilt.edu

COLLABORATIVE FOR ACADEMIC, SOCIAL, AND EMOTIONAL LEARNING
https://casel.org

POSITIVE BEHAVIORAL INTERVENTIONS AND SUPPORTS
www.pbis.org

WELLNESS/MENTAL HEALTH RESOURCES FOR COPING DURING THE OUTBREAK OF COVID-19
https://spanadvocacy.org/wp-content/uploads/2020/05/Wellness-Mental-Health-Resource-List-C19-1.pdf

UNIVERSAL DESIGN FOR LEARNING

BUILDING ACCESSIBILITY
www.nacarchitecture.com/publications/DesignForSpecialEducation.pdf

UDL GUIDELINES FOR INSTRUCTION
https://udlguidelines.cast.org

ensure additional programming is complementary and aligned to developmentally appropriate expectations.

- *Provide coaching to all educators to ensure they are implementing new practices with fidelity, and high-quality instruction is available for all students, especially those facing the greatest challenging, including students with disabilities.*
- *Invest in one-to-one technology devices, Internet access, and assistive technology for all students to increase virtual and hybrid learning opportunities at home.*

HOW FAMILIES CAN BE INVOLVED

- *Ensure diverse family members and community-based organizations serve as members and facilitators in a full spectrum of district- and school-level decision-making groups, including Board of Education, special education parent advisory council, PTA, Title 1 committee, bi-lingual committee, school climate, school health, and school reopening committee and/or pandemic response team.*
- *Anticipate that families may require language interpretation or translation services to meaningfully collaborate with schools.*

The Elementary/Secondary School Emergency Relief can help address learning and social-emotional adjustments for students facing the greatest challenges, including those with disabilities.•

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https://spanadvocacy.org/programs/start/.
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Advance Payments of the 2021 Child Tax Credit

THE BASICS

WHAT?

For tax year 2021, families claiming the Child Tax Credit will receive:

- Up to $3,000 per qualifying child between the ages of 6 and 17 at the end of 2021
- Up to $3,600 per qualifying child under age 6 at the end of 2021

The total of the advance payments will be up to 50 percent of the Child Tax Credit.

WHO?

The maximum credit is available to taxpayers with a modified adjusted gross income of:

- $75,000 or less for single filers and married persons filing separate returns,
- $112,500 or less for heads of household, and
- $150,000 or less for married couples filing a joint return and qualifying widows and widowers.

Eligible taxpayers don't need to take any action now other than to file their 2020 tax return if they haven't done so. Taxpayers can benefit from the credit even if they don't have earned income or don't owe any income taxes.

WHEN?

Advance payments of the 2021 Child Tax Credit will be made monthly from July 15 through December 15 to eligible taxpayers who have a main home in the United States for more than half the year.

HOW?

- Advance payments will be calculated and paid automatically.
- Eligible taxpayers who don't want to receive advance payment of the 2021 Child Tax Credit can unenroll from payments.
- Eligible taxpayers who don't normally file a tax return can register for the monthly advance payments using the **Non-filer Sign-up Tool**.

Visit **IRS.gov/childtaxcredit2021** for more information and to access the online tools.

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READING MAKES MY BRAIN HURT:

ONE FAMILY'S PATH TO A READING SOLUTION

BY DR. MARIA FINARO CLEARY

Our daughter, Desi, came to us from an orphanage in Bulgaria when she was almost three. We had no idea she had special needs until she started having difficulty acquiring language. After a visit with a neurologist and an MRI, we were told she had left brain hemiatrophy, a form of cerebral palsy. The left side of her brain was half the size of the right, probably as a result of a stroke or some other vascular event either in utero or at birth. When we asked about her prospects, one doctor said, "Well, she probably won't go to Harvard."

PHOTOS PROVIDED BY DR. MARIA FINARO CLEARY

GOING PLACES: Desi has some fun with brother Jeff. "We hope that Readeezy can be the kind of place where any reader who wants can climb inside the pages, learn something new, go on an adventure and most of all, have a wonderful time doing it."

However, Desi just forged ahead, blithely unaware of her "prospects." She was a patient student, sitting for hours trying to learn. In fact, there was nothing she wouldn't try. We found out that, contrary to expectations, Desi was athletically inclined and we enrolled her in Special Olympics where she gave her all to soccer, basketball, and track. She would run races, have a seizure in the middle of the track, and get up and finish the race. She left everyone speechless.

Despite great success in some areas, her learning problems persisted. Math was always a hurdle because it involved abstract thinking, which was a challenge for her. But we made some progress with reading and had hopes that she would be able to manage books on grade level, at least through adolescence.

We were wrong. By middle school, she had outgrown the picture books that had supported her reading. And books that were age-appropriate were not illustrated and difficult to understand. So she just stopped reading altogether. In fact, she said, "Reading makes my brain hurt."

This was very alarming because of what we'd learned about brain development. Neuroplasticity is the brain's ability to reorganize itself by forming new neural connections throughout life. Recent research in neuroscience shows that our brains are not static, but rather are dynamically changing and undergoing transformation throughout our entire lives.

However, brain stimulation must stay constant or increase in order for us to make these neural connections. (You know all those "brain games" that are always being advertised for adults? That's the reason!) If adolescents give up on reading once they get to middle school, the brain's reading network will cease to develop. "When we reach adolescence, a massive 'pruning back' operation begins in the brain and synaptic connections and neurons that have not been used extensively suddenly die off – a classic case of 'use it or lose it.'" (Doidge, 2007, 2015).

Another thing to worry about.

The good news is that when challenged, readers learn that their brain capacity can expand, they are encouraged, and their performance, morale and self-image improve. (Blackwell, Trzesniewski & Dweck, 2007). So our challenge as parents is to motivate them to read more. Fortunately, there are two promising resources than can help: illustrations and digital media.

Younger children with reading difficulties often find support in books with pictures that reinforce the text. Illustrations help them create mental images of simple story lines and characters. In many ways, pictures serve as the key to reading enjoyment for children who have difficulty turning abstract concepts into concrete thoughts.

However, there are very few resources for older readers in the form of the picture book. This audience has long outgrown the juvenile story lines and characters that mark many of the choices in this category. Illustrated books for older readers, although they do exist in the form of "Hi-Lo" readers (high interest, low reading level), are limited in number and scope. Graphic novels offer illustrations, but sometimes in a frenzied format with many panels on a page and dialogue bubbles to advance the story, which some readers with learning disabilities find confusing.

"Once our special needs daughter reached adolescence, she said her brain 'hurt' when she tried to read books that were age-appropriate. This is the story of our journey to help her read."

Digital illustrations can offer the same comprehension support as print, but can also provide two real advantages: the appeal of digital resources to young people, and the potential to interact with a book.

So that's how Readeezy came to be. I decided to create something that was digital, because it kept her attention for a longer time. Desi's brother, Jeff, is a reading teacher, so he and I wrote a book that we thought would be appealing to this audience. I then hired folks to illustrate and animate it and a developer to program it. As educators, Jeff and I knew that challenged readers often have trouble keeping their focus, so we included checks for understanding at the end of every chapter.

Best of all, we tested it. We did a peer-reviewed study with readers at least two grades below level and were overwhelmed at the positive results. In every category – comprehension, retention and engagement – readers rated it over 85%. We were overjoyed.

Of course, now, we had to spread the word that we had this resource and we had to figure out how to create a whole library. One book was great but wouldn't have the kind of impact we wanted. And that's the journey we're on now. The dream is to have an entire collection of books that challenged readers can just visit and enjoy

AN OPEN BOOK: *(Clockwise from top left)* Desi in Bulgaria; with her mother Maria; leading the Special Olympics Torch Run; and finishing a Midland School race.

whenever they want. So we're reaching out to the world to help make that happen.

But while we're working to create the Readeezy library, we parents can provide some of these aids to our children as they read. Find pictures that match those in the stories they like. Make up a simple game to check for understanding when you finish a chapter. Perhaps you can even record a narration for easy books that you can play while your child follows along. (There are also some books online for this age group that have a text-to-speech feature.) It's extra work but worth it if it can help a young person be motivated to read more. You can also visit our website at **www.readeezy.com** for links to research on neuroplasticity of the brain and how neural connections can both strengthen and weaken, depending on how they're stimulated. It may inspire you to create reading solutions of your own.

For those of us who've ever enjoyed a good book, we know the fun of losing yourself in a story. We hope that Readeezy can be the kind of place where any reader who wants can climb inside the pages, learn something new, go on an adventure and most of all, have a wonderful time doing it. •

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

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ENGAGING LEARNERS WITH DIVERSE NEEDS THROUGH IEP SUPPORTS

BY ANGELA SHAW

Engagement, practice and understanding are universal components that are keys to student learning. However, when a student is identified with a special need that has the potential to impact their ease with attending and planning, their engagement in the learning progression can become a challenge. In this scenario, the mission for the educational team becomes accessibility as a vital learning component of engagement. In special education, this team of experts is called the IEP team, which includes the student's parent(s) or legal guardian, educators and related service providers, and an administrator.

The team's purpose is to create a specialized learning plan, supports and services built upon the student's present levels of performance (PLOP), strengths, and needs. The learning plan, termed an Individualized Education Program (IEP), is intended at its core to provide specialized academic instruction (SAI) tailored to the needs of the student. Since individuality often plays a key role in determining what a person needs in order to thrive and learn, rather than a rigid one-stop shopping list containing accommodations, modifications and presentation, IEP teams should allow for a certain level of flexibility—as this takes into consideration appropriate scaffolds to support the student where the need arises, as well as the distinctive strengths of the student. To be prepared for your vital mission as an IEP team member and ensure a mindful trajectory for student learning and engagement, please read on.

As focus on determining appropriate supports for student engagement, we should first reflect upon the process of just how our brains work when we are learning. The causation pattern needed in order to assure efficient learning for students of all ages and learning styles involves processing information within a small space in our brains called the working memory. The road to the realm of the working memory is through engagement, but entry within this processing center may be impeded if a student is externally or internally distracted. Teachers strive each day to capture their students' attention with the goal of boosting engagement, practice and exponential understanding. They have an array of strategies within their tool boxes, as well as a skilled learning community to support this endeavor. However, students identified with special needs may process auditory or visual information differently. They may have difficulties with executive functioning, such as attention and planning. They may have delays in the areas of receptive or expressive language. Such diverse challenges may cause a student to struggle with engagement, due to an unseen barrier. Through the IEP meeting and the resulting IEP document, the identification, acknowledgement and consideration applicable to the learner's unique learning profile now become readily accessible to educators and parents. This helps implement the mindfully planned scaffolds built into the plan to bolster the student's access to engagement and learning progression.

In addition to increasing access to the working memory, engaging students in the learning process may help in increasing productivity, enhancing performance and connecting to community. Actively engaging students through guided discussions, structured small group activities, and planned creative play, promote a treasure trove of social, emotional and academic benefits, including the students':

- *Learning with peers in a more inclusive manner*
- *Making friends through shared interests and perspectives*
- *Having fun with learning through a variety of sensory and social experiences*
- *Developing leadership skills through collaboration, negotiation, cooperation and creative problem solving*
- *Learning life skills through peer models, as well as the tasks and responsibilities within the group*
- *Learning how to be a part of a group, which becomes a natural progression through team work and respectful relationships*
- *Learning how to include others through sharing strengths and supporting others on the journey.*

STRENGTH ASSESMENT: Teachers and parents are better able to construct scaffolds of support that provide for appropriate tools of engagement through improved understanding of what a student needs to access the curriculum and what strengths the student possesses.

"Learning how to learn" takes place through fun, as well as opportunities for engagement within an inclusive learning community. Additionally, measurable outcomes linking increased student engagement levels may be seen through:

- *Improved attendance: Absences, even excused ones, can signal a lack of student engagement and connection. When students are engaged in the learning process, they often feel a part of the learning community; therefore, will make an effort to be with their classmates.*
- *Productivity and practice: Students who are engaged in the process of learning relish completing a project. They understand the critical aspects of connecting the dots of their learning through their classwork and homework practice. They feel connected to their learning community and are proud of their ability to contribute; therefore, student behavior tends to be more on task when they are actively engaged learners.*
- *Fun for everyone: Teachers and students who are actively engaged in learning radiate their happiness through smiles and kindness to one another. This often equates to less referrals and more time spent learning.*

With such rewards, engaging our students can provide the basis for long-term success. Through improved understanding of what a student needs to access the curriculum and what strengths the student possesses, teachers and parents are better able to construct scaffolds of support that provide for appropriate tools of engagement. Therefore, rather than providing a simple check-list, naming the action or tool required to support the student, try adding a reason or purpose for accommodations – or modifications to provide a perspective of understanding relative to a student's needs and support their strengths.

CUSTOM COVERAGE : PURPOSING ACCOMMODATIONS

An exhaustive list relative to creating operationalized scaffolds of support could fill a volume of books, but may not necessarily cover all of a student's unique needs. Rather, offered within this article is a launchpad of ideas and examples that teams may customize to their student's unique needs and include:

SUPPORT	PURPOSE
Take weekly spelling test in separate setting	to allow student to experience sounds through kinesthetic/movement.
Opportunity to pass out class/group materials	to support student's desire to help and be included.
Visual schedule	to lessen anxiety and support memory through student's visual strength.
Shortened in-class assignments	to support some students' ability to complete projects with classmates.
ELA tests presented via computer	to support student's engagement in the testing process.
Teacher provides visual cueing system to student prior to asking direct questions pertaining to the lesson	to support student's readiness and focus.

BUILDING ON SUCCESS : SPOTLIGHT ON HOME APPLICATION

Generalization of scaffolds on the home-front is more readily accessible when IEP supports are operationalized. Parents have an easy reference to accommodations or modifications and the purpose of those supports, in order to guide their child's learning activities. Students thrive on authentic parental praise and continued learning opportunities as they build their engagement as a learner. As IEP team members, parents are able to gain better understanding of their child's needs, strengths, and progress they are making with their individual IEP goals. When students complete class projects or homework with parents, this gives parents opportunity to offer praise for their efforts, neatness, correctness and creativity.

GETTING ENGAGED

Extending learning opportunities through virtual or real time explorations with family are brilliant ways to inspire engagement while learning.

GRAND OPPORTUNITIES

Involving grandparents in extended learning journeys can add more sparkle and zest to your child's engagement, especially those activities that highlight the grandparents' specific expertise or interest.

MAKING HOMEWORK WORK

Homework is better supported when parents have a ready list of supports. Student's self-management skills are fine-tuned and internalized through the practice of using supports at home, during homework time. Through practice and generalization of IEP supports across the learning of environments of home and school, students are provided the opportunities and benefits of practice, internalization, and self-advocating for their supports in a variety of learning environments with confidence. Further, students become the leaders of their current and future supports, through self-knowledge about how they learn. Additionally, the collaboration of monitoring the progression and need for continued support is easily communicated through the duration of the IEP, and within the next IEP meeting.

Consider one or more of these additional tips relative to facility with implementation in the classroom(s):

- *Systematize. Creating or following an agenda for the IEP meeting creates a clear set of topics and time frames, as well as encouraging participation and keeping the discussion on track. The agenda assists team members in determining when and where they plan to share in the discussion, and lessens anxiety relating to the unknown. The meeting facilitator often presents an agenda via whiteboard or hardcopy for the team. Parents or other team members may wish to bring a copy of the previous IEP to the meeting, with areas of discussion points highlighted. This helps provide an informal self-agenda, particularly if a group agenda is not presented.*
- *Organizing the list by categories, such as presentation, social/emotional, etc., can be a helpful approach for all educational caregivers. This menu approach through categorization of purpose, subject matter, or learning modalities, etc.; creates ease of reference and implementation for parents and educators.*
- *Try synthesizing the suggested supports into one, if they are operationalized for the same purpose. Oftentimes teachers, service providers, and parents recommend the same support for the identical purpose, but use different wording. By synthesizing identical supports, a more concise list is possible.*

> ***"Teachers and students who are actively engaged in learning radiate their happiness through smiles and kindness to one another."***

Through mindful consideration of key elements linked to a student's unique learning profile, access to learning is scaffolded in a proactive manner. The educators are provided insight into the student's unique needs and may be possibly extended to students who are not identified as having special needs.

Deepening the learning for all—including students, parents and educators—provides a pathway of ensuring inclusive learning today and beyond. •

ABOUT THE AUTHOR:

Angela Shaw is a writer and retired special educator. With over 25 years in the field of public education, Angela synthesizes her diverse teaching experiences and education to support and encourage families and educators as they navigate the diverse learning needs of the children in their care across a changing educational landscape.

Advance Payments of the 2021 Child Tax Credit

THE BASICS

WHAT?

For tax year 2021, families claiming the Child Tax Credit will receive:

- Up to $3,000 per qualifying child between the ages of 6 and 17 at the end of 2021
- Up to $3,600 per qualifying child under age 6 at the end of 2021

The total of the advance payments will be up to 50 percent of the Child Tax Credit.

WHO?

The maximum credit is available to taxpayers with a modified adjusted gross income of:

- $75,000 or less for single filers and married persons filing separate returns,
- $112,500 or less for heads of household, and
- $150,000 or less for married couples filing a joint return and qualifying widows and widowers.

Eligible taxpayers don't need to take any action now other than to file their 2020 tax return if they haven't done so. Taxpayers can benefit from the credit even if they don't have earned income or don't owe any income taxes.

WHEN?

Advance payments of the 2021 Child Tax Credit will be made monthly from July 15 through December 15 to eligible taxpayers who have a main home in the United States for more than half the year.

HOW?

- Advance payments will be calculated and paid automatically.
- Eligible taxpayers who don't want to receive advance payment of the 2021 Child Tax Credit can unenroll from payments.
- Eligible taxpayers who don't normally file a tax return can register for the monthly advance payments using the **Non-filer Sign-up Tool**.

Visit **IRS.gov/childtaxcredit2021** for more information and to access the online tools.

Publication 5534-B (6-2021) Catalog Number 38828A Department of the Treasury **Internal Revenue Service** www.irs.gov

EP LOOKS BACK: SEPTEMBER 2002

TWINS TRANSITION AND LEAVE BEHIND A CHANGED SCHOOL SYSTEM IN THEIR WAKE

By Laura Apel

Alba and Anastasia Somoza will be two of the thousands of freshmen entering the college graduating class of 2006, but this achievement did not come easily for them, their family, or the New York City Board of Education.

The twin girls were both born with quadriplegia cerebral palsy, and because of this no one expected them even to earn a high school diploma. However, this past June the girls graduated as honor roll students from Manhattan's "School of the Future." Now they head off to two of the country's top colleges: Alba to Queens College in New York City and Anastasia to Georgetown University in Washington, DC.

> In a nationolly televised town hall meeting that year, Anastasia Somoza appealed to then-president Bill Clinton as well as the New York City school system, asking that she, as well as her sister Alba (the more severely disabled of the two), be allowed to learn in regular classes.

Many parents of children with disabilities spend a great deal of time considering the academic options for their children after high school. More and more parents and students are utilizing schools that are solely devoted to those with learning and physical disabilities, but many families neglect to consider the possibility that their children will be able to live and thrive at a regular four-year college or university.

Every situation is unique to a particular student and family, but Alba and Anastasia have proven that just because something appears to be beyond their capabilities does not meant that it truly is, but instead that it has simply not yet been tested. They have faced a challenge at each level of their academic lives so far and come away among the top students entering college this year, proving that they have deserved every success they have accumulated.

EP Magazine has already chronicled the Somoza family's many hardships and battles to receive proper treatment within the public school system and the medical community (May, 1996). Now, six years later, Alba and Anastasia have proven that it was worth the effort.

Alba and Anastasia's mother, Mary, began her battle with the New York City school system in 1993, asking for the inclusion of her daughters into the mainstream program at P.S. 234. In a nationally televised town hall meeting that year, Anastasia Somoza appealed to then-president Bill Clinton as well as the New York City school system, asking that she, as well as her sister Alba (the more severely disabled of the two), be allowed to learn in regular classes.

The Somoza family succeeded in their quest and the girls were mainstreamed, making Alba the first significantly disabled student to be fully integrated into the New York City Public Schools. The

Filled with a number of different emotions ranging from excitement to intimidation, the girls and their family are looking forward to the new adventure ...

girls faced another challenge three years later when Mary found that she now needed to struggle in order to send her daughters to District 2's "School of the Future" junior high school in 1996.

Mary saw the technologically advanced, junior high/high school as the ideal place for her daughters, especially Alba, as she is dependent on a computer for her communication. Placement there would also obviate the girls' need for another transition from junior high to high school levels.

The school district estimated that the cost of creating the appropriate facilities for the girls, mainly wheelchair accessibility, would be more than $1.2 million dollars. Somoza found the estimate excessive and began another battle in the name of her daughters' rights. With the help of the Eastern Paralyzed Veterans' Association and the New York City Lawyers in the Public Interest, Mary prepared her own report. This finding put the cost at $15,000.

The report forced the school administration to back down, and the girls were enrolled at the "School of the Future." There, they experienced many academic successes but are nevertheless eagerly anticipating their transition to college. Filled with a number of different emotions ranging from excitement to intimidation, the girls and their family are looking forward to the new adventure but feel, as Mary Somoza explained, that it is nevertheless "a daunting time."

Top: Anastasia making her way in her graduation procession.

Above: Anastasia and Alba proudly converse with former president Bill Clinton.

TWINS TRANSITION

Both girls have begun their studies at their respective schools, as they have each taken part in summer programs and events. Alba will commute to Queens College from her family's home in New York City. She is currently making arrangements with the school's disability coordinator to accommodate her needs, which Mary Samoza will no doubt ensure are met. Alba is undeclared as to her major at this time but may pursue her interest in art as her study there progresses.

Anastasia also began her activities at Georgetown University this summer, but will move down permanently this fall with an aide. Also undeclared as of yet, Anastasia has expressed an interest in political science and may concentrate on it as her major in the future. Alba, Anastasia, their mother Mary, father Gerardo, older brother Oliver and younger sister Gabriella are excited and concerned for the twins as they leave their home for the first time, transition to new schools, and face life apart from one another – something they have never before experienced. Their collective hopes for this new adjustment are that the girls will find in their college educations all that every other incoming freshman has the opportunity to experience. Although the twins succeeded academically at the high school level, the social aspect of their time there was far less fulfilling. Mary's desire for her two daughters is that they will find the open-mindedness and tolerance in their peers at college that are so often absent from the thoughts of the average high school student. All she wants for her daughters, all she has ever wanted for them, is for them to be given the opportunity to have access to everything that others have received so freely.

All mothers are apprehensive about sending their children to college and being away from them for the first time. Because of her daughters' conditions, Mary Samoza is finding these feelings occurring at a much greater level. Nevertheless, her fears were lessened and replaced with another emotion when she called Anastasia during her recent stay at Georgetown. Excited to hear all about her daughter's time there, she was instead answered with the generic college-student-to-mother axiom, "Listen Mom, I have to go now; my friends are waiting. I'll call you later!" •

Excited to hear all about her daughter's time there, she was instead answered with the generic college-student-to-mother axiom, "Listen Mom, I have to go now; my friends are waiting. I'll call you later!"

When determination wins

Mary Samoza described an experience that Anastasia recently had while on a summer nature retreat at Georgetown with some of her classmates. In an attempt to create relationships and bonds among the freshman class, the students took part in exercises including mountain climbing and rope bridges in Virginia.

A quadrapalegic, Anastasia faced the mountain in her wheelchair and informed her peers that she would be waiting at the bottom. To her surpise, her decision was not accepted by her classmates and friends, which included three members of the Division One University's football team. Together, the teammates carried Anastasia and her chair all the way up the mountain. When they reached the top and approached the rope course ahead, those around her realized that this time she would wait behind, as the rope would only allow for one person at a time in single file.

However, Anastasia decided to get up from her chair and walk across the bridge. To help with her balance, which is impeded by the cerebral palsy, the football players guided her, and thirty minutes later she was across and received with a sea of cheering and smiles. The end of the journey came in the form of a rope drop down the mountain in what Anastasia described to her mother as the most "awesome" thing she had ever done. Shortly after the event, the students wrote apout their experiences that day and many chose to comment on Anasatsia, what she had done, and how they were now awakened to how much a person could truly overcome

READERS PLEASE NOTE: OUR WEBSITE IS NOW

WWW.EPMAGAZINE.COM

EP's Innovative New Digital Strategy

Exceptional Parent Magazine is proud to announce the launch of www.epmagazine.com – our all new website which coincides with our expanding role as a leader in the field of special needs publishing and communications.

www.ep-magazine.com now features a bold new design and intuitive site-wide navigation system with improved menu functionality that directs you to the information most relevant to you. It is also fully responsive with mobile devices, making it easy to navigate on a wide range of web browsers and portable devices.

We've introduced a range of new content to the website, including In This Issue that highlights selected content from our latest issue, and From Our Contributors, which features the most recent offerings from regulars such as Genetic Alliance and the AADMD.

Our eNewsletter is the latest innovation in our digital strategy, enabling you to sign up for updates right on the homepage, and access the articles that matter to you each and every week. We also plan to continue adding more video content and product information to provide you with all of the resources you need to care and plan for your loved one with special needs.

We're really proud of the new website and feel it will create the experience you're looking for when you pay us a visit. Check it out here: www.epmagazine.com

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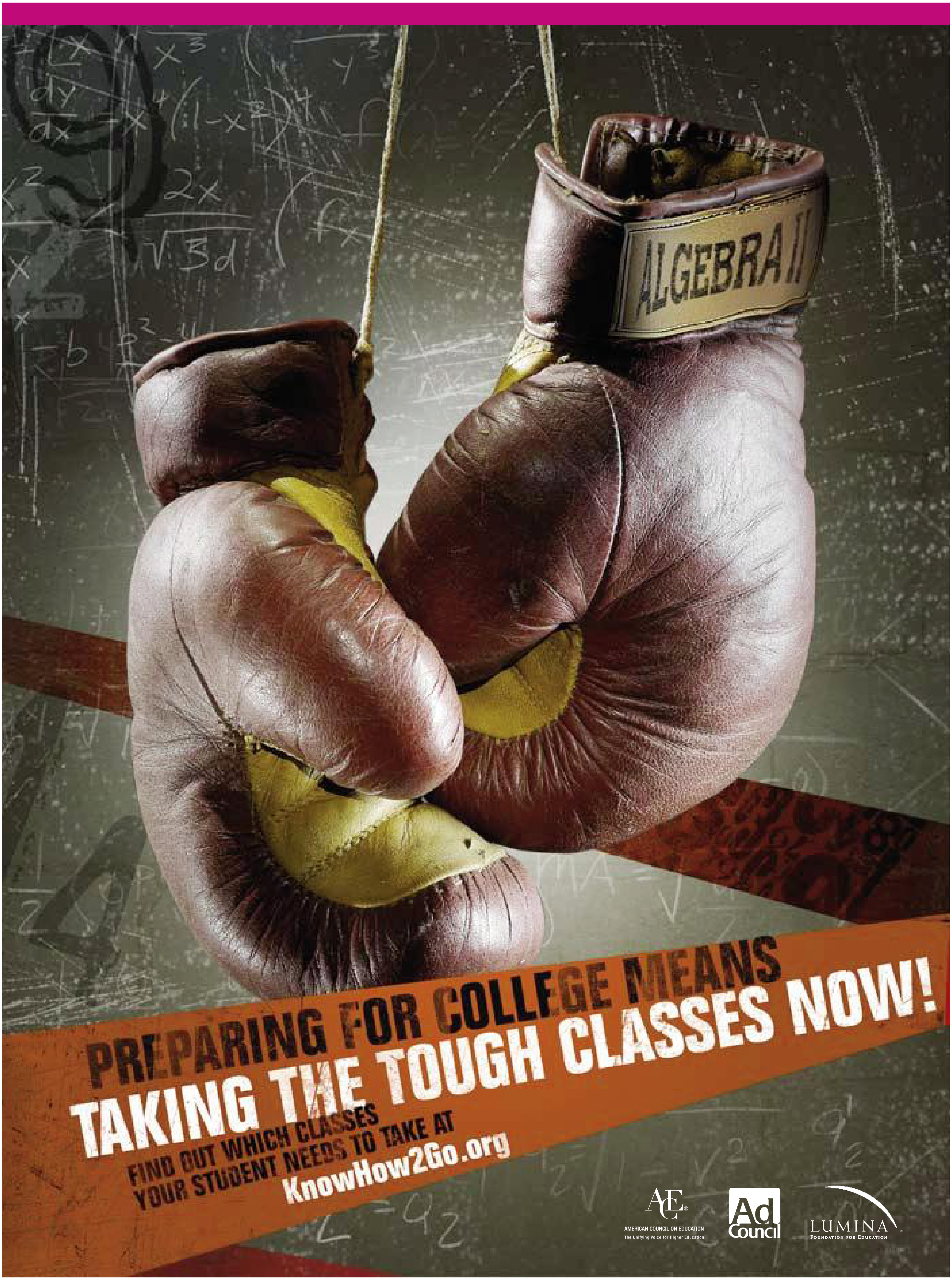

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MY CHILD'S NAME IS NOT LIABILITY

BY LAURA GEORGE

> *"It is my job to disturb the comfortable and comfort the disturbed."*
>
> ~ Steven W. Godby, Honors Professor,
> Broward Community College, 2001

It is nearly 20 years since I heard that statement from my ethics professor on the first day of class, yet it has left a permanent mark on me and how I look at things in life. The statement above is both disturbing and comforting. You, obviously, have chosen to continue reading this article as it relates to the title because of one of two reasons: you are upset by it, or you would like some comfort as a result of some familiarity with it. That said, I ask that you open your mind and place yourself either in the child's or parent's shoes and think of how you feel about the name "Liability" in place of your given birth name. If you are uncomfortable, then I hope that this essay brings you some comfort.

As a society, we have been taught that a human is a non-animal concept with the ability to demonstrate qualities that are unique to being a human, such as intelligence, the ability to speak, demonstrate emotion, and be curious. Based upon the composition of those qualities and other determining factors, society then applies a given term; a name, to describe that human. What many seem to forget is that exceptional children have those qualities too. They, too, are humans with given names. In fact, as loving parents, many of us consider our children to be super humans with super amazing strength.

PERSON FIRST POWER: Many of us consider our exceptional children to be super humans with super amazing strength.

And that is why we cry. Confused? There is so much love for our children because we know every word, sound, smell, touch, and item looked at, that our exceptional child has experienced in climbing over that over the next stage in life. We know how they had to enter life, take their first special steps (talking, walking, etc.), watch as they gave us their first handmade art projects and other momentous events. They accomplished all of that while attending the multitudes of medical appointments, school appointments, and all the while enduring critical and judgmental thinking from everyone they know.

The term liability may have been placed upon your child by people who take care of your child's education, medical care, sports/art/music programs, relatives (or other people), and stated directly to us, because they may have felt that we do not understand the gravity of the situation. We apparently do not understand that our children cannot do the things other children do, and therefore they are no longer human because they can easily become a problem in today's litigious society and cost money to the bottom line.

By applying the term liability to the exceptional child, it is implied that the young human (biologically ours or not) is not a human. In fact, the term liability makes them:

- *A contract for inappropriate behavior,*
- *a legal document to negate a lawsuit,*
- *an expenditure for equipment or technology to include them in mainstream society,*
- *a cost figure to be included in a spreadsheet,*
- *a tool to be used for research and development that needs profitable marketing,*
- *a purchasable product with an allotted risk factor margin for breakage or harm,*
- *a mandated way of life that our exceptional child has to perform or reach, or they will not be rewarded ("We do not like it when our children cannot sit still"),*
- *a pre-measured item of how well they do not behave, versus how well they do behave,*
- *a robot with artificial intelligence devoid of human attributes,*
- *an example of economic prowess.*

Obviously, the list can be much longer, and with more specific examples that have been heard on a regular basis. If you think this list is outlandish, then you have had the good fortune of never experiencing being treated as less than human. But for those of you who have heard these phrases (and more detailed than the generalized list noted above), you have sadly experienced and watched as your exceptional child was reduced in words, from human to non-human.

Even with my own daughter, I have heard the phrase, "Of course your daughter cannot do that! She's a liability!" My response is always the same. "Her name is not Liability!

PHOTO PROVIDED BY LAURA GEORGE

She has a name, and she is human. So what, if she has a disability? She has thoughts, dreams, hopes, and aspirations. I share those with her, hoping that she will be smiling when she makes her mark on the world one day. She deserves to attend school and have the same fun experiences you and I had when we went. She is not a piece of paper. Not only that, she is your blood relative. As adults, we should be embarrassed that we cannot act with courteous manners and kind words, even half as well as she has endured your constant, repetitive negative thoughts to her face while experiencing voice loss and multiple chemical sensitivities. She gets straight A's in school, plays ten or more percussion instruments in the school band, and is published. If she was a liability, how could she accomplish so many wonderful things? This beautiful human before you is not a liability choosing to cause you harm. She is my amazing daughter and is growing up giving light and energy to the world."

Something tells me that you, the reader, could equally or maybe, with more emphasis, replace the above paragraph with one of your own, and it would fit inside this essay just as nicely with just as much if not more finesse.

By labeling the exceptional child with their human name and addressing concerns that might arise, after their name in the sentences, we make a statement to the world. We then state that the being in front of us has thoughts, emotions, intellect, character, and is recognized as a human. While the discussion is simplistic in nature, the "People First Respectful Language Modernization Act of 2006," created in the District of Columbia (https://odr.dc.gov/page/people-first-language) was created to address the need of referring to people with disabilities as humans and not as terminology which, in turn, took away their dehumanization. Basically, it states that the person is to be recognized as a person, and not the medical condition assigned to them. Likewise, we would not say, "Liability" but instead say, "a person who can cause a situation or be held responsibly liable."

Thus, it is important to be advocating for the proper way to address our exceptional children by using their given birth names. It should be recognized that they are a part of us; a part of society, and that they can and should intermingle with the rest of us, equally. So let us publicly shout to the world that our exceptional children are exceptional human beings. We can do this by telling others how:

- *A financial value cannot be put on their worth,*
- *they are beautiful to look at and watch,*
- *they have the capacity to do something great in the world, such as become a sports person, an intellect, a president, an artist, or more,*
- *they are able to provide insight and wisdom into world events when we forget how to find to do it ourselves,*
- *they provide us with a positive mission in life,*
- *they are able to move about in the world independently in the manner that they feel is best and allows them to be at their best,*
- *they have amazing skills, talents, thoughts, and personalities that the world needs,*
- *they motivate us to be better than we are,*
- *they are capable of being leaders and caregivers to take care of us when we will need it (Because they have been through it.),*
- *they loudly demonstrate how miserable our world would be without them in it.*

DUE RESPECT : PERSON FIRST LANGUAGE BASICS

Rather than using labels to define individuals, person first language (PFL) puts the person before the condition or trait. PFL is about respect and dignity and focuses on the person, not the label.

SAY:	INSTEAD OF:
✓ A person with a disability	✗ A special needs child
✓ He is a person with an intellectual disability	✗ He is slow
✓ Maria is a student with Autism	✗ The Autistic girl
✓ Thomas has Down syndrome	✗ Thomas is Downs
✓ She has a learning disability	✗ She is LD or learning disabled
✓ Jade receives special education services	✗ Jade is ESE or in special ed
✓ He has an emotional or behavioral disability	✗ That EBD kid
✓ Lee has developmental delays	✗ Lee is developmentally delayed
✓ She rides in an accessible bus	✗ She rides the handicap bus
✓ He has ADHD	✗ He is ADHD

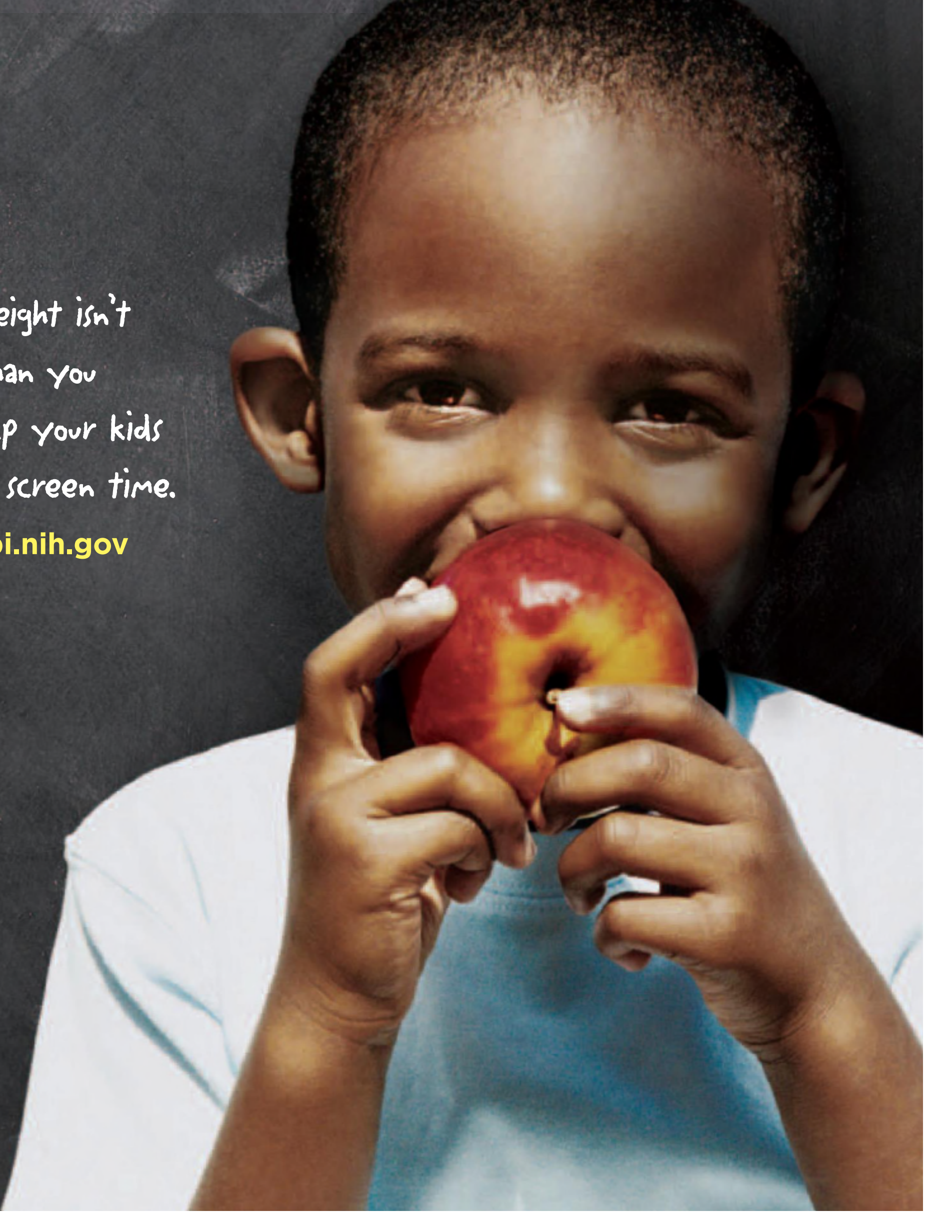
GRAPHIC COURTESY FLORIDAYINCLUSIONNETWORK.COM

Liability is a term incapable of human thought. We have often been told that our exceptional children are a liability, costly, and an inconvenience. Yet, without stopping, we advocate for them endlessly, so they can participate in life on the same level as all other children. We put them in our hearts with immense love. A love that will never end, because they are human, and all humans have the characteristic of independent thought. I may be disturbed that you think my child's name is "Liability" and yet I am comforted because I know that one day, everyone else will agree with me that she is funny, talented, smart, amazing, and will soon make her amazing mark on the world! •

ABOUT THE AUTHOR:

Laura George, EMDL (Emergency Management Disability Liaison) has a long history of providing education and advocacy towards the improvement of emergency preparedness planning of people with disabilities. In addition to being a presenter, she also authored *Emergency Preparedness Plan: A Workbook for Caregivers, People with Disabilities, the Elderly and Others*. She has a Bachelor's

A LESSON FOR RAISING A HEALTHY CHILD



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ADULTHOOD

BY KIMBERLEE MCCAFFERTY

Dear Justin,

My dear boy, you've recently rounded the corner into adulthood, which is still a difficult concept for me to grasp. It was just yesterday that I held you tightly as we danced around to your favorite tunes in your nursery in our little house in northern VA, oblivious to the world. To say there have been ups and downs in your childhood would be the understatement of the century, but I feel in my soul has been mostly good there. You have grown into a loving and predominantly happy adult, and for that I am eternally grateful.

There were months, no years, I thought we'd never get to this place.

Eighteen is a real reckoning, just like 21 will be, years from now. Your dad and I are in the process of acquiring guardianship over you so we can make important decisions on your behalf, and we are wading through the morass of Social Security, the DDD, and Medicaid to make sure you receive all the benefits you are entitled to. Several years from now, we will choose a day program for you, an agency and a coordinator, and eventually a residential placement where you will hopefully live not too far from us.

It's this latter decision that gets me every time.

You see my son, I know in my heart that someday you will live apart from us, that this is a necessary and even a good thing. A few of my friends and I are trying very hard to secure a safe place for you, one where you will have good caregivers and maybe the opportunity to work, and hopefully lots of fun. I know your dad and I have to place you there because, try though I might, I won't live forever, and I certainly don't want my demise to be what precipitates a drastic change in residence for you. No, I'd see you settled earlier rather than later, have the kinks of placement worked out, make sure you're thriving before I depart this world.

One thing before I go, my son – I just desperately wish you could tell me how you feel about all of this.

You see, when I contemplate your future away from your family, there is both a feeling of peace and of guilt that co-exist. I don't know if you'd like to live out your burgeoning adulthood with us, or if you want more independence without us. I can ask you many questions and get the "yes or no nod," but not this question. This is too complex a topic to be able to rely on that subtle shift of your head, and I know I'll never know the answer. To be honest, the hardest part of placing you for me is the worry you won't understand why, that you won't comprehend that your dad and I won't be here forever.

It hurts my heart to think you won't understand.

And yet, I have to remind myself of how many things you've adapted to brilliantly over the years. New teachers, and a new school building. Losing seeing your favorite people for over a year. Not being able to frequent your favorite haunts.

This past year there has been a ton of change for you, and you have conquered it all.

In the end, I know we simply have to continue to move forward. I know I have to do my best to create a continuation of the good life you've had at home and at your school, continue to find things that delight and challenge you in the years to come.

I need to let you go, just a little.

I have to hope the choices I make for you are those you'd want too.

I'll always wish I knew for sure.

I love you. •

ABOUT THE AUTHOR:

Kimberlee Rutan McCafferty, mother to two sons on the autism spectrum and an Autism Family Partner at the Children's Hospital of Philadelphia (CHOP). Kim is also the author of a blog at autismmommytherapist.wordpress.com. Kim's book *Raising Autism: Surviving the Early Years* is on sale on Amazon here.

PHOTO PROVIDED BY KIMBERLEE MCCAFFERTY

HOW VACCINES STRENGTHEN YOUR BABY'S IMMUNE SYSTEM

Your child is exposed to thousands of germs every day in his environment.

This happens through the food he eats, air he breathes and things he puts in his mouth.

Babies are born with immune systems that can fight most germs, but there are some deadly diseases they can't handle.

That's why they need vaccines to strengthen their immune system.

Vaccines use very small amounts of antigens to help your child's immune system recognize and learn to fight serious diseases.

Antigens are parts of germs that cause the body's immune system to go to work.

30 YEARS AGO
vaccines used
3,000 antigens
to protect against
8 diseases
by age two

TODAY
vaccines use
305 antigens
to protect against
14 diseases
by age two

Thanks to scientific advances, today's vaccines can protect children from more diseases using fewer antigens.

Vaccines contain only a tiny fraction of the antigens that babies encounter in their environment every day.

Vaccines help strengthen your baby's immune system and keep him safe from vaccine-preventable diseases.

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NCIRDig603 | 02/06/20

The generous spirit at the heart of GSF and the positive impact of making healthy smiles possible for patients born with cleft goes far beyond one individual, or even one family, to reach larger communities.

THE POWER OF A HEALTHY SMILE

FROM THE GLOBAL SMILE FOUNDATION

Diana Ramirez knew that her infant son, Sebastian, needed special help and attention. He was born with a cleft lip and a cleft palate, and she was worried about the subsequent health complications that he would suffer if not given the appropriate care. Like so many parents in the developing world, Diana and her husband Javier live in a distant area of Ecuador with limited access to healthcare and virtually nonexistent cleft care.

Even though cleft is one of the most common birth defects in the world, affecting an estimated 1 in every 700 babies born in developing countries, providers in remote areas are often unfamiliar with the condition and are unable to assist parents with the specialized care their babies require.

Diana and Javier were committed to finding much-needed help for their son. When Sebastian was three months old, they traveled five hours to Dr. Roberto Gilbert Children's Hospital in Guayaquil, Ecuador to meet the Global Smile Foundation (GSF) team. Unfortunately, they arrived on the last day of the outreach program. Volunteers had already packed up their supplies in preparation to head back to their home countries. The hospital operating rooms were also shut down by the time Sebastian's family had arrived.

Diana had learned about cleft surgery, and she insisted on talking to the GSF team about her son's care. Diana's determination was so emotionally touching and heartwarming that the GSF team relented to her request to evaluate her son. After examining Sebastian, the team reported that he was clear to undergo surgery and unpacked their bags to proceed with the operation.

"You could see it on her face," said Dr. Usama Hamdan, President and Co-Founder of GSF, recalling the moments of that day, "She was so distraught and worried for her son. We knew we had to help him."

In the decade that followed, Sebastian continued to receive comprehensive cleft care, including repair of his cleft lip, repair of his cleft palate, dental treatment, and speech therapy among other services. At every step along the way, Sebastian was under exclusive care of the GSF team, comprised of volunteer medical experts who specialize in cleft care, including surgeons, dentists, pediatricians, anesthesiologists, nurses, speech therapists, and child psychologists. Sebastian and other patients who come to GSF receive long-term care from an interdisciplinary team of

PHOTOS PROVIDED BY LISA CRIST

SMILING THROUGH: *(Opposite page)* Sebastian in 2020; *(Above)* Sebastian with mother Diana in 2008, and with Peri-Op Nurse and caregiver Jeanne Paolilli in 2020.

cleft specialists – the kind of care that is standard in developed the United States. GSF firmly believes that all patients deserve the best quality cleft care regardless of geographic, religious, or socioeconomic factors.

Ever since that first meeting, Sebastian's family has been part of the GSF family, and they have expressed their appreciation to the team for providing life-changing cleft care for their son. Sebastian has indeed grown up with GSF. He and his family have returned to the outreach mission site every year to see the team without fail, bringing Sebastian's two younger sisters, born in 2011 and 2013. Javier has spoken to the team to share his appreciation and experience. They also keep in touch by email and send photos of all three children at birthdays and other important life milestones.

Relationships such as the one between Sebastian's family and GSF make it easy to see why volunteers are so dedicated to GSF's mission. Treating cleft involves a range of care throughout a patient's childhood, so GSF returns to the same locations every year to support its patients. This continuity is part of what makes the GSF family so special and why they have maintained relationships with patients and families longer than any other NGO doing similar work. Dr. Hamdan and other founding members have been involved in outreach cleft care in the country for more than 34 years.

Even as GSF's work in Ecuador has expanded, the spirit of connectedness and bonding among team members, volunteers, and patients has remained strong. As more and more patients learned about GSF and the free comprehensive cleft care that their volunteers help provide, GSF decided to open a Cleft Center to provide year-round care for patients. The Center is located at Hospital León Becerra, a facility dedicated to pediatric care for children and families of low socioeconomic status. In 2012, GSF established Fundación Global Smile-Ecuador to run the Cleft Center and advance the GSF vision for sustainable cleft care in the country.

Many former GSF patients have become volunteers with Fundación Global Smile-Ecuador and provide critical support such as patient communications, public relations, and logistical help during outreach programs. One volunteer in particular, Diego De La S, became a mentor and friend to Sebastian.

Diego and Sebastian met in 2016. Diego had undergone his first surgery as an infant in 1996 with some of GSF's founding members and could talk to young patients and their families about his own experience. At age 20, Diego was nearing the end of his cleft care treatment. He met Javier and Sebastian and formed an instant friendship with the family.

“We always greet each other with hugs. I used to carry Sebastian around, but he’s too big for that now,” Diego says fondly. He remembers that Sebastian had always wanted to help during the outreach program, but he was too young. Diego often volunteered as a photographer with Fundación Global Smile-Ecuador and included Sebastian when he could.

In 2020, Sebastian finally got his chance to help during a mission and was Fundación Global Smile-Ecuador’s youngest volunteer. He worked with Jeanne Paolilli, who has volunteered as a Peri-Op Nurse with GSF for close to 10 years and had been one of Sebastian’s caregivers in the past. Sebastian helped Jeanne make ID bands for patients and assisted her as she prepared patients for surgery. Jeanne said that Sebastian was very helpful to her, “He figured out very quickly what I was doing and anticipated what I needed.”

She continued, “Sebastian is amazingly kind to our patients. He was very willing to share his experiences about having cleft lip and palate. He also spoke with the parents to make them more comfortable about their children’s care.”

Like Jeanne, many GSF volunteers return to the same locations year after year and say that watching patients grow up is one of the most special rewards of participating in GSF outreach programs.


KINDNESS IN ACTION: Sebastian with mentor and friend Diego De La S; Both have started a new cycle of “paying it forward” to future GSF patients.

Sebastian’s desire to assist GSF’s work follows the path of many former patients in Ecuador who have returned as volunteers. Just like Diego and many others, Sebastian has started a new cycle of “paying it forward” to future GSF patients. This generous spirit is at the heart of GSF and the positive impact of making healthy smiles possible for patients born with cleft goes far beyond one individual, or even one family, to reach larger communities.

Denise Franco Mera, President of Fundación Global Smile-Ecuador, accurately described the feeling of being part of the GSF family when she said, “It’s not what fills your pockets. It’s what fills your heart.”

And there are many hearts around the world that have been filled by the remarkable power of healthy smiles made possible by the GSF family. •

GSF relies on support from corporations, private foundations, and individuals to accomplish its mission. More information can be found at **www.gsmile.org**

FACING ADVERSITY : SEBASTIAN AND THE GSF

Sebastian began giving to others at the young age of eight. In 2016, a 7.8 magnitude earthquake hit the Manabí Province in Ecuador where Sebastian’s family lives. The damage was widespread, destroying homes and buildings for hundreds of miles, causing more than 676 deaths and 16,600 injuries. Nearly 100,000 people were left homeless.

NGOs and local groups approached GSF and Fundación Global Smile-Ecuador to help, not only because so many of their patients are from the Manabí Province, but also because they were well-known and trusted organizations. Javier approached Fundación Global Smile-Ecuador to help distribute donated goods because it was difficult to reach people who urgently needed help.

As soon as Sebastian learned about what his father was doing, he asked if he could help, “Just like GSF helped me,” he said. In total, GSF and Fundación Global Smile-Ecuador distributed more than 150 tons of food, water, and medications. They also helped build 25 homes for displaced families.

Global Smile Foundation is an NGO based in Norwood, MA whose mission is to provide comprehensive cleft care for patients in underserved areas throughout the world and to build global capacity for cleft care though empowerment and sustainability initiatives. In developing countries, the consequences of untreated cleft lip and palate are devastating, yet access to specialized care is extremely limited. GSF believes that every child born with cleft deserves the chance for a healthy smile – and a healthy life – regardless of geographic or socioeconomic barriers.

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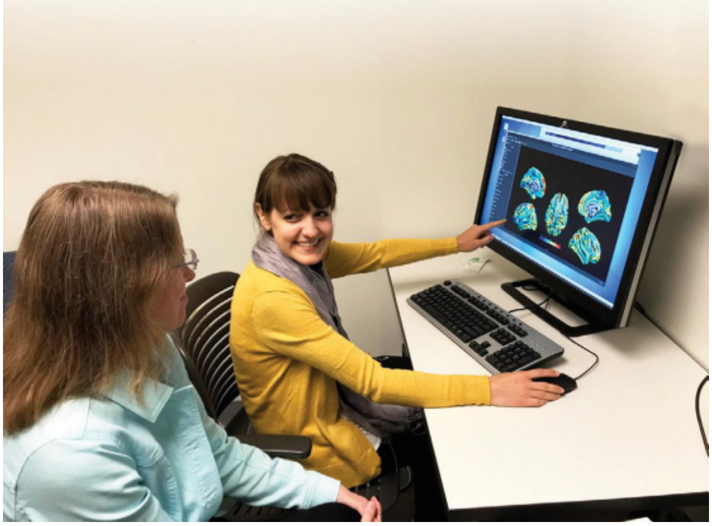

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IES Brain Research Foundation thanks everyone who has participated & donated and wishes everyone a safe 2021.

I CAN'T BREATHE

SHINING A LIGHT ON AUTISM AND XENOPHOBIA

BY AMANDA HARRINAUTH

I am an autistic female who identifies as Black and Indian. Biracial, some might say. Race relations have always been showcased in the media, however, after the passing of George Floyd, it opened Pandora's box to what racism really is.

And now, it's not enough to just have autism for if you're of color, that's an added stressor in America.

I participated in one protest in my life; it was a faith-based protest when we took a knee for fallen lives. It helped to make me more aware of my role in society. As a disability rights activist, I thought I was doing well by bringing light to the discrimination facing those with autism, Down syndrome cerebral palsy, and other conditions.

Then, I was challenged as a life coach by the editor in chief of Worldwide Coaching Magazine. I was asked to write a poem dealing with grief and loss. My response to his challenge was "I Can't Breathe."

Entitling that poem, those words stuck out in my head greatly.

Let's think about those words "I can't breathe."

Myself, as someone who struggled to breathe on her own due to premature birth – I was actually placed on a ventilator – I can't imagine that right forcefully being taken away from me.

What worries me is that so many of us on the autism spectrum are loving individuals. Many of us are afraid of loud noises, especially if we are being yelled at to do something or we see someone in a uniform. That could be quite intimidating.

One solution that I am thankful for is the Special Olympics partnering with law-enforcement.

Special Olympics athletes will actually receive their medals and awards from police officers.

I think that's one strategy to making the gap between law-enforcement and those with special needs even smaller.

"An Asian invasion and human rights and human dignity" is a line in one of my latest poems just written. The poem is entitled "Black and Asian hands." The poem was written just a week ago.

My father is a native from Trinidad, my dad and his family are immigrants. Growing up he and his siblings would play soccer (referred to as football in Trinidad) with a grapefruit. He came to this country at the age of 10 on November 20th 1969.

My dad had a heavy Trinidadian accent, sometimes he came to school smelling of curry and other traditional Indian spices. The American students would mock him for not having an understanding of American sports such as baseball and other American customs.

My parents met in 1983, and they were married the following year. A few years later they would welcome my older sister into the world, and then 19 months later in 1989, I was born.

Hearing the perspective from both of my parents, my mom providing the African-American perspective, and my father providing the Asian perspective, I knew from a young age that I was different, racially, and would encounter some hardships due to also being disabled. My parents raised two strong daughters. My sister Ashley is finishing up her doctorate in clinical psychology, and I became a writer.

And as I always say, with God, anything is possible. We were placed on this earth to do his work and his will.

ABOUT THE AUTHOR:

Amanda Harrinauth is a proud Special Olympics (S.O.) Athlete in Northern California. She has been competing in Bocce ball and Bowling and has enjoyed writing for five years. Her passion is to bring joy to a broken world and help advocate for inclusive health. As a S.O. Health Messenger, she encourages health to the Athletes and the community about disparity of care. Amanda grew up in the Bay Area and is looking forward to sharing her writing with the world.

#CelebrateDifferences

WHAT IS AUTISM?

Autism is a complex, lifelong developmental disability that typically appears during early childhood and can impact a person's...

RELATIONSHIPS SELF-REGULATION COMMUNICATION SOCIAL SKILLS

While there is currently no known single cause of autism, early diagnosis helps a person receive the support and services that they need, which can lead to a quality life filled with opportunity.

With nearly 1 in 54 Americans affected by autism, it's likely you know someone who loves someone with autism.

Awareness promotes acceptance and change, get to know the basics about autism...

AUTISM AWARENESS SIGNS

- Repetitive behaviors, movements, or phrases
- Lack of response to normal stimuli
  (i.e. his/her name, visual cues)
- Atypical verbal communication or non-speaking
- Difficulty understanding or expressing feelings
- Avoiding eye contact

AWARENESS TO ACCEPTANCE

The Autism Society is dedicated to improving the quality of life for every person affected by autism, and we create opportunities by building a more inclusive world.

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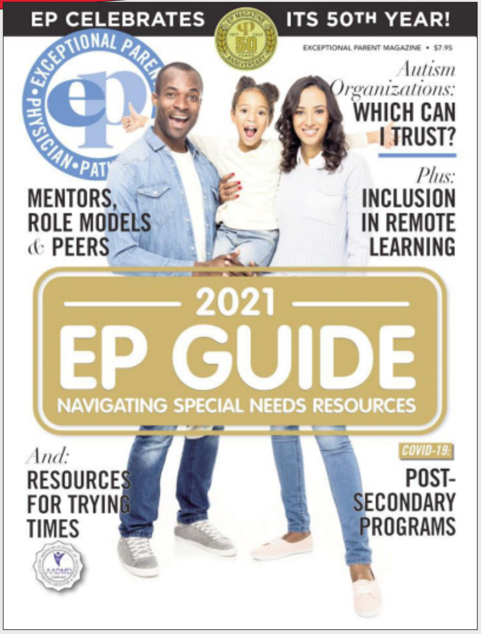

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PART IV: EP MAGAZINE SLEEP SERIES

INSOMNIA IN AUTISM AND RELATED DISABILITIES

BY BETH MALOW, MD, MS

Sleep is an important part of our health and well-being. We all know how our emotions can spiral out of control when we aren't sleeping well. We are prone to pounce on our friends, or send that email we will regret later. Individuals on the autism spectrum, and other disabilities, struggle with regulating emotions, and their struggles can be amplified by poor sleep. The good news is that sleep problems are easily treatable in autism and related disabilities. In this article, we will discuss a common sleep problem, insomnia, and understand its causes and treatments.

AN EP SPECIAL SLEEP SERIES PART IV

Autism is a common disability, affecting as many as 1 in 54 children. With more than 50,000 children on the autism spectrum turning 18 each year, we are looking at more than 500,000 autistic individuals entering adulthood over the next decade. Sleep affects 50-80% of those with autism and is the most common co-occurring condition that parents report to their child's healthcare provider. Insomnia, which has been defined as difficulty falling asleep, staying asleep, poor sleep quality, or short sleep duration, is the most common sleep problem within autism. As we will discuss in a future article, sleep affects health and well-being, in both the individual and family.

Causes of insomnia in autism and related disabilities can be placed into three simple buckets—medical, behavioral, and biological. The medical bucket includes other sleep disorders such as obstructive sleep apnea, which can affect both children and adults, especially those carrying excessive weight. Add restless legs syndrome, and psychiatric conditions such as attention deficit hyperactivity disorder, anxiety, and depression, all of which can affect sleep. Medical conditions such as seizures, gastrointestinal problems, pain, and eczema can also interfere with falling asleep or contribute to night wakings. Low or low normal ferritin (iron stores) levels below 50 ng/ml can cause restless legs, leg kicks, or restless sleep, and iron supplements can help. Medications to treat a variety of conditions, including antidepressants and stimulants, can make it harder to fall asleep. The good news is that many of these medical conditions are treatable and addressing them can restore restful sleep.

> **IT IS HELPFUL TO VIEW INSOMNIA AS A CONDITION THAT IS NOT "ONE SIZE FITS ALL" BUT INSTEAD SELECT TREATMENTS THAT MEET THE NEEDS OF THE CHILD AND FAMILY, WHILE ALWAYS SEARCHING FOR A POSSIBLE MEDICAL OR BIOLOGICAL CAUSE OR CONTRIBUTOR.**

The behavioral bucket touches upon aspects of good sleep habits, also referred to as sleep hygiene. These include not only what happens at bedtime, but what occurs throughout the entire day. For example, getting enough light in the morning can actually make it easier to fall asleep at night, as any of us who have traveled overseas can attest to. Physical exercise has a similar effect on promoting sleep, although exercise too close to bedtime may keep us up. Limiting drinks with caffeine, including sodas, tea, and chocolate milk, can promote sleep. Screens—whether from video games, phones, laptops, or televisions—can keep us awake through the stimulating "blue" light they emit, the content they provide, or both. Even the timing of when we go to bed can make a difference, with teens who have gone through puberty finding they require later bedtimes (our brains release melatonin two hours later, on average, after puberty). In those with sensory sensitivities, the level of noises and light can affect sleep at bedtime. The firm pressure of a weighted blanket can be comforting and sleep-producing.

Bedtime routines, including visual schedules with photos or line drawings, in those with limited language, and checklists in those with more advanced language, can be very helpful. We also have found that simple visual aids, such as a stop sign on a child's door to remind them to go "back to bed," coupled with bells or something else on the door to alert the parents to their awakening, can be very helpful. A bedtime pass is a small card (that may include a picture of the child's favorite animal or cartoon character) that encourages children to stay in bed and "exchange" their pass in the morning for a reward. Parents can also be taught strategies to comfort their children while minimizing interactions that stimulate them.

The biological bucket includes areas such as being overly arousable, having difficulty with processing melatonin, or having the genes for poor sleep. Many parents report that their children "can't turn their brains off." Overarousal, or hyperarousal, can tie together anxiety, insomnia, or being more sensitive to sensory stimuli in the environment. A vicious circle can be set up, with insomnia at night leading to more behavioral problems during the day, and then more insomnia at night. Daytime stressors can make everything worse, and result in increased levels of cortisol at night. Even when asleep, children on the autism spectrum have exhibited elevated heart rates, a sign of overarousal. Medications can often help with overarousal, but behavioral approaches (see above) can be helpful as well.

Melatonin, referred to as the "hormone of darkness," is released at night, with its production suppressed during the daylight hours. In addition to promoting sleep and synchronizing our biological clocks, it may act to decrease anxiety and decrease overarousal. Some studies have shown that melatonin is deficient in children or adults on the autism spectrum. Other studies have documented normal melatonin levels but have shown that melatonin supplements can promote sleep. Genes that regulate melatonin production or breakdown are altered in autism and other psychiatric conditions.

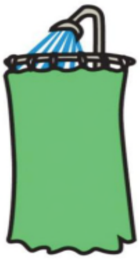
While insomnia is very treatable in many on the autism spectrum, or with related disabilities, we are still learning the best ways to provide treatment to children, teens and adults. While many benefit from working with a trained psychologist or therapist, there are some parents who can learn these strategies on their own. Older children and adults may also benefit from formal CBTI (cognitive-behavioral therapy for insomnia) but may also be successful with "do-it-yourself" strategies *(see resources at end of article)*. It is helpful to view insomnia as a condition that is not "one size fits all" but instead select treatments that meet the needs of the child and family, while always searching for a possible medical or biological cause or contributor.

Behavioral treatments should be considered the "first-line treatment" for insomnia, given that they often help many children and do not have the side effects of medications. However, some children require supplemental melatonin or prescription medications to fall asleep or stay asleep. These should be used sparingly – to promote behavioral strategies rather than substitute for them. Whenever possible, work with the healthcare provider to use a medication that will treat a co-occurring condition such as epilepsy, anxiety, or depression. Starting at low doses can avoid excess sedation and other side effects. It is important to avoid adding more medications to those that aren't working but instead substitute new medications for those that aren't working. More studies of medication effectiveness for sleep, and side effects are needed, in real world settings that collect data from people with autism and related disabilities, and their families. •

HABIT FORMING : STRATEGIES FOR AUTISM AND RELATED DISABILITIES SLEEP PROBLEMS

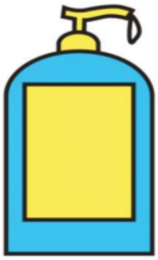
Bedtime routines that include visual schedules with photos or line drawings, such as the examples below, can be helpful for those with limited language. Checklists can be very helpful for those with more advanced language.

Take a shower



Wash hair

Lotion



Put on pajamas

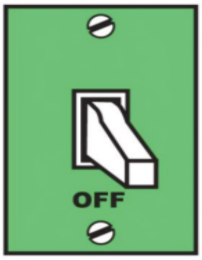
Brush teeth

Get a drink

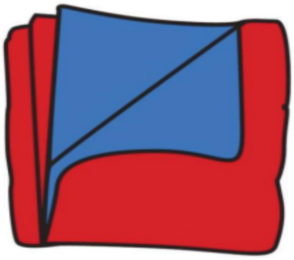
Go to the bathroom

Hug & kiss goodnight

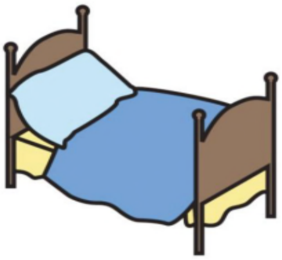
Lights off



Weighted blanket



Go to bed



Go to sleep

ABOUT THE AUTHOR:

Beth Malow, MD, MS is Burry Chair of Cognitive Childhood Development and Professor of Neurology and Pediatrics at Vanderbilt University Medical Center.

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“It has been an extraordinary privilege and joy to work, as a volunteer, with and on behalf of persons with special needs, over the last several decades. They and their families have taught me so much, and the bonds of friendship and mutual respect formed are enduring. The world would be so much better off if it appreciated their contributions – and so we must keep working toward that end.”

~ – Bill Alford, EP 2021 Advocate Hero

CONGRATULATIONS AND THANK YOU, EP MAGAZINE ADVOCATE HEROES!

50 FOR 50

50 YEARS OF EP • 50 ADVOCATE HEROES • PART IV OF A SERIES

EP *Magazine*, formerly called *Exceptional Parent,* is celebrating its 50th anniversary of providing an award-winning forum for the disability community. With the recognition that it’s the advocates who have provided the landmark events in the disability rights movement, *EP* is proud to honor 50 Advocate Heroes and showcase their extraordinary work and achievements in the following pages. While we have all had the opportunity to learn from those giants and pioneers that came before us, we are honoring living advocates.

Although it's safe to say that every parent of a child with complex disabilities is indeed an advocate, many of them have also distinguished themselves in advocating in a larger arena. Many of our showcased advocate heroes started out as parents, exceptional parents for sure. They combined their efforts in becoming teachers, therapists, counselors, lawyers, healthcare providers, researchers and activists. This special brand of advocates – along with all the others we honor – will always have a unique place in the disability movement, not only for what they have done, but also for those they have inspired.

On behalf of *EP Magazine*, its Editors, the EP Editorial Advisory Board, and a group of our peers in the disability field, we congratulate and thank our 50 Advocate Heroes for their tireless work in support of the special needs community.

WILLIAM P. (BILL) ALFORD, MA, JD

“It has been an extraordinary privilege and joy to work, as a volunteer, with and on behalf of persons with special needs, over the last several decades. They and their families have taught me so much and the bonds of friendship and mutual respect formed are enduring. The world would be so much better off if it appreciated their contributions – and so we must keep working toward that end.”

William P. (Bill) Alford, MA, JD, is the founding Chair of the Harvard Law School Project on Disability, which since 2004, has worked, on a pro bono basis, on disability law and policy in China, Bangladesh, the Philippines, Vietnam, the United States and several other nations. He has also long been involved with Special Olympics International (which serves individuals with intellectual disabilities in more than 180 nations), having first been elected to its board in 2005, and now serves as Lead Director and Chair of the Executive Committee of the board. In 2008, Special Olympics honored him for his work for persons with intellectual disabilities in China.

INTERNATIONAL REACH: “People with special needs and their families have taught me so much over the last several decades.”

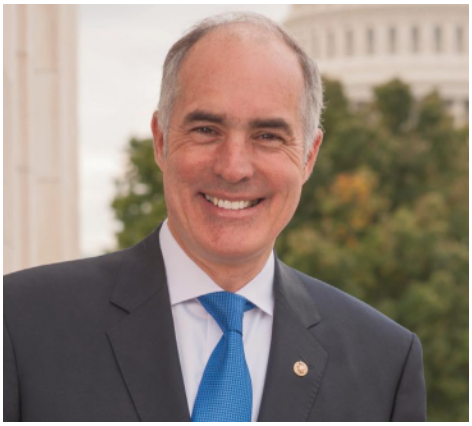
Mr. Alford is a graduate of Amherst College (B.A. magna cum laude), the University of Cambridge (LL.B.), Yale University (M.A. in History and M.A. in Chinese Studies) and Harvard Law School (J.D.). He was awarded an honorary doctorate in law by the University of Geneva in 2010, has been an honorary professor at Renmin University of China and Zhejiang University – and was a recipient of the Li Buyun Prize of the Shanghai Institute of Finance and Law in 2018; the American Society of International Law Certificate of Merit for the Best Specialized Work in International Law in 2020; and a National Order of Merit from the President of Ecuador in 2021 for his work on disability.

ROBERT PATRICK (BOB) CASEY, JD, U.S. SENATOR

"The Americans with Disabilities Act affirmed the rights of people with disabilities: to be included in all aspects of American society, to be economically self-sufficient, to live independently, and to have an equal opportunity to pursue one's dreams.

But a declaration of rights without resources isn't enough. We must put in place the services and support for people with disabilities to exercise those rights. That means tearing down barriers to economic success like I did when I worked to pass the ABLE Act, which makes it possible for people to save for the future and not risk losing their federal disability benefits. It also means fighting to bolster home-based services during a pandemic so that people with disabilities aren't forced to live in congregate settings where they are more likely to be exposed to COVID.

In my role as senior U.S. Senator from Pennsylvania, I will always support the rights of people with disabilities and fight to ensure they have the resources necessary to make those rights a reality."



FIGHTING FOR FAMILIES: "I will always fight to ensure people with disabilities have the resources necessary to make their rights a reality."

United States Senator Robert Patrick (Bob) Casey, Jr. fights every day for Pennsylvania families. He is a strong advocate for policies that improve the health care and early learning of children and policies that will raise wages for the middle class. Senator Casey serves on four committees including the Senate Finance Committee, Senate HELP Committee and Senate Select Committee on Intelligence. He is also the Chairman of the Special Committee on Aging, where his agenda is focused on policies that support seniors and individuals with disabilities.

Senator Casey and his wife, Terese, live in Scranton and have four adult daughters.

GERALDINE (GERRI) COLLINS-BRIDE, RN, MS, ANP-BC, FAAN

LUCY CRAIN, MD, MPH, FAAP

"Advocacy for people with special needs has been the focus of my career as a primary care clinician and educator. Very early in my graduate nurse practitioner training, I discovered the massive health inequities of people with developmental and psychiatric disabilities, both in the healthcare delivery system and in our educational training programs. It has been, and continues to be my mission to advocate for inclusion, quality and equity of healthcare for this population through mentoring, teaching and practice. Advocacy is a necessary and powerful tool for promoting change." (Gerri Collins-Bride)

Gerri Collins-Bride, RN, MS, ANP-BC, FAAN, is an adult nurse practitioner and Professor Emeritus in the University of California, San Francisco (UCSF) School of Nursing where she is the Co-director of the Adult Gerontology Primary Care Nurse Practitioner program. For over 35 years she has been practicing in General Internal Medicine at UCSF as a primary care provider for adults with developmental and psychiatric disabilities.

Ms. Collins-Bride is a founding member of the Redwood Coast Regional Center Telemedicine "TACT" team and for the past 20 years, has co-ed the annual CME course on "Developmental Disabilities: An Update for Health Professionals" with her partner and treasured colleague, Dr. Lucy Crain.

"As a pediatrician with a university-based primary care practice which welcomed children and youth with disabilities, I found the majority of my medical and pediatric colleagues inadequately informed about current diagnostic and resource needs of their patients with disabilities. It became my mission, in practice and after retirement, to advocate for children and adults with disabilities and special needs and to fill in the gaps of pediatric training by providing continuing medical education (CME) of healthcare clinicians with an annual CME conference, now approaching its 21st year: Developmental Disabilities: Update for Health Professionals. The success of our interdisciplinary conference would not have been possible were it not for a terrific co-chair (Gerri Collins-Bride, UCSF Adult Nurse Practitioner), dedicated parent advocates, self-advocates, and the Americans with Disabilities Act, all demanding informed respect and individualized support for people with disabilities." (Dr. Lucy Crain)

MISSION FOR INCLUSION: Lucy Crain, MD, MPH, FAAP *(left)* and Geraldine Collins-Bride, RN, MS, ANP-BC, FAAN *(right)*.

Lucy Crain MD MPH FAAP, is Clinical Professor of Pediatrics Emerita at the University of California San Francisco; Adjunct Clinical Professor, Stanford University. Dr. Crain is originally from a small town in Kentucky and earned B.A. and M.D. degrees from the University of Kentucky. Moving to Seattle for pediatrics residency at the University of Washington was followed by a year of service at Presbyterian Hospital in Daegu, Korea, and an MPH at UC Berkeley before settling in San Francisco.

Dr. Crain practiced primary care and developmental pediatrics at UCSF for 30-plus years, and another 10 years in the Child Development Clinic at Lucile Packard Children's Hospital at Stanford University. She and her husband have two grown children and two grandsons and have called San Francisco home for the past 50 years. A past member of the Board of Directors of the American Academy of Pediatrics, Dr. Crain remains actively involved in a number of local and national advocacy efforts for people with disabilities.

MARTHA E. (MARTY) FORD, JD

"I came to this field because my younger brother, Jud, was born in 1956 with profound intellectual disability and autism. Long before the law establishing the right to a free, appropriate, public education, he was expelled for disability-related behavior from a public, segregated, special education school.

I believe that each person has a role – a unique and important role – in their own time and in their own place, and given the circumstances with which they are faced. The joining of our efforts into a larger whole, working together, is what can make us an unstoppable force with impacts well beyond our immediate surroundings.

In our role as advocates, working together, we must be eternally vigilant – we must never rest on policy achievements of the past, but must protect them from opponents who would destroy them, and we must continually look forward for what still needs to be done."

Marty Ford, JD, is a Senior Advisor in Public Policy at The Arc of the United States, a national community-based organization advocating for and serving people with intellectual and developmental disabilities (IDD) and their families. Ms. Ford is a recognized leader in federal public policy affecting people with disabilities, and with 37 years of experience representing The Arc on Capitol Hill, and before federal agencies in long-term services and supports, Medicaid, Social Security, Supplemental Security Income (SSI), and other disability issues.

She worked extensively on numerous Medicaid issues of importance to individuals with IDD and their families, including the development of the law around special needs trusts that are allowed for certain Medicaid and SSI beneficiaries, and the ABLE program that allows people in certain circumstances to save funds without impacting their Medicaid or SSI eligibility. She also successfully co-led major efforts to save the SSI program for children with disabilities when it was under major attack in Congress and in the press and to save the Medicaid program for people with disabilities from block grants or other devastating changes and cuts.


AN UNSTOPPABLE FORCE: In our role as advocates, working together, we must be eternally vigilant – we must never rest on policy achievements of the past, but must protect them from opponents who would destroy them'"

She worked on numerous other policy issues including: discriminatory removal of life-sustaining food and hydration based on disability; prohibition of the death penalty for people with ID; discrimination against people with IDD in the provision of healthcare; guardianship and less restrictive alternatives such as supported decision-making; protection from discrimination against people with IDD under the Americans with Disabilities Act; and the inclusion of long-term supports and services in the Affordable Care Act.

Ms. Ford received her J.D. from the George Washington University National Law Center; M.S. in Communications Design from Pratt Institute; and B.A. from the University of Virginia. Her brother, Jud, has been a guiding force throughout her life.

SUSAN M. HAVERCAMP, PHD, FAAIDD, NADD-CC

"I believe that health is closely related to quality of life. People with disabilities have a right to make informed health choices and to receive high quality, respectful healthcare. In my disability and health work, I have had the privilege of teaching people with disabilities and their families about health, in addition to teaching healthcare professionals about caring for patients with disabilities. I strongly believe that education is the solution to many health inequities people with disabilities face."


THE KEY IS KNOWLEDGE: "Education is the solution to many health inequities people with disabilities face."

Susan M. Havercamp, PhD, FAAIDD, NADD-CC, directs the Centers for Disease Control and Prevention (CDC)-funded Ohio Disability and Health Program, a state, capacity-building program to improve the health of Ohioans with disabilities. In this role, she works closely with the Ohio Department of Health, the University of Cincinnati University Center for Excellence on Developmental Disabilities, and the Ohio Colleges of Medicine Government Resource Center. This program contributed to our understanding of health disparities for people with disabilities, developing inclusive health promotion programs for people with disabilities, and providing disability training for physicians, nurses, and other health professional students and practitioners.

Dr. Havercamp is the Principal Investigator of the Rehabilitation Research and Training Center to improve the health and function of adults with intellectual and developmental disabilities and co-occurring mental health conditions. She serves the disability field as a consulting editor for *Intellectual and Developmental Disabilities,* the *Disability and Health Journal,* and *Inclusion,* and was a founding member of the Student and Early Career Professional Committee. She is past president of the American Association on Intellectual and Developmental Disabilities and the Alliance for Disability in Health Care Education.

TAMAR HELLER, PHD

"Advocacy for and with people with disabilities has been a guiding focus of my research, teaching and organizational activities. It is the motivation behind the national Sibling Leadership Network, which I co-founded, and the research I have been conducting on policies and practices that promote the health and community inclusion of people with disabilities."

A GUIDING FOCUS: "Advocacy for and with people with disabilities is the motivation behind my research on policies and practices that promote the health and community inclusion of people with disabilities."

Tamar Heller, PhD, Distinguished Professor, heads the Department of Disability and Human Development at the University of Illinois, Chicago (UIC) and its University Center of Excellence in Developmental Disabilities. She also directed the Rehabilitation Research and Training Center (RRTC) on Developmental Disabilities and Health and the Family Support Research and Training Center. Her research focuses on health and long-term services and supports for individuals with disabilities and their families through the life course.

Dr. Heller serves on the executive council, directs its publication committee, and is Vice President of the Americas for the International Association for the Scientific Study of Intellectual and Developmental Disabilities (IASSIDD). She was President of the Association of University Centers on Disabilities (AUCD) board, a delegate to the 2005 White House Conference on Aging, and co-founder of the national Sibling Leadership Network.

Dr. Heller's awards include the 2009 Arc of Illinois Autism Ally for Public Policy Award; the 2008 Lifetime Research Achievement Award, IASSIDD, Interest Group on Aging; the 2009 Community Support Services Community Partner Award; the 2010 College of Applied Health Sciences, UIC Outstanding Researcher Award; and the AUCD 2012 International Award.

AMY HEWITT, PHD

"I am driven by social justice and the need to make our communities inclusive for everyone because we all belong here. The committed direct support professionals who make community living possible for many people with intellectual and developmental disabilities have extremely difficult jobs that demand high levels of skill, yet policymakers, systems, and society have not valued, rewarded, and respected them as professionals. I conduct research that provides ammunition for addressing the high turnover, high vacancy rates, and low wages for this essential workforce. As we struggle with the devastation of the COVID-19 pandemic, there has never been a greater need for this change, nor a better time to recognize the immense value of direct support professionals."

Amy Hewitt, PhD, has an extensive background in the field of intellectual and developmental disabilities. She has worked in various positions over the past 39 years to improve community inclusion and quality of life for children and adults with disabilities and their families. Her career began as a Direct Support Professional, and she currently employs DSPs to support her brother-in-law. She is the Director of the University of Minnesota's Institute on Community Integration, and conducts research, evaluation and demonstration projects about community services for children, youth and adults with intellectual and developmental disabilities.

Dr. Hewitt has authored numerous journal articles, curriculum, technical reports, including a book entitled, *Staff Recruitment, Retention and Training.* She is on the editorial board of *Inclusion* and associate editor of *Intellectual and Developmental Disabilities* both journals of the AAIDD. She is a Past President of the Association of University Centers on Disability (AUCD) and Past President of the American Association on Intellectual and Developmental Disabilities (AAIDD).

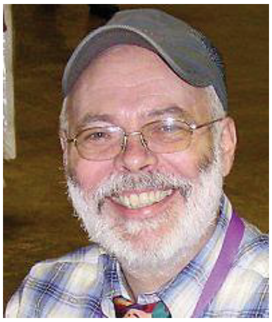
DRIVEN BY SOCIAL JUSTICE: "There has never been a better time to recognize the immense value of direct support professionals."

JOAV MERRICK, MD, MEDSCI, DMSC

"My guidelines in my work with people with intellectual and developmental disabilities has always been the wise words of Hubert H. Humphrey: 'The moral test of government is how that government treats those who are in the dawn of life, the children; those who are in the twilight of life, the elderly; and those who are in shadows of life, the sick, the needy, and the handicapped.' I have made that my own test also."

Joav Merrick, MD, MMedSci, DMSc, born and educated in Denmark, is Professor of Pediatrics. affiliated with the Division of Pediatrics, Hadassah Hebrew University Medical Center, Mt Scopus Campus, Jerusalem, Israel; Kentucky Children's Hospital, University of Kentucky, Lexington; and Professor of Public Health at the Center for Healthy Development, School of Public Health, Georgia State University, Atlanta; the former medical director of the Disability Administration, Ministry of Social Affairs and Social Services, Jerusalem; and the founder and director of the National Institute of Child Health and Human Development in Israel.

A book Dr. Merrick co-authored, *Health Care for People with Intellectual and Developmental Disabilities across the Lifespan,* is considered by many to be the "Bible" in the field of healthcare for people with IDD since 1989, when the first edition came out. He received the Peter Sabroe Child Award for outstanding work on behalf of Danish Children in 1985 and the International LEGO-Prize ("The Children's Nobel Prize") for an extraordinary contribution towards improvement in child welfare and well-being in 1987.



A MORAL TEST: "My guidelines in my work have always been the wise words of Hubert H. Humphrey. I have made that my own test also."

JOAV MERRICK PHOTO COURTESY CECENTRAL.COM

SUSAN L. PARISH, PHD, MSW

"Beginning in college, I worked as a direct care worker, and later administrator for nine years in residential and family support programs for people with intellectual disabilities. I started as a direct care worker. I am fundamentally driven by a feminist worldview, and believe every person should have robust quality of life, and the chance to achieve their potential, regardless of their disability, gender, or racial identity. My work has been shaped by this worldview, and the empirical evidence that Americans with disabilities and their family caregivers contend with an utterly inadequate and unfair social safety net. My research aims to improve the disability, health, and social welfare policies that make living in the US with disabilities expensive, unhealthy, and stigmatizing."

A STRONGER SYSTEM: "I believe every person should have robust quality of life and the chance to achieve their potential."

Susan L. Parish, PhD, MSW is dean of the College of Health Professions, and professor of Health Administration at Virginia Commonwealth University. Prior to joining VCU in 2019, she served as Dean of Bouvé College of Health Sciences at Northeastern University. She was also the inaugural Nancy Lurie Marks Professor of Disability Policy, and directed the Lurie Institute for Disability Policy at Brandeis University. She began her academic career as an assistant professor of social work at UNC- Chapel Hill. Her research examines the health and financial well-being of women and children with disabilities and their caregiving families.

Dr. Parish has garnered more than $12 million in external research funding from a range of federal, state, and foundation sources. She has published more than 130 peer-reviewed journal articles, and is a fellow of the American Association on Intellectual and Developmental Disabilities, the Society for Social Work and Research. She received numerous teaching and mentoring awards as a faculty member at UNC and Brandeis. Her research has been recognized with national awards from the Arc of the United States, the American Public Health Association, the American Association on Intellectual and Developmental Disabilities. She is a member of the National Academy of Social Insurance.

Dr. Parish earned her BA in English Literature and MSW from Rutgers University. She earned her PhD in Public Health from the University of Illinois at Chicago, and completed and National Institutes of Health-funded postdoctoral fellowship at the Waisman Center, University of Wisconsin-Madison.

I. LESLIE RUBIN, MD

"Every day, each one of us conducts our lives with physical, emotional, and social abilities fulfilling our needs while participating and contributing to society. Every day, we are reminded of our own vulnerability and the vulnerability of others who do not have access to the same resources. Every day, we are reminded that we are all part of a larger society, and for all of us to enjoy the benefits and bounty of society, we must work together to ensure that all our fellow men, women and children have opportunities to live healthy and full lives. Transferring these thoughts into action is the essence of advocacy."

I. Leslie Rubin MD is Associate Professor in the Department of Pediatrics at Morehouse School of Medicine; Adjunct Associate Professor in the Department of Pediatrics at the Emory University School of Medicine; Co-director of the Southeast Pediatric Environmental Health Unit at Emory University; President and Founder or Break the Cycle of Health Disparities, Inc.; and Medical Director of The Rubin Center for Autism and Developmental Pediatrics, in Atlanta, GA.

DAILY REMINDER: "We must work together to ensure that all our fellow men, women and children have opportunities to live healthy and full lives."

Dr. Rubin is originally from South Africa, where he trained in Pediatrics and arrived in the USA in 1976. He was initially at the Hospitals of the Case Western Reserve University in Cleveland Ohio. In 1980, he moved to The Children's Hospital in Boston and the Harvard Medical School where he spent 14 years. In 1994, he moved to Atlanta, Georgia as Director of Developmental Pediatrics at Emory University and Medical Director of the Marcus Center. Since 1998 he has been involved with the Southeast Pediatric Environmental Health Specialty Unit (PEHSU) at Emory. In 2004, he joined the Department of Pediatrics at Morehouse School of Medicine. He has been involved in the healthcare of children and adults with intellectual and developmental disabilities since 1977. In 1989, he and Allen Crocker published the first textbook on medical care for children and adults with developmental disabilities and in 2006 they published the 2nd edition. Allen Crocker passed away in 2011, but with other partners Dr Rubin published the 3rd edition: *Health Care for People with Intellectual and Developmental Disabilities Across the Lifespan, Springer 2016.*

He currently directs interdisciplinary clinical programs for children with autism, cerebral palsy, and other developmental disabilities at Hughes Spalding Children's Hospital and at Developmental Pediatric Specialists in Sandy Springs, GA. He has a faculty appointment in the Department of Pediatrics at Morehouse School of Medicine, and teaches Medical Students and Pediatrics Residents, as well as Pediatric Residents from Emory University Department of Pediatrics. He also provides consultation and clinical services to the Hall County Children's Medical Services on a regular basis, serving many families who are immigrants from Mexico. He is a pediatric consultant to the Emory Neurodevelopment Exposure Clinic, which evaluates children who had been exposed to alcohol, drugs and other substances in utero, and who have developmental and behavioral disorders, living in foster or adoptive homes.

He is the recipient of the Robert E. Cooke Lifetime Achievement Award from the AADMD in 2015; the Autism Achievement Award from the Annual Conference and Exposition of Georgia, in 2016; a Children's Environmental Health Hero recognition, by Region 4 EPA; the Children's Environmental Health Excellence Award from the Office of Children's Health Protection, US EPA for Break the Cycle; and the AAP F. Edwards Rushton CATCH Award in 2018.

CATHY FICKER TERRILL, M.S

"We must support people to dream their biggest dream. The most important job for every professional in the field of disabilities is to support people to find and use their voice to advocate for their own individual dreams for the future."

LIFTING VOICES: **"We must support people to find and use their voice to advocate for their own individual dreams for the future."**

For the past 45 years, Cathy Ficker Terrill's career has included working in leadership positions in government, non-profit organizations, university teaching, advocacy and supporting and mentoring self-advocates. She has worked internationally to define, measure and improve personal quality of life for people with disabilities. She is a Past President of the American Association on Intellectual and Developmental Disabilities (AAIDD). She is a past two-term White House Appointee to the President's Committee for People with Intellectual Disabilities (PCPID).

Ms. Terrill has drafted and worked with self-advocates and families to pass state and national legislation in the US for early intervention, inclusive education, successful transition, competitive employment, family support, comprehensive healthcare for children, autism insurance coverage, housing, and disability rights. She wrote and implemented seven different Medicaid waiver plans for states. She has worked at the local, state and national stage for comprehensive organizational change toward fully inclusive supports and services for children and adults with disabilities. She has served on numerous boards, task forces and committees to create systems of services that have as their core, self-advocacy, self-determination and inclusion for all.

She has volunteered internationally, helping to create services for people with disabilities in many countries, including Russia and Lithuania. Under the direction of President George Bush, Sr., she joined a team of professionals who went to Saudi Arabia after Dessert Storm to conduct a comprehensive country-wide assessment of services and strategic plan for people with disabilities and people receiving aging services. She has been volunteering in Poland with family advocates wanting to set up programs and strategic plans for young Polish adults with IDD. She arranged for the families to also tour programs in the US.

Over the years, Ms. Terrill has helped to bring groups of self-advocates and professional to the U.S. to see community supports in action. She also volunteered in Kosovo, with Mental Disability Rights International to promote community-based services and institutional closures. She led a delegation of 40 self-advocates and professionals on a professional exchange in China on IDD and brain injury. She has done volunteer work in South Korea, Japan and Taiwan.

JAMES R. (JIM) THOMPSON, PHD

"Being an advocate means believing in and taking action to support a cause that is bigger than oneself. The cause that has captured my imagination for over 40 years has been to assure that people with disabilities have full access to all of the opportunities that community life has to offer. My advocacy is fueled by the knowledge that people with and without disabilities have much to gain when people with disabilities are supported to be full participants in all aspects of community life."

BELIEF IN A BIGGER CAUSE: **"People with and without disabilities have much to gain when people with disabilities are supported to be full participants in all aspects of community life."**

James R. Thompson, Ph.D. has over 40 years of experience in the field of developmental disabilities, as a direct support professional, special educator, rehabilitation counselor, teacher educator, and researcher. He has authored or co-authored over 70 books, book chapters, monographs, and articles in professional journals, and has directed multiple federal and state-funded research and model demonstration projects. He pioneered assessment and planning practices that are focused on understanding people with disabilities by their needs for extra support. He is the lead author of the adult and children's version of the *Supports Intensity Scales,* the first assessment tools to provide a standardized measure of the support needs of people with developmental disabilities. The SIS scales have been translated and published in 17 languages and are being used throughout North America and world. Dr. Thompson's latest book, *Planning for the Success of Students with IEPs: A Support-Based Approach to Inclusive Education,* will be published in 2022 by W. W. Norton & Company.

Dr. Thompson earned his undergraduate degree in special education (1980) and a master's degree in educational administration (1989) from Illinois State University. He earned a doctoral degree in educational psychology (1994) from the University of Minnesota. He currently serves at the University of Kansas as a Professor in the Department of Special Education, a Senior Scientist in the Beach Center on Disability, and an Associate Director of the Kansas University Center on Developmental Disabilities. He also maintains a courtesy appointment as a Visiting Professor at the University College Ghent (Belgium), and serves as a consultant with the Het EQUALITY Research Collective (the EQUAL Center), a center that is devoted to the study of Quality of Life and disability populations.

He is a past President of the American Association on Intellectual and Developmental Disabilities (AAIDD) and is currently on the Board of Directors for the Council for Exceptional Children's Autism and Developmental Disabilities Division as well as The Arc of Douglas County (KS). He is the Editor in Chief of Intellectual and Developmental Disabilities, a professional journal of research, policy, and practice published by the AAIDD.

ELIZABETH (LIZ) WEINTRAUB

"When people refer to us as 'special needs,' that bothers me, because we are also citizens of this country with needs just like anyone else. I love being an advocate for people with disabilities and helping them 'grow' just like people have taught me how to grow."

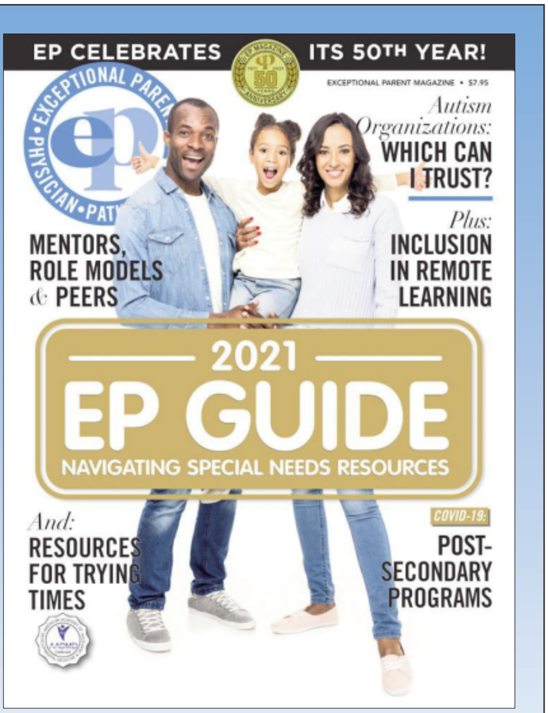
ENCOURAGING GROWTH: "I love being an advocate for people with disabilities and helping them 'grow' just like people have taught me how to grow."

Elizabeth (Liz) Weintraub has a long history of leadership in self-advocacy, and has held many board and advisory positions at state and national organizations. She is a full-time member and Senior Advocacy Specialist of the AUCD's policy team, and also the host of "Tuesdays With Liz: Disability Policy For All," where she works to make polices in accessible language, so policy is accessible to all.

In the Spring of 2018, Ms. Weintraub served as a Fellow for Senator Bob Casey of Pennsylvania, working in his DC Office where she helped lead the way on disability policy by helping the Senator hold the administration accountable for disability stakeholder input into key programs; calling attention to the need for accessible supports and services for students and employees with disabilities on college campuses who have been sexually assaulted. She helped organize a first-of-its-kind Pennsylvania Disability Employment Summit with over 250 participants. Said Senator Casey: "Liz has shown the Senate how important it is to have staff members who have developmental and intellectual disabilities. She's helped reshape the culture of the Senate."

In the fall of 2018, Ms. Weintraub told the story of her personal experience as a woman with disabilities, as she testified before the Senate Judiciary Committee about the potential implications of a Kavanaugh confirmation to the civil rights of people with disabilities.

Prior to coming to AUCD, Ms. Weintraub worked for the Council on Quality & Leadership (CQL). She completed the LEND training program at the Center for Leadership in Disability at Georgia State University. She was past Chair of the Maryland Developmental Disabilities Council. She is rejoining the Council for another term. Ms. Weintraub has received numerous awards, recognition, and commendations for her work. She enjoys mentoring people with disabilities. •



FROM OUR FAMILIES... TO YOUR FAMILIES

MILITARY

CTION

HOW SCHOOL LIAISONS HELP STUDENTS REALIZE EDUCATION GOALS AND MORE

Parents have many questions about their children's education, and military life can create even more. If you're looking for answers to your education questions, your installation school liaison can connect you with the support you need.

The School Liaison Program offers an array of services and resources to support children, parents, installation leadership, schools and the surrounding community. By working together with these stakeholders, the School Liaison Program builds a support network to provide the best possible education experience for military-connected children and youth worldwide.

School liaisons are located at each installation and are the main contact for military families, local school systems and installation leadership for school-related matters pre-K through 12. School liaisons are experienced professionals who advocate, advise and build partnerships with the civilian and military community to help address common education challenges of military families. School liaison support is free of charge and open to all Department of Defense identification card holders, educators who serve military students and community partners involved with pre-K-12 education.

STUDENT AND FAMILY SUPPORT

School liaisons provide a wide variety of services for students and families, including:

- **Transition support – for PCS moves, as well as general education transitions**
  - o *Information on campus specific programs and courses of study, school districts and boundaries*
  - o *Assistance with transferring credits and registering for classes*
  - o *Help with locating after-school and extracurricular programs*

  - *Tutoring referrals*
  - *Youth sponsorship referrals*
  - *Support for transitions to elementary, middle and high school and beyond*
- **Alternative schooling support – including information about private, parochial, charter and homeschool options**
- **Special education support and referrals – including referral to the Exceptional Family Member Program (www.militaryonesource.mil/family-relationships/special-needs/exceptional-family-member/exceptional-family-member-program-family-support) and other local resources**
- **Deployment support – including parental absence coping strategies, educator awareness of deployment cycles, accommodation compliance and non-medical counseling referrals to minimize the negative academic, social and emotional impact.**
- **College, career and military readiness:**
  - *Test preparation and scheduling*
  - *Scholarship and financial aid information*
  - *Postsecondary opportunities*
  - *College, vocational and career fairs*
- **Parent workshops on topics such as:**
  - *Smooth transitions*
  - *College and career preparation*

School liaisons know that transitions are more than just permanent changes of station. Children move to new schools, and they also move within schools. In addition, military children transition from parent(s) being home to being deployed. Rest assured that whatever transition your military child is navigating, school liaisons are available to help improve their academic experience, promote social and life skills, offer vocational guidance and build education partnerships to help them thrive.

EDUCATION COMMUNITY SUPPORT

In addition to working with students and families, school liaisons work with local education community partners and installation leadership to meet military children's education needs. School liaisons offer information workshops and professional development opportunities. Topics include:

- **The social and emotional effects of military transition**
- **Reducing test anxiety in youth**
- **Grant resources for school systems (such as Federal Impact Aid and DOD grant opportunities)**
- **Military Interstate Children's Compact Commission compliance support**
- **Military culture**
- **Installation tours**

PARTNERS IN EDUCATION

On the program level, school liaisons collaborate with national educational and local community organizations to promote the best education for military children. Some educational partners include:

- **Military Interstate Children's Compact Commission:** https://mic3.net
- **National Military Family Association:** www.militaryfamily.org
- **Military Child Education Coalition:** www.militarychild.org
- **Project Search**
- **DOD Starbase:** https://dodstarbase.org
- **DOD STEM:** https://dodstem.us
- **DODEA:** www.dodea.edu/partnership/index.cfm
- **Service branch adopt-a-school partnerships:** www.army.mil/article/203389/adopt_a_school_partnerships_enrich_lives
- **National Association of Federally Impacted Schools:** www.nafisdc.org

The partnerships, resources and services that school liaisons develop and coordinate play a key role in creating a collaborative relationship between the military community and school systems worldwide to support the educational needs of military children and families.

School Liaison Program support is open to all DOD ID card holders, educators who service military students and community partners involved with pre-K-12 education. For more information, contact your local installation school liaison office.

– Military OneSource

LOOKING FOR YOUR SCHOOL LIAISON?

Contact your local school liaison for all of your pre-K-12 education needs.

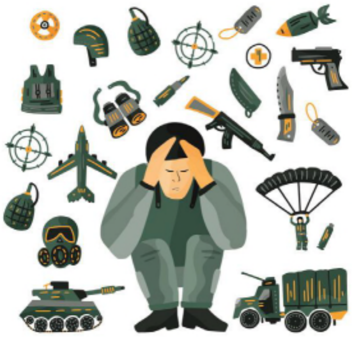
https://installations.militaryonesource.mil/search?program-service=12/view-by=ALL

SUICIDE PREVENTION: THE ESSENTIALS

The Department of Defense is strongly committed to preventing suicide within our military community through suicide prevention, intervention and postvention initiatives.

If you are in crisis, or you know someone who is, there are immediate resources available to support you or your loved ones. The Military Crisis Line connects those in need to a trained counselor with a single phone call or click of a mouse. This confidential, immediate help is available 24/7 at no cost to active-duty, Guard and reserve members, their families and friends. Contact the Military Crisis Line at 800-273-8255, then press 1, or access online chat by texting 838255. Learn more about suicide:

SUICIDE IS A PUBLIC HEALTH ISSUE



Suicide is a public health issue that affects Americans across all communities and walks of life, including the military. Its causes are complex and involve a number of factors, including biological, psychological, environmental, and social influences. A key goal of suicide prevention is to reduce risk factors and increase resilience and wellness.

Relevant Articles:

- Suicide Awareness: www.militaryonesource.mil/health-wellness/mental-health/suicide/suicide-awareness

Relevant Resources:

- Military Crisis Line: www.veteranscrisisline.net/get-help/military-crisis-line
- Defense Suicide Prevention Office: www.dspo.mil

SUICIDE IS PREVENTABLE

The Department of Defense embraces the public health approach to suicide prevention. This evidence-based approach shows that providing support services, talking about suicide, reducing access to means of self-harm and following up with loved ones are just some of the actions we can all take to help others.

If you are feeling alone, tap into the strength of your fellow members of the military community. People are the military's greatest resource – each individual is a part of something bigger than themselves, protected, and understood. You can also turn to Military OneSource 24/7 for free resources and counseling to help you through challenges and daily stress before they become a crisis.

Each member of the military community has a responsibility to look after one another. If a service member or family member distances himself or herself from the community or begins to show any warning signs of suicide — such as threatening to hurt themselves, expressing feelings of hopelessness or increasing alcohol or drug use — call the Military Crisis Line (www.veteranscrisisline.net/get-help/military-crisis-line) or National Suicide Prevention Lifeline (https://suicidepreventionlifeline.org).

Relevant Resources:

- Supporting Military Families in Crisis guide: https://www.dspo.mil/Portals/113/Documents/Family-Guide-DSPO-2014.pdf
- Address That Stress: Confidential, Short-term Counseling for a Range of Stressors: www.militaryonesource.mil/confidential-help/non-medical-counseling/military-one-source/military-counseling-for-stress/
- Re The We: Support for Relationship Challenges: www.militaryonesource.mil/family-relationships/relationships/military-relationships-support

EVERYONE HAS A ROLE IN PREVENTING SUICIDE

Suicide is not inevitable for anyone. By starting the conversation, providing support, and directing help to those who need it, we can prevent suicides and save lives.

Sometimes just talking to someone is a critical first step towards wellness and resilience. Encourage your fellow service members, family members and those you lead to ask for help before issues become a crisis. Resources from the DOD can guide you as you support those who may be struggling. Military OneSource can help service members and families address life's daily stressors and get support for rebuilding critical relationships.

Relevant Resources:

- Leaders Suicide Prevention Safe Messaging Guide: www.dspo.mil/Portals/113/Documents/DSPO_LSP_SafeMsgGuid%20(Final).pdf
- Lethal Means Safety Guide for Military Service Members and Their Families: www.dspo.mil/Portals/113/Documents/DSPO%20Lethal%20Means%20Safety%20Guide%20for%20Military%20Service%20Members%20and%20Their%20Families_v34_FINAL.pdf
- Postvention Toolkit for a Military Suicide Loss: https://www.dspo.mil/Portals/113/Documents/PostventionToolkit.pdf
- The How We R.E.A.C.H. Coaching Tool: www.reach.gov/resources/tool

PROMOTE HEALING AND MINIMIZE RISK FOR SURVIVORS

Many survivors experience a range of emotions including blame, guilt or anger. They may face mental health challenges from the experience. It is important to know that support is available to help in the process of rebuilding after loss.

Relevant Articles:

- Helping You and Your Family Survive a Suicide Death: www.militaryonesource.mil/health-wellness/mental-health/suicide/helping-you-and-your-family-survive-a-suicide

Relevant Resources:

- Grief and Loss Webinars: www.militaryonesource.mil/leaders-service-providers/military-and-family-life-counseling-program/grief-and-loss

– Military OneSource

Beach Visitor

Mark assured Broden that we had two more days at the beach and then we would drive home, “We will spend the day at the beach, eat steak for dinner, sleep, then wake up and pack the car to drive home.”

My parents came to visit for our annual beach trip this past month. In the beginning of the week, the beach did not disappoint. We had enjoyable temperatures with a few clouds here and there to cool off periodically through the day. Towards the end of the day, everyone would do the towel shuffle, sliding our towels farther from the shoreline as the waves crashed closer to our feet. Each year at the beach, we see changes and we're able to witness the progression in Broden. Our family knows that this is the one family trip that he looks forward to every year. Maybe because he feels similar to how we feel about the beach. There is a sense of comfort going to the same beach each year and reconnecting with a special place that gives us time to reflect and enjoy the predictability of it all. There will always be waves, sand on our toes, and the sound of seagulls that you can hear over the sound of pounding waves. It never changes, and as I watch Broden, he has expressed comfort in that respect.

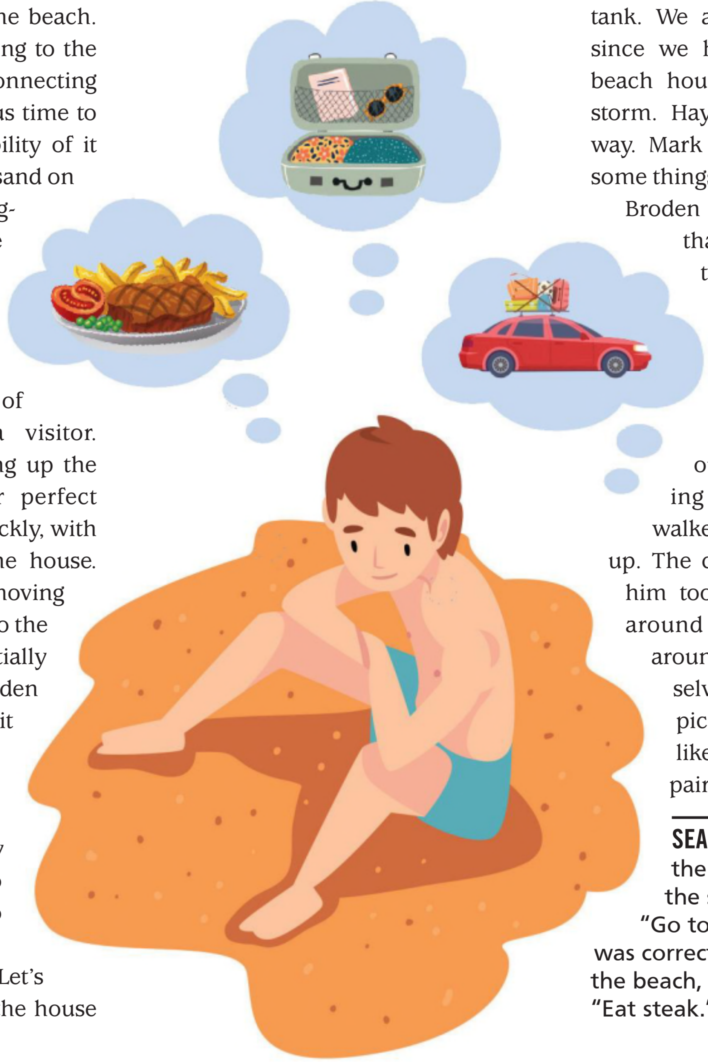
This year, towards the end of our beach trip, we had a visitor. Hurricane Elsa decided to swing up the east coast and interrupt our perfect beach weather. Elsa came in quickly, with pounding winds that shook the house. The wind was so strong it was moving our rocking chairs on the patio to the far side of the porch. We had initially scheduled a college trip for Hayden to visit Coastal Carolina, but it was postponed due to a tornado warning north of us. When the weather subsided, the beach still looked like it wasn't ready for visitors, so we decided to take a short road trip inland to check out a shopping area.

I looked over at Broden, “Let's take a road trip and get out of the house since we can't enjoy the beach right now.” Broden looked confused and said, “My sheets.” I was confused by his response, “Your sheets? We aren't leaving the beach and going home. We're just taking a little trip, then coming back.”

I ran into the living room to tell Mark what he had said to me. That was the first time Broden had ever mentioned any concerns with taking his belongings with him if he thought he was leaving. He was starting to connect with our schedule and how it would affect him. What was even more exciting was that he was using his words to vocalize what he was thinking, not just basic wants such as “juice” or “food.” This was different. Broden was telling us what he needed to pack for the trip. This was new.

Eventually, we all slid in the car and drove inland to a Bass Pro shop. We thought Broden would enjoy the big fish tank. We allowed everyone to explore, since we had been couped up in the beach house that morning due to the storm. Hayden and my dad went one way. Mark went another way to check some things out, and mom and I followed Broden around the store. It seemed that everyone had the same idea that we had due to the weather. If the beach wasn't ready for visitors, the Bass Pro shop was the place to be that day.

Broden was weaving in and out of groups of people, exploring shelves while we briskly walked behind him trying to keep up. The crowds didn't seem to bother him too much and he was looking around and taking in everything around him. We finally found ourselves in the shoe section. He picked out a pair of shoes he liked. It was the most colorful pair of sandals on the rack. The



SEA CHANGE: Broden woke up the next morning, remembering the schedule Mark had told him, “Go to beach?” We assured him he was correct. That evening walking off the beach, he turned to Mark and said, “Eat steak.”

sandals were a pair of Tevas with yellow, green, blue and pink straps. After offering him other sandals as options, he said no to all of them and pointed again to the colorful Tevas. After submitting to his choice and finding the right size, we paid for them and headed back to the car. The clouds were starting to part so we began our trek back to the beach house.

That night, Broden grew upset and said, "Go home." Mark assured him that we had two more days at the beach and then we would drive home, "We will spend the day at the beach, eat steak for dinner, sleep, then wake up and pack the car to drive home."

Broden surprised us again that morning. He woke up the next morning, remembering the schedule Mark had told him, "Go to beach?" We assured him he was correct and, after breakfast, we got him ready for the beach. That evening walking off the beach, he turned to Mark and said, "Eat steak." Again, Mark nodded and told him he was correct. Mark and I were shocked. He was verbalizing the schedule back to us and had remembered what Mark had told him the night before. Again, this was new.

The next morning, as I started packing, I did something different than I normally do. Instead of mostly packing his stuff up myself, I gave Broden tasks so he could actively participate in packing up his room: "Take your sheets off your bed. Stuff your woobies in your bag. Pull your pillowcase off your pillow." I gave him one task at a time. Once he was packed and had his breakfast, he patiently sat in a chair on the front porch as everyone packed the car to head home. This was the first time Broden had been active in the process and waited patiently for the car to be packed.

> "Broden is an active participant in our family, teaching us that he is still growing as a person."

Years ago, I was told that most of Broden's progress would be seen in his younger years and that as he got older, his progression would lessen. They would discuss children's brain development and how, after a while, Broden may not make the strides that we may have experienced when he was younger. What scares me is that I listened to them. I don't believe them anymore.

Progress is progress in my mind, and Broden continues to surprise us with what he knows and now, what he remembers. He is an active participant in our family and we look forward to new days of him continuing to show us what he can do, and teaching us that he is still growing as a person. •

PUZZLES & CAMO

Shelly Huhtanen is an Army wife stationed at Fort Benning, GA who has a child with autism. She enjoys sharing her experiences of day-to-day life caring for her son with autism while serving as an Army spouse. She authored *"Giving a Voice to the Silent Many"* that encompasses many stories of raising a child with autism in the military. Shelly is passionate about autism advocacy for our military and works to bring awareness to our local legislators and command about providing better support for our military autism community, such as better health care and education.

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