EP CELEBRATES ITS 50TH YEAR!

EP MAGAZINE 1971 2021 50 YEARS ANNIVERSARY

EXCEPTIONAL PARENT
MAGAZINE

OCTOBER 2021
$7.95

IN THIS ISSUE:

TRANSITIONING YOUNG ADULTS WITH IDD *to* ADULT HEALTHCARE

PLUS • ADULTS WITH SPECIAL NEEDS:

REINVENTING COLLEGIATE OPPORTUNITIES

AND • DURING TRANSITION:

ASSESSING THE NEEDS *of* STUDENTS

EMPLOYMENT AND TRANSITION

ALSO • ERIK'S RANCH:

OPERATED *by* YOUNG ADULTS WITH AUTISM

AADMD Endorsed

CONTENTS

OCTOBER 2021 VOLUME 51 ISSUE 10

EMPLOYMENT AND TRANSITION

FEATURES

ON OUR COVER

EP's Employment and Transition Issue examines school, job and healthcare transitions for youth with special needs. *Coverage begins on page 18.*

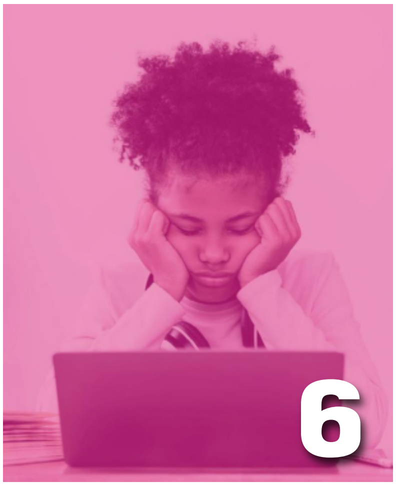
CONTENTS

OCTOBER 2021 VOLUME 51 ISSUE 10

DEPARTMENTS

ANCORO IMPARO

AMERICAN ACADEMY OF DEVELOPMENTAL MEDICINE & DENTISTRY



MILITARY SECTION

MILITARY LIFE

PUZZLES AND CAMO

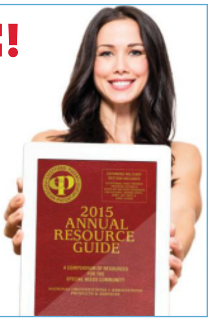

FROM OUR FAMILIES… TO YOUR FAMILIES
MILITARY
SECTION

MILITARY LIFE
54 MOVING WITH AN INDIVIDUALIZED EDUCATION PROGRAM

57 TEN QUESTIONS TO ASK CHILD CARE PROVIDERS FOR YOUR CHILD WITH SPECIAL NEEDS

PUZZLES AND CAMO
58 HE'S GOT A JOB
By Shelly Huhtanen

The contents of *EP* magazine's Military Section are not necessarily the official views of, or endorsed by, the United States Government, the Department of Defense, or the Department of the Army. The appearance of advertising adjacent to the Military Section does not constitute endorsement by the United States Government, the Department of Defense, or the Department of the Army of the products or services advertised.



Information and Support for the Special Needs Community

VOLUME 51 ISSUE 10 ▪ ESTABLISHED 1971

Editor-In-Chief	**Rick Rader, MD**	habctrmd@aol.com
Managing Editor	**Vanessa B. Ira**	vira@epmagazine.com
Senior Editor for Special Projects	**Steven P. Perlman, DDS**	sperlmandds@gmail.com
Publisher	**Len Harac**	LHarac@epmagazine.com
Vice President of Business Development & Sales	**Faye Simon**	fsimon@epmagazine.com
Art Direction & Design	**Leverett Cooper**	lev@foxprintdesign.com

Exceptional Parent magazine was founded in 1971 by Maxwell J. Schleifer, PhD

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

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

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

Exceptional Parent (ISSN 0046-9157) is published monthly 11 times per year plus the special January Annual Resource Guide by TCA EP World, LLC, dba Exceptional Parent Magazine, 1360 Clifton Avenue, Ste. 327, Clifton, NJ 07012 Internet address: www.epmagazine.com. All rights reserved. Copyright ©2021 by TCA EP World, LLC. Exceptional Parent™ is a registered trademark of TCA EP World, LLC Postmaster: Please send address changes to: Exceptional Parent,1360 Clifton Avenue, Ste. 327, Clifton, NJ 07012. Any applicable periodical postage paid at Johnstown, PA and additional mailing offices (USPS 557-810). Basic annual subscription for EP Digital is free. Limited edition print subscription $95.00. Subscriber Service: Direct all inquiries & address changes to: Exceptional Parent, 1360 Clifton Avenue, Ste. 327, Clifton, NJ 07012 08758. Customer Service/New Orders: E-mail: fsimon@epmagazine.com or call (973) 726-6218. Back issues incur a charge of $10.00 each and depend upon availability, call (973) 726-6218. Agreement #1420542

EP EDITORIAL ADVISORY BOARD

Lauren Agoratus
Parent, NJ state and MCH Region II (NJ, NY, PR, VI) Coordinator for Family Voices, NJ CCAN (Caregiver Community Action Network), National Family Caregivers Association, Mercerville, NJ

Mark L. Batshaw, MD
Prof. and Chairman, Dept. of Pediatrics, The George Washington University Medical Center, Washington, DC

Jean F. Campbell
Principal, JF Campbell Consultants; Founding Board Member, Professional Patient Advocates in Life Sciences (PPALS)

Henry G. Chambers, MD
Director, Southern California Cerebral Palsy Center at Rady Children's Hospital San Diego, Co-Director 360 Sports Medicine Program

Steven M. Eidelman
H. Rodney Sharp Professor of Human Services Policy and Leadership, Faculty Director, The National Leadership Consortium on Developmental Disabilities The University of Delaware

David Fray, DDS, MBA
Associate Professor, Department of General Practice and Dental Public Health, University of Texas School of Dentistry, Houston, TX

Allen Friedland, MD
Pediatrician and Internist Pediatric to Adult care Advisor, Wilmington, DE

Saadi Ghatan, MD
Site Chair, Neurosurgery, Mount Sinai West, Mount Sinai St. Luke's, New York, NY

Matthew Holder, MD
CEO, Lee Specialty Clinic, Louisville, KY Global Medical Advisor for Special Olympics International

Gary Liguori, Ph.D
Fellow of the American College of Sports Medicine (ACSM), Dean, College of Health Sciences, University of Rhode Island

Joseph M. Macbeth
President/Chief Executive Officer, National Alliance for Direct Support Professionals, Inc.

Tera Roberts
Executive Director, Orange Grove Center, Chattanooga, TN

Robert K. Ross Ed.D., BCBA-D, LBA
President of the Autism Special Interest Group, Association for Behavior Analysis International, Senior VP at Beacon ABA Services of MA & CT

Amged M. Soliman, Esq.
Attorney, US Federal Government

Stephen B. Sulkes, MD
Pediatrician, University of Rochester Medical Center, Rochester, NY

Allen Wong, DDS, EdD, DABSCD
Professor and Director AEGD Program/Hospital Dentistry, University of the Pacific, Dugoni School of Dentistry, AADMD President

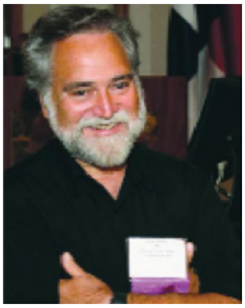
Note from the Editor-in-chief: EP World, Inc. advocates for the dignity of all citizens with disabilities including the use of "people first language" where possible. We do not normally edit articles and submissions that do not reflect this language, therefore, at times, readers might see alternative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

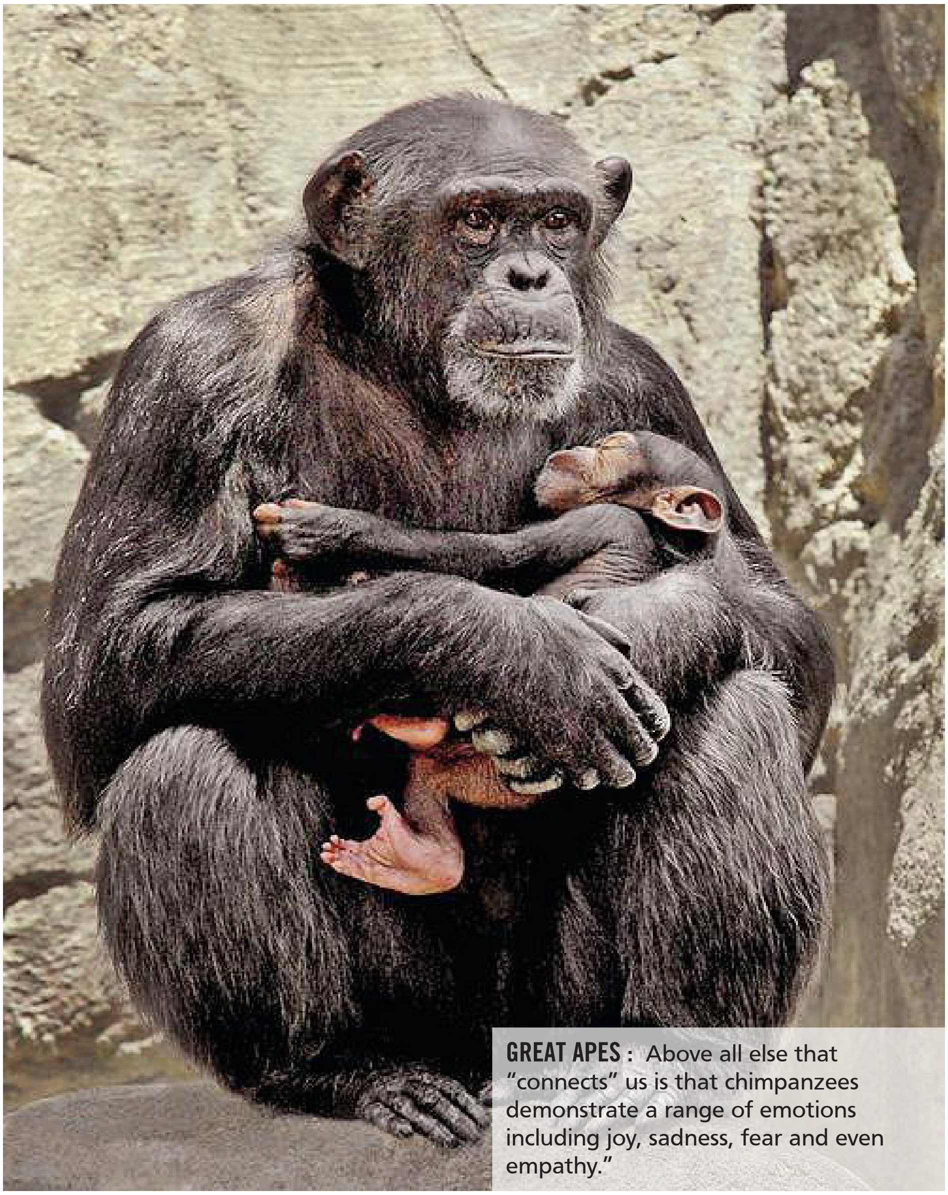
One Exceptional Parent Swinging from the Trees

While there is no evidence that XT (the devoted mother) ever belonged to a support group, received any training, or read *EP Magazine,* she perhaps redefined the term"exceptional parent."

Ten chimpanzees are standing in a line. The 1st, 3rd, 5th, and 7th chimps are asked to step forward. They are the prime apes (I couldn't resist).



And indeed, they are. There is no doubt that humans have been intrigued, fascinated, and attracted to chimps since they were first encountered in Angola in the 17th century by the Portuguese explorer Duarte Pacheco. His diary is possibly the first document written by a European that acknowledges the ability of the chimpanzees to make basic tools.



GREAT APES: Above all else that "connects" us is that chimpanzees demonstrate a range of emotions including joy, sadness, fear and even empathy."

PHOTO COURTESY TAD MOTOYAMA

And how could humans not feel some kinship to the chimpanzees? They share nearly 99% of our DNA. According to Anna Muir of the Jane Goodall Institute of Canada (research and advocacy group for chimpanzees), "Chimps are more closely related to humans than they are to gorillas. Like humans they laugh when tickled. Like us, the first five years of a chimp's life are spent playing, socializing and developing a strong infant-mother bond. The human brain is structurally identical to a chimpanzee's. This means that chimpanzees are capable of reasoned thought, abstraction and generalization. They can even recognize themselves in a mirror – most other animals cannot! The human body is very similar to that of a chimp. We share the same bones, muscles, nervous system and the same number of fingers and toes. They share the same senses that we see and experience the world with. And to clinch the deal that they are human-like, we know they share things with one another (like tools and food) and use body language to communicate. They kiss, hug, pat each other on the back, hold hands and shake their fists. But above all else that "connects" us is that they demonstrate a range of emotions including joy, sadness, fear and even empathy."

For me personally, it is their ability to exhibit and express empathy that begs the question, "Who learned it from whom?"

The Turkish novelist Mehmet Murat Ildan suggests, "Watching our closest living relatives, the chimpanzees, is reading the first chapter of human beings' adventures in this universe!"

A team of Japanese scientists have observed a mother chimpanzee taking care of her severely disabled baby!

The baby, nicknamed XT11, was born in Tanzania's Mahale Mountains National Park and was studied for about two years. An account of the mother-baby interaction, believed to be the first detailed report of its kind, was published in the journal *Primates*. The disabled baby was born to Christina, a 36-year-old mother.

> “XT may have understood that her infant required unusual extra care and that letting others carry the infant was unsafe.”

XT11 had disabilities that were similar to those of Down syndrome seen in a chimpanzee born in captivity. She was described as having her eyes look empty and her mouth was often half open. She had an extra finger on her left hand, and a bald patch on her back. Shreya Dasgupta, a writer for Mongabay Reports, describes the chimp's behavior, “XT11 was less active than typical infants of her age. While healthy infants can sit up by six months, she could do so only after her twentieth month. She was never observed walking or feeding on plants on her own. She remained dependent on her mother's milk for much longer than chimps of her age typically are.”

Given these severe abnormalities, XT11 managed to survive until she was nearly two years old. This was largely due to her mother's care. And while there is no evidence that XT (the devoted mother) ever belonged to a support group, received any training, or read *EP Magazine,* she apparently defined, or perhaps redefined the “exceptional parent.” XT carried XT11 all day long, both while walking and while climbing trees. And like most parents of children with special healthcare needs, this regimen interfered with her own feeding. The researchers reported, “XT had to carry XT11 ventrally all the time, support her with a hand and walk tripedally, support her posture on trees, place her on her breast before suckling, and put her on the ground while grooming. Without this kind of unusual and flexible maternal care, XT11 might not have survived for her entire 23 months in the wild.”

Of particular interest is that chimpanzees have been known to allow non-relatives to help to care for their babies. XT did not allow non-relatives to take care of XT11. The authors concluded that, “As there was no evidence that other individuals showed any aversion to, or fear of the disabled infant, XT's intolerance might have been due to understanding that her infant required unusual extra care and that letting others carry the infant was unsafe.”

Dr. Michio Nakamura, one of the lead researchers: “It is the first time it was observed in the wild that a disabled chimpanzee was receiving social care. We believe the study offers a fresh clue as to how human society, which socially cares for disabled members, has evolved.”

And while this study demonstrates how our close relatives can show empathy, we are reminded that chimpanzees have also ripped the faces off of caretakers, tracked, assaulted and killed humans, and killed and eaten gorillas.

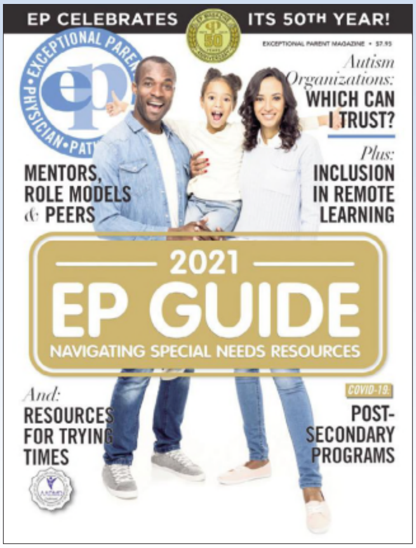
Learned behavior, evolution or survival tactics; or perhaps most depressing, is that it is a reflection of just how close to humans the chimpanzees have evolved. The term chimpanzee is derived from the word “kivili-chimpenze” – a Tsiluba language which means “mockman”. The idea that both their empathy and aggressiveness are behaviors that they are “mocking” should remind us of how lessons are learned.

With mothers like XT, perhaps there is hope.•

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.

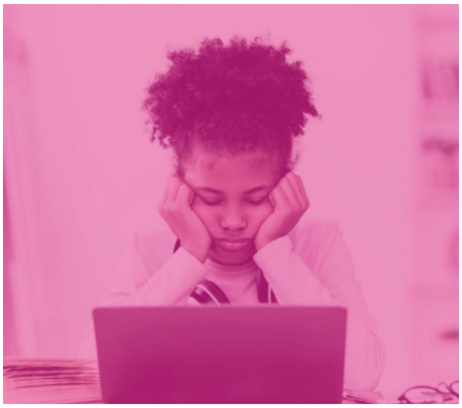
— Rick Rader, MD, Editor-in-Chief, EP Magazine
Director, Morton J. Kent Habilitation Center
Orange Grove Center, Chattanooga, TN



WHAT'S HAPPENING

APA: CONGRESS SHOULD INCREASE CHILD AND ADOLESCENT MENTAL HEALTHCARE

The COVID-19 pandemic is putting enormous stress on children's mental health, which is why Congress should act now to protect our nation's youth over the long term by addressing shortages of mental health providers and increasing access to school-based behavioral and physical health care, according to the chief executive officer of the American Psychological Association (APA).



STRESSED STUDENTS: The mental health of children is tied to the health of their communities, their schools and their homes.

"Children and adolescents have been especially affected by the COVID-19 pandemic, experiencing higher rates of stress, anxiety and fear. Social isolation, financial uncertainty and disrupted routines place considerable stress on children and their families," APA CEO Arthur C. Evans Jr., PhD, told the House Energy and Commerce Subcommittee on Oversight and Investigations. "While APA appreciates Congress' significant investments in mental health during the COVID-19 pandemic, part of the problem is that such funding is temporary, which often inhibits the ability of states and school systems to make long-term investments in their mental health workforce and infrastructure. New investments must be made with the understanding that a long-term commitment is needed."

Evans cited psychological research showing that the mental health of children is frequently tied to the health of their surroundings, including their communities, their schools and their homes. "If traumatic events are occurring in these settings, they almost always have a downstream impact on children's well-being," he said.

Failing to treat children's mental health needs can have an impact on the overall trajectory of their lives, he said. "This can include a greater likelihood of difficulties with learning, addiction to substances, lower employment prospects and involvement with the criminal justice system," he told the subcommittee. "This concern is amplified for individuals from underserved communities and communities of color, who have long struggled with the social determinants that lead to behavioral health concerns and inadequate access to behavioral health services."

Evans called for moving away from the over reliance on acute care and crisis services for children and adolescents toward a population health approach that emphasizes prevention and treatment and moves services into the places where people live, work and play, thus reaching more children at their earliest point of need. This involves a multi-tiered approach, including: 1) effective and efficient clinical care for those experiencing behavioral health disorders; 2) mitigating the impact of risk factors for those individuals who have elevated risk for behavioral health disorders and intervening early if those efforts are not successful; and 3) providing tools and resources that promote wellness for those who are relatively healthy, according to Evans.

"Communities – when properly empowered – play a pivotal role in shaping solutions to their unique challenge," Evans said. "Research on children's mental health is urgently needed as we see how the pandemic has uniquely and disproportionately affected children. Scientific research is our best tool for improving public health and educational systems to help children overcome the challenges of the pandemic and ensuring preparedness for subsequent crises."

Evans called on Congress to pass legislation that would increase the number of psychologists and other mental health providers, including school-based mental health professionals, who are in very short supply, with only one school psychologist for every 1,400 students. He also called on the panel to increase Medicaid funding to schools and to permanently extend the Children's Health Insurance Program.

"Federal, state and local governments should be working in concert to ensure that all children continue to have access to equitable education and support services, while staying mentally and physically healthy," he said.

ABOUT THE APA

AMERICAN
PSYCHOLOGICAL
ASSOCIATION

The American Psychological Association, in Washington, D.C., is the largest scientific and professional organization representing psychology in the United States. APA's membership includes nearly 122,000 researchers, educators, clinicians, consultants and students. Through its divisions in 54 subfields of psychology and affiliations with 60 state, territorial and Canadian provincial associations, APA works to advance the creation, communication and application of psychological knowledge to benefit society and improve people's lives.

WHAT'S HAPPENING

STUTTERING ASSOCIATION SHINES A SPOTLIGHT ON KIDS WHO STUTTER IN NEW PSA

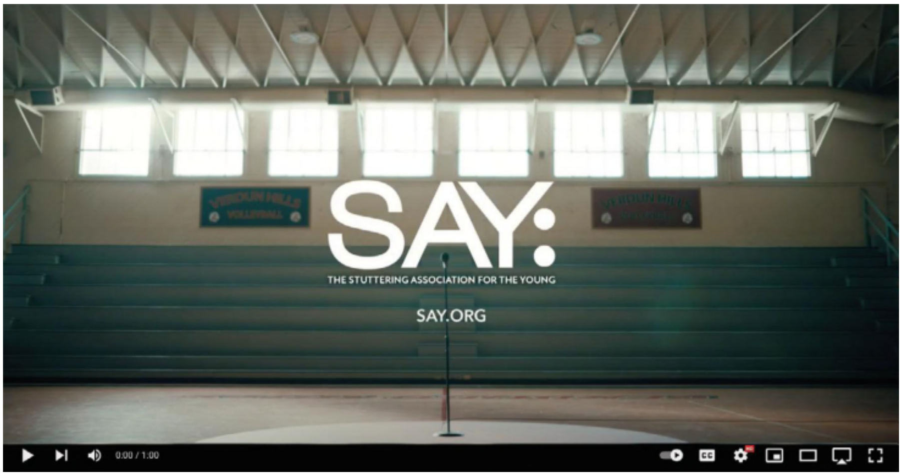
For the over 70 million people who stutter, every conversation can feel like speaking in front of a crowd: all eyes on you as you know what to say but cannot seem to get the words out fast enough.

"In the Spotlight," a powerful PSA from the Stuttering Association for the Young (SAY) and BBDO, portrays the emotional weight of young people living with a stutter to ignite a conversation and bring awareness to this common yet stigmatized speech disorder. With the incredible challenges faced by kids who stutter after a year of home learning, "In the Spotlight" educates viewers on how to treat their peers who stutter, stressing empathy and patience. View the "In the Spotlight" PSA at **www.youtube.com/watch?v=mp9voC0QymU**

"Too often we hear people speak about stuttering in a negative light," says Noah Cornman, Executive Director of SAY. "There's a common misconception that people stutter because they are nervous, when in reality, they might be nervous out of fear for how the public will react to their stutter."

Stuttering is common, yet young people are often taught that it is something they should be ashamed of, or fix. "In the Spotlight" changes the narrative around youth who stutter by featuring real members of the SAY community in public speaking scenarios. But instead of giving a presentation or belting into song, they deliver speech from everyday interactions – such as asking for a job application or ordering food at a restaurant. This helps viewers understand what ordinary conversations can feel like for youth who stutter, where finishing one sentence can sometimes take as much courage as public speaking. It also tells them to give young people who stutter time to share their voices, as every voice deserves to be heard and respected.

BBDO NY was inspired to partner with SAY to produce "In the Spotlight" after their own Junior Copywriter Aaron Marshall shared his experience of growing up with a stutter and brought attention to the struggles that kids who stutter face. Young people who stutter can get discouraged to speak up and often purposely stay quiet out of fear of others' reactions to how they speak, even when they know the answer, and have so much to offer and share. In Marshall's experience, there were times he would order something at a restaurant that he did not want, just to avoid stuttering. He believes this PSA will shift the narrative from fixing stutters to accepting and celebrating all voices, so that a child never has to compromise again.



SPACE TO SPEAK: This powerful PSA from SAY aims to ignite an overdue national conversation around stuttering to educate viewers about how to supportively listen to people who stutter – by giving them as much time as they need to speak.

For 20 years, SAY has empowered kids to own their voice and teach them that there is nothing wrong with the way they speak. SAY's leadership team works year-round to provide kids with access to arts programs, speech therapy, and summer camp, regardless of a family's ability to pay. The annual two-week sleep-away camp builds a community of acceptance, friendship, and encouragement where young people who stutter can develop the confidence and communication skills they need to thrive. To learn more about SAY, their programs, and how to support, visit SAY.org.

SAY is a national 501(c)(3) non-profit organization that provides support, advocacy and life-changing experiences for young people who stutter. SAY grants access to its valuable programs, which include year-round arts programs, speech therapy, and summer camp – regardless of a family's ability to pay. SAY believes that every voice matters and hopes to educate those who are unaffected.

ABOUT SAY:

SAY:
The Stuttering Association for the Young

SAY: The Stuttering Association for the Young is a national non-profit organization that provides support, advocacy, and life-changing experiences for young people who stutter, ages 3-18. Since 2001, SAY has offered comprehensive and innovative programs that address the physical, social, and emotional impacts of stuttering. Through summer camp, regional day camps, speech therapy, and creative arts programming, SAY builds a community of acceptance, friendship, and encouragement where kids and teens who stutter can develop the confidence and communication skills they need to thrive.

WHAT'S HAPPENING

SALK TEAMS ADVANCE EFFORTS TO TREAT, PREVENT AND CURE BRAIN DISORDERS VIA NIH BRAIN ATLAS

It takes billions of cells to make a human brain, and scientists have long struggled to map this complex network of neurons.

Now, dozens of research teams around the country, led in part by Salk scientists, have made inroads into creating an atlas of the mouse brain as a first step toward a human brain atlas.

The researchers, collaborating as part of the National Institute of Health's BRAIN Initiative Cell Census Network (BICCN), report the new data today in a special issue of the journal *Nature.* The results describe how different cell types are organized and connected throughout the mouse brain.

"Our first goal is to use the mouse brain as a model to really understand the diversity of cells in the brain and how they're regulated," says Salk Professor and Howard Hughes Medical Institute Investigator Joseph Ecker, co-director of the BICCN. "Once we've established tools to do this, we can move to working on primate and human brains."

The NIH Brain Research through Advancing Innovative Neurotechnologies® (BRAIN) Initiative is "a large-scale effort that seeks to deepen understanding of the inner workings of the human mind and to improve how we treat, prevent and cure disorders of the brain." Since its initial funding in 2014, the BRAIN Initiative has awarded more than $1.8 billion in research awards.

ARTICLE IN BRIEF

The international journal of science / 7 October 2021

nature

BRAIN CENSUS

A comprehensive cell atlas of the mammalian motor cortex

City heat
Urban governance must account for rising temperatures

Contrast adjustment
Plasmonic microscope slides add colour to tissue samples

Accessible science
Reflections on how to make research and results more inclusive

DNA Methylation Atlas of the Mouse Brain at Single-Cell Resolution

A comprehensive cell census and atlas of the mammalian primary motor cortex, a region of the brain responsible for movement. The atlas integrates information from various sources to define the molecular, anatomical and physiological identities of specific cell types, while also revealing where they reside in the motor cortex tissue. A significant number of cell types are conserved across mice, marmosets and humans, suggesting those cell types play important roles in cortical circuitry and function in mammals.

www.nature.com/articles/s41586-020-03182-8

The BICCN, one subset of the BRAIN Initiative, specifically focuses on creating brain atlases that describe the full plethora of cells—as characterized by many different techniques—in mammalian brains. Salk is one of three institutions that were given U19 awards to act as central players in generating data for the BICCN.

"This is not just a phone book for the brain," says Margarita Behrens, a Salk associate research professor who helped lead the new BICCN papers. "In the long run, to treat brain diseases, we need to be able to hone in on exactly which cell types are having trouble."

The special issue of Nature has 17 total BICCN articles, including five co-authored by Salk researchers that describe approaches to studying brain cells and new characterizations of subtypes of brain cells in mice. Some highlights include:

DNA METHYLATION ANALYSIS

While other papers in the special issue relate to the function or structure of mouse brain cells, the work led by Ecker, Behrens and their colleagues largely focuses on the epigenomics of brain cells in mice. Every cell in a mouse brain contains the same sequence of DNA, but variations in how this DNA is regulated – its so-called "epigenome" – give cells their unique identity. The arrangement of methyl chemical groups on the cytosine base in DNA (known as "cytosine methylation"), which specifies when genes are to be turned on or off, are one form of epigenomic regulation that may highly influence disease and health in the brain.

In one of the new papers, the Salk team analyzed 103,982 mouse brain cells using single-cell DNA methylation sequencing. This approach, developed in the Ecker lab, lets researchers study the pattern of methyl chemical groups on each strand of DNA in brain cells.

When they applied the technique to the thousands of cells collected from 45 different regions of the mouse brain, they were able to identify 161 clusters of cell types, each distinguished by their pattern of methylation.

"Before now, there have been a handful of ways to describe brain cells based on their location or their electrical activity," says Hanqing Liu, a graduate student in the Ecker lab and co-first author of the paper. "We've really extended the definition of cell type here and used epigenomics to define hundreds of potential cell types."

The team went on to show that the methylation patterns could be used to predict where in the brain any given cell came from—not just within broad regions but down to specific layers of cells within a region. This means that eventually, drugs could be developed that act only on small groups of cells, by targeting their unique epigenomics.

NEURON DESTINATION PATTERNS

In another paper, co-authored by Ecker and Salk Professor Edward Callaway, researchers studied the association between DNA methylation and neural connections. The team developed a new way of isolating cells that connect regions of the brain, then studying their methylation. They used the approach on 11,827 individual mouse neurons, all extending outward from the mouse cortex. The patterns of methylation in the cells, they discovered, correlated with cells' projection (destination) patterns. Neurons that led from the motor cortex to the striatum, for instance, had distinct epigenomics from neurons that connected the primary visual cortex and the thalamus.

"Neurons don't function in isolation, they function by communicating with each other, so understanding how these connections are established and how they work is really fundamental to understanding the brain," says Zhuzhu Zhang, a Salk postdoctoral fellow and a co-first author of the paper with graduate student Jingtian Zhou, both members of Ecker's laboratory.

The researchers say that the new data on the mouse brain cells is merely the first step in creating a complete atlas of the mouse brain – let alone the human brain. But understanding what differentiates cell types is critical to future research and future brain therapeutics.

"In these foundational studies, we're describing the 'parts list' for the brain," says Callaway. "Having this parts list is revolutionary, and will open up a whole new set of opportunities for studying the brain." •

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

Publiction 5534 (6-2021) Catalog 38425P Department of the Treasury **Internal Revenue Service** www.irs.gov

AMERICAN ACADEMY OF DEVELOPMENTAL MEDICINE & DENTISTRY

Can Parents with Disabilities Care for their Children?

BY H. BARRY WALDMAN, DDS, MPH, PHD, RICK RADER, MD, FAAIDD, FAADMD, DHL (HON)
AND STEVEN P. PERLMAN, DDS, MSCD, DHL (HON)

*"**Exceptional Parent Magazine** provides advice, **emotional** support, and the most up-to-date **educational** information for families of children and adults with disabilities and special health care needs."* (Internet description of the magazine)

The title of the publication emphasizes (rightfully) the **Exceptional Parent.** The care and support of the members of the family with disabilities impacts upon the parents; in most situations, the mother (and grandmother). What if the mother has a disability? Can she provide the needed care? The titles of a series of studies and articles detail the difficulties, outcomes, and consequences.

- *Parents with disabilities: these moms live in fear of losing their kids* [1]
- *Disabled parents face bias, loss of kids* [2]
- *Can parents lose custody simply because they are disabled?* [3]
- *For parents around the country, having a disability can mean losing custody of their kids* [4]
- *Disability and discrimination in custody battles* [5]

SPECIFICS

> *"Millions of Americans with disabilities have gained innumerable rights and opportunities since Congress passed landmark legislation on their behalf in 1990. And yet advocates say barriers and bias still abound when it comes to one basic human right: **To be a parent**.* (emphasis added) *…A California woman paid an advance fee to an adoption agency, then was told she might be unfit to adopt because she has cerebral palsy."* [2]

Historically, society has been worried about people with disabilities becoming parents. "In the late 19th and early 20th centuries, many Americans grew infatuated with the American eugenics movement, which sought to 'breed' a superior race through government intervention. This led to Buck v. Bell, a 1927 Supreme Court decision that allowed states to sterilize inmates of public institutions who they considered to be 'mentally unfit' or generically inferior. The ruling… allowed at least 70,000 forced sterilizations (without consent) …Justice Oliver Wendell Homes Jr., who wrote the decision, declared: **'Three generations of imbeciles are enough.'**" [6] *(emphasis added)*

Mothers with disabilities, were (and are) often told that having children will worsen their conditions, that their disabilities will be passed on to their children, and that they won't be competent mothers. "The majority of parents with disabilities have a fear of their children being apprehended, because you know you are being watched (by Social Service Organizations) right, wrong or otherwise." [1]

- *Even if they are struggling, they are afraid to ask for help, because they are seen as a bad parent failing to meet all the needs of their children, and it must be because of their disability.*
- *The U.S. legal system is not adequately protecting the rights of parents with disabilities. Child welfare laws in most states allow courts to determine that a parent is unfit on the basis of a disability.*
- *Parents with all types of disabilities – physical or intellectual – are more likely to lose custody of their children after divorce, have more difficulty accessing assisted-reproductive treatments to bear children and face significant barriers to adopting children.* [1]

AMERICAN ACADEMY OF DEVELOPMENTAL MEDICINE AND DENTISTRY

AADMD

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.

- *“… the bias against parents with disabilities is such that judges tend to grant custody to an able-bodied partner, even if they have a history that might usually be a heavy mark against them – not having been in the child's life, a history of violence, etc.“*[3]
- *“ … a young mother with an intellectual disability, had her two-day-old daughter taken by the state of Massachusetts and placed in foster care. Specifically, the state believed she was unable to care for her newborn because of her disability… officials said she displayed with feeding and diapering. While these are common challenges for most new mothers,(sic) … it led to a battle involving the federal government.”*[4]
- *“ … parents with disabilities often contend with bias and speculation concerning their parenting ability, especially by the child welfare system, (sic)… ”*[4]

More than two-thirds of state child welfare laws still allow for a parent’s disability to be considered for the purposes of terminating parental rights. A recent study found that 19 percent of children in foster care had been removed from their home at least in part because they had a parent with a disability.[4]

- *According to the National Council on Disability, “The child welfare system is ill-equipped to support parents with disabilities and their families, resulting in: 1) the disproportionately high rates of involvement with child welfare services and 2) devastatingly high rates of parents with disabilities losing their parental rights… Oftentimes, disabled parents are not receiving the accommodations they are entitled to. Too often, decisions are made to prevent a child from going home, without providing parents a fair opportunity to parent.”*[4]
- *“… disability rates are higher among Black and Native parents, (sic) meaning that many parents with disabilities face double discrimination because of their multiple marginalized identities. As persons of color and parents (with disabilities), our abilities are often second-guessed, given a side-eye, and profiled in disproportionate ways.”*[4]
- *The right to raise a family is undeniably one of our most cherished in the United States. However, for people with disabilities, especially those from marginalized communities, it is often challenged solely because of bias and speculation.*[4]

CONSIDER

“Imagine you are a parent who has overcome a disability. The disability could be physical that confines you to a wheelchair; or a psychiatric disability that requires you to take medication. You are living a perfectly normal life with your disability, so much so that your disability isn’t really a disability in your mind - it is just part of living. You have learned to overcome what some other people who had a similar diagnosis have not yet learned to overcome. The disability has proved that you have the ability to live a normal life.”[5]

Then imagine that you are now going through a divorce, you have children and you need to go to court to fight for custody of your children Although you have been the primary caregiver for your child or children, a judge now decides that you are unfit for custody of your child. Imagine!

YOU ARE NOT ALONE

“Research indicates that parents with disabilities and their families are over-represented in the child welfare system. While parents with disabilities make up only 6.2 percent of all parents in the United States, a recent study found that 19 percent of children in foster care have a parent with a disability.”[7]

“35 states include disability as grounds for termination of parental rights.”[5]

A CHANCE TO SUCCEED: “Oftentimes, disabled parents are not receiving the accommodations they are entitled to. Too often, decisions are made to prevent a child from going home, without providing parents a fair opportunity to parent.”

Indeed, ***EP Magazine*** is a publication for all families with youngsters and the not-so-young with disabilities, as well as their caregivers – especially mothers (and grandmothers), who themselves may have disabilities.•

ABOUT THE AUTHORS:

H. Barry Waldman, DDS, MPH, PhD is a SUNY Distinguished Teaching Professor, Department of General Dentistry, Stony Brook University, NY.
E-mail: h.waldman@stonybrook.edu.
Rick Rader, MD, DHL (Hon) is the Director of the Morton J. Kent Habilitation Center, Orange Groove, Chattanooga, TN; Senior VP Public Policy, American Academy of Developmental Medicine and Dentistry; Adjunct Professor, Human Development, University of Tennessee-Chattanooga. He is Exceptional Parent Magazine’s Editor in Chief.
Steven P. Perlman, DDS, MScD, DHL (Hon) is the Global Clinical Director and founder, Special Olympics, Special Smiles; and Clinical Professor of Pediatric Dentistry, The Boston University Goldman School of Dental Medicine.

References

1. Tomasi P. The Huffington Post Canada. Parents with disabilities: these moms live in fear of losing their kids. Available from: https://www.huffingtonpost.ca/2015/05/10/parents-with-disabilities_n_7251484.html Accessed October 13, 2020.
2. CBS News. Disabled parents face bias, loss of kids: Report. Available from: https://www.cbsnews.com/news/disabled-parents-face-bias-loss-of-kids-report Accessed October 13, 2020.
3. Powell R. American Bar Association. Can parents lose custody simply because they are disabled? Available from: https://www.americanbar.org/groups/gpsolo/publications/gp_solo/2014/march_april/can_parents_lose_custody_simply_because_they_are_disabled/ Accessed October 13, 2020.
4. Powell R. Rewire News Group. For parents around the country, having a disability can mean losing custody of their kids. Available from: https://rewirenewsgroup.com/article/2018/03/12/parents-around-country-disability-can-mean-losing-custody-kids/ Accessed from: October 13, 2020.
5. Heroux P. Huffpost. Disability and discrimination in custody battles, Available from: https://www.huffpost.com/entry/disability-and-discrimina_b_5616446 Accessed October 13, 2020.
6. Fayyad A. The whole purpose of forcibly sterilizing women was to root out undesirable genes. Boston Globe. Available from: Abdallah.fayyad@globe.com Accessed October 19, 2020.
7. Parent Rights Foundation. Parental rights and disabilities. Available from: https://parentalrightsfoundation.org/parental-rights-and-disabilities/#parents Accessed October 14, 2020.

Accepting
Applications
SY 2021-2022
Rolling Admissions

AYM

Academy for
Young Minds

Behavioral Approach to Learning

New Private **School** for Mid- to High-Functioning Children on the Autism Spectrum in Long Island City

Discover Our
School
Just Steps from Manhattan

Scan the
QR
CODE

Instructional Approach & Program Focus

- Applied Behavior Analysis
- Individualized Instruction
- ST, OT, PT, & CO Services
- Social & Functional Language Skills

State-of-the-Art Facility:

- A Sensory Gym, Multi-Purpose Room, Outdoor Playground, and Therapy Rooms!
- Steps from Parks (basketball & baseball fields)
- Security Zone Entrance, Access Control and Video Management System
- Air Purification System throughout the Facility, Hand Sanitizing Stations, Touchless Faucets and Soap Dispensers

www.AYMSchool.org ◆

11-20 46th Road,
Long Island City,
NY, 11101

Schedule a Tour Today
info@AYMSchool.org
(646) 670-5999

BY ROB WRUBEL, CFP®

"Fly me to the moon, let me play among the stars." Frank Sinatra sang that great song in August of 1964, when the space program and dreams of setting foot on the moon excited the imaginations of people around the world.

DOLLARS & SENSE
A SPECIAL SECTION

Last summer, the space race was back, with billionaires Branson, Musk and Bezos reigniting the dream to put themselves and others in outer orbit. Hundreds of people plopped down giant sums of money to have a chance to ride a rocket and float weightlessly in the nearer realms of outer space.

Do you have big dreams that require a financial commitment? It doesn't have to be creating an aircraft or rocket to fly into space. Sure, if someone else paid, I might take a ride on the rocket. But my dreams and visions of the future start with taking care of my family, creating memories through shared experiences, and providing support for my daughter with Down syndrome during her entire time on earth, so she can live her best life possible.

There are lessons to be learned from watching the new space races, lessons we can all use in our financial lives and planning for the future.

1. ***Build a strong financial base.*** *It's unlikely any of us will become billionaires – there are about 3,200 of them as of 2020 – but we can all focus on getting out of debt, funding trust and retirement accounts and having enough money to feel comfortable. Once the base is in place, then excess funds can be used to pursue passion projects.*
2. ***Know that you're on track.*** *Branson, Musk and Bezos passed the point where they have to think if they'll have enough funds to last a lifetime. A financial plan can let you know if you're "on track" or not to have enough money to last, and to fund estate goals to a special-needs trust and to gift to other children.*
3. ***Invest for your future.*** *These billionaires put money to work. They each created wealth by the stock they held in their companies (and in others, I'd guess). To grow wealth, take a portion of your earnings and put it towards something that has the chance to gain in value. This can be done by investing in stocks, bonds, real estate, commodities or your own business. You cannot create wealth by spending everything you earn.*
4. ***Envision your future and take action.*** *I don't know their stories, but somewhere along the way, those three billionaires sat down and imagined themselves in space and then put action plans in place to get there. Sometimes, I imagine myself flying around the earth as well, but I haven't done one thing about it (and really I'm not too interested). That's a dream without a goal and one unlikely to happen.*

In my work with families with special-needs members, the first step is to get a piece of paper and write all that's desired from the future. Imagine the focus required to build a rocket to fly to space. Now, imagine taking that same effort to some of your goals and dreams – we have enormous capacity when we put our desires, passion and intensity towards achievement.

Fly to the moon – maybe not for me. Helping my daughter gain independence – count me in. That's a goal that will help me feel like I am flying around the stars. •

ABOUT THE AUTHOR:

Rob Wrubel is a CFP who has a daughter with Down syndrome. He is recognized as a leading expert on financial planning for families with special needs members. Wrubel has written two books about financial planning and special needs families – *Financial Freedom for Special Needs Families: 9 Building Blocks to Reduce Stress, Preserve Benefits, Create a Fulfilling Future* and *Protect Your Family: Life Insurance Basics For Special Needs Planning* – and he has been published recently by Law360.com and The Good Men Project. Wrubel holds the Certified Financial Planning (CFP®) designation, the Accredited Investment Fiduciary® (AIF®) designation from Fi360, and the Accredited Estate Planner (AEP®) designation from the National Estate Planning Council.

“I’m employed today…

because *we* worked together.”

Working Works.

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

WhatCanYouDoCampaign.org

ODEP
Office of Disability Employment Policy

OFFICE OF DISABILITY EMPLOYMENT POLICY
UNITED STATES DEPARTMENT OF LABOR

What can YOU do?
THE CAMPAIGN FOR
DISABILITY EMPLOYMENT

ASSESSING THE NEEDS OF STUDENTS WITH DISABILITIES DURING TRANSITION

BY CHERYL THOMPSON

What happens to students with disabilities as they transition from high school and how can the process be improved? *When transition-aged youth are unaware of the variety of services available to them during and after high school, an information gap in successful post-secondary outcomes in the areas of independent living, employment and education or training can occur. The national RAISE (Resources for Advocacy, Independence, Self-determination and Employment) Center and MPACT (Missouri Parents Act) are working together to identify programs and professionals that are key in accessible transition of young adults with disabilities into adulthood through survey input.*

DISCOVERING WHAT WORKS

We are looking for young adults nationally who have exited school, are between the ages of 18 through 26, and have disabilities to complete a short survey about their experience. The first 100 young adults who complete this survey will receive a $10 gift card from Amazon. We also welcome feedback from parents or other family members of young adults with disabilities aged 18-26.

RAISE works with the eight Rehabilitation Service Administration Parent Training and Information Centers (RSA-PTIs), Parent Centers, youth with disabilities, families, and other transition organizations to improve transition for youth and families.

MPACT is Missouri's only federally-funded Parent Training and Information Center. Its mission is to empower families to advocate for themselves so that children with special education needs can reach their full potential in education and life – through support, training, and education.

The feedback from this survey will identify the products for the Get Linked project. Get Linked will help parent centers, families, and youth to be able to better work with service providers and organizations to make transition smoother.

TRANSITION TOPICS ADDRESSED

Transition is more than school-to-work. The data collected will focus on multifaceted issues regarding transition to adult life. These include:

- **Post-secondary outcomes**
  This section looks at employment, college, and training.
- **Job satisfaction**
  Questions are asked regarding full/part time, disability disclosure, fulfillment, and benefits.
- **College or training**
  This section examines major course of study, or satisfaction with training.
- **Housing**
  Questions determine the living situation whether it is in their own home, family home, supported living, etc.
- **Preparation**
  Various topics are explored beyond job training to include self-advocacy, independent living, and community inclusion. Then each area is drilled down to discover who prepared students, whether it was the child study team, transition coordinator, vocational rehabilitation, or Center for Independent Living.
- **Quality of Life**
  The last area looks at current challenges, what's working, and what students wished they knew.

Remember: Effective transition for students with disabilities to adult life is key to successful outcomes. •

PROVIDE FEEDBACK

LINK TO THE ONLINE SURVEY:

www.surveymonkey.com/r/RAISE-MPACT-Transition-Survey

For direct assistance completing the survey, please call 800-743-7634, or email **info@missouriparentsact.org**.

ABOUT THE AUTHOR:

Cheryl Thompson is the Program Director of MPACT, Missouri Parents Act. For more information, see www.missouriparentsact.org

ON THE MOVE : TRANSITIONING RESOURCES

MPACT

MPACT: MISSOURI PARENTS ACT

www.missouriparentsact.org

RAISE

RAISE

Resources for Advocacy, Independence, Self-Determination, and Employment

www.raisecenter.org

PARENT TRAINING AND INFORMATION CENTERS

www.parentcenterhub.org/find-your-center

NCIL
National Council on Independent Living

NATIONAL COUNCIL FOR INDEPENDENT LIVING

www.ilru.org/projects/cil-net/cil-center-and-association-directory

THE CDA DENTAL PATIENT WITH SPECIAL HEALTHCARE NEEDS TRANSITION PROCESS

BY CLIVE S. FRIEDMAN, DDS

In dentistry, when a young person reaches 12 to 18 years of age, they usually transfer from a pediatric dentist to a general dentist who will continue to provide oral healthcare for them in a new dental home. This process is called ***transition****.*

The oro-facial region is subject to increased sensitivity, and when invaded can elicit responses that are far more impactful than a typical medical exam. Behavioral interventions are thus more complex in pediatric dentistry and this is just one of the reasons this transition can be particularly difficult. Few resources are available to help parents/caregivers when the time comes to transfer to a new provider. There are transitioning documents available, such as the GOT transition process, but they are not designed for oral healthcare.

In 2019, I partnered with a general practitioner and a parent of a child with special needs to create a better resource to help families navigate the oral health care transition. Beyond helping patients and their families, we wanted this resource to arm new providers with information that would enable them to provide the highest level of care possible to the patients they were welcoming into their practices.

TEETH WISDOM : CREATING AN ORAL HEALTH CARE TRANSITION PROCESS

We began by assessing available medical transitioning documents, and created a process and series of adapted forms to more specifically address oral healthcare needs. The process and forms were piloted in my pediatric practice and in the GP's practice, and updated to reflect the results of that pilot. They are currently being prepared for publication by the Canadian Dental Association. The process includes three key steps:

STEP 1: TRANSITION READINESS ASSESSMENT

This step is an assessment of the patient's ability to take care of their oral health. *Are they able to make oral healthcare decisions? What is their awareness of their oral health needs? Do they have the ability to express these needs? How well do they tolerate the dental environment?*

The assessment also has patients and families identify difficult issues that might come up during the transition, and consider actions that can be taken to alleviate these problems.

STEP 2: DENTAL SUMMARY AND CARE PLAN

In this step, the current dental home care provider (often a pediatric specialist) completes a dental summary and care plan. The specialist will outline the specifics of what works and what does not work for the individual. Specific behavioral interventions can be highlighted. *What treatment has been accomplished successfully? How was this treatment provided?*

Sometimes the new practitioner may be unaware of specific techniques, and in certain areas of the form, it will have embedded video material to help demonstrate some of the nuances of the methodologies used by the current provider.

STEP 3: MEET AND GREET

Here, we provide a brief example of a letter that the new practitioner can send out to the family, welcoming them to the new practice and detailing the process by which they plan on incorporating them into the new office.

SMILES AHEAD: "This pilot project has allowed for a more concise and effective method of communication between the specialist and general practitioner related to the patient's medical history, social behavior, and dental needs."

THE FORMS WE ADAPTED TO GUIDE THIS PROCESS INCLUDE:

- *A form to assess a patient's readiness for transitioning;*
- *A letter to parents explaining the steps of the transition process in detail;*
- *An in-depth oral health history and behavior form;*
- *An example of a welcome letter that the GP can send to the parent before the transition process begins.*

The two most common barriers identified by caregivers that enable adequate transfer from a pediatric dental home to an adult dental home are understanding SHCN and insurance. The dental summary care plan is an attempt to provide extra educational material to the new dental team. It also offers an opportunity to discuss financial and other perceived barriers individualized to each family.

QUOTE FROM PARENT (HELPED DESIGN THE TRANSITIONING FORM)

"It's true; parents do know their children best, especially when their child has been in their care for many years and may require their assistance and advocacy. It's important that parents see themselves as an integral part of the treatment team. It's doubly important that parents willingly and knowingly appreciate the role they play in the successful transition from the care of a pediatric dental environment to one serving the community at large."

"Change can be stressful. Parents will have questions. The new, receiving dentist will have questions. Take the necessary time to ask those questions, to listen, and provide each other with helpful feedback. Working together works best. Dentists, dental technicians, reception staff, patients and parents alike are key to a smooth outcome –one more likely to ensure that all participants are comfortable and ready to make the change."

QUOTE FROM GP

"Transitioning patients with special needs from an office of a specialist to general practitioner can be quite challenging for all parties involved, including both the practitioners, staff members, as well as the parents/caregivers of the patient. This pilot project has been quite successful in making this transition process much more straightforward and effective. It has allowed for a more concise and effective method of communication between the specialist and general practitioner related to the patient's medical history, social behavior, and dental needs. In addition, the easy-to-use template helps staff members become effective liaisons of this transition. More important, this process has provided the parents/caregivers with the comfort and confidence that a smooth and seamless transition is taking place from one environment to another. I am both proud and happy to have been a part of this project, and am hoping that it becomes more mainstream in the years ahead. •

ABOUT THE AUTHOR:

Clive Friedman, DDS, FAAPD, is a pediatric dentist who sees patients at Pediatric Oral Health and Dentistry, his private practice located in London, Ontario, Canada. He has an impressive professional journey, spanning more than four decades, and has a special interest in persons with special needs, behavior, prevention, education, and wellness. Contact him at clive@dentistryforkids.ca

HELPING YOU COMBAT COVID-19

BANTEC SANITIZING

COMMERCIAL AND RESIDENTIAL CLEANING PRODUCTS & SERVICES

Bantec Sanitizing is your ally in the fight against Covid-19. With efficient and affordable solutions for cleaning and safely sanitizing residential, school and business settings, Bantec Sanitizing can help you prepare for living, learning and working in a safe and healthy environment.

HOME

SCHOOL

OFFICE

Bantec Sanitizing offers a wide selection of industry-leading products for all of your sanitizing needs. In addition, we are introducing groundbreaking technological innovations that can be custom tailored for your particular specifications. Visit bantec.store/pages/bantec-sanitizer-service for more information.

Our products are easy for anyone to use in multiple environments to protect themselves by disinfecting surfaces they encounter throughout the day.

CLEANING PRODUCTS
www.bantec.store/collections/all

Our service provides the safest, most environmentally friendly hygiene strategy. Easy to use and implement while being efficient and cost effective.

CLEANING SERVICES
www.bantec.store/pages/bantec-sanitizer-service

EXCLUSIVE OFFER!

BANTEC DISINFECTING KIT

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

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

Clean Smart

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

Bantec Sanitizing is committed to providing their customers the most comprehensive cleaning products and services that are safe, environmentally friendly, easy to use, efficient and affordable.
Contact us today!

A DIVISION OF BANTEC

HELPING YOU COMBAT COVID-19
BANTEC SANITIZING **www.bantec.store**

TRANSITIONING YOUNG ADULTS WITH AN INTELLECTUAL OR OTHER DEVELOPMENTAL DISABILITY TO ADULT HEALTHCARE

BY CARL V. TYLER, JR, MD, MSC AND MOLLY MCDERMOTT, DO

Some teenagers and young adults who have an intellectual or other developmental disability (IDD) require extensive subspecialty care; many, however, depend primarily on their pediatrician or family physician for the bulk of healthcare. With that reliance in mind, this article provides (1) an overview of important services that primary care physicians can provide for their young adult patients with an IDD and (2) pragmatic clinical suggestions for tailoring that care.

ESSENTIAL TRANSITION: PEDIATRIC TO ADULT HEALTHCARE

Healthcare transition is the planned process of transferring care from a pediatric to an adult-based healthcare setting, comprising three phases:

- *preparation*
- *transfer from pediatric to adult care*
- *integration into adult-based care.*

Two critical components of a smooth healthcare transition include initiating the transition early in adolescence and providing transition-support resources, which are often lacking, even in large, integrated health systems. Got Transition®, created by the National Alliance to Advance Adolescent Health, outlines core elements of an organized healthcare transition process (**www.gottransition.org**) specific to young adults with an IDD, including young adults with autism spectrum disorder.

Even youth served by a family physician and who intend to remain in that family practice as they age into adulthood require healthcare transition services, including:

- *assessing readiness to transition to adult care*
- *updating the medical history*
- *assessing and promoting self-care skills*
- *discussing consent and optimizing participation in decision-making as adulthood approaches*
- *transferring specialty care from pediatric to adult specialists.*

For an ideal healthcare transition, full engagement of the patient, the medical home (physicians, nursing staff, and care coordinators) and the patient's family (including the primary caregiver or guardian) are critical. In addition to preventive care visits and management of chronic disease, additional domains that require explicit attention in transitioning youth with an IDD include health insurance, transportation, employment, and postsecondary education.

Youth who have special healthcare needs and receive high-quality healthcare transition demonstrate improvements in adherence to care, disease-specific measures, quality of life, self-care skills, satisfaction with care, and healthcare utilization.

PREPARING FOR IN-PERSON VISITS

Pre-visit preparation, by telephone or a virtual visit, is often critical for a successful first face-to-face encounter. Pre-visit preparation should include identifying words or actions that can trigger anxiety or panic; recommending de-escalation techniques, such as specific calming words and actions; and detailing strategies for optimal communication, physical access, and physical examination. Initial appointments should focus on building trust and rapport with the healthcare team and desensitizing the patient to the clinical environment.

THE VALUE OF SYSTEMATIC HEALTH CHECKS

A *health check* is a systematic and comprehensive health assessment that is provided annually to adults with IDD, and includes:

- *specific review of signs and symptoms of health conditions that often co-occur in adults with IDD (See Table 1).*
- *screening for changes in adaptive functioning and secondary disability*
- *lifestyle counseling*
- *medication review and counseling*
- *immunization update*
- *discussion of caregiver concerns.*

Many caregivers are the aging parents of the adult patient with IDD and have their own emerging health and support needs. Conversations about advanced planning for the future needs of patients are essential, and may lead to engaging siblings or other family members to assume a greater role in caregiving.

Table 1. *Commonly co-occurring medical conditions in adults with an IDD*

Cerumen impaction
Chronic sinusitis
Constipation
Degenerative joint disease
Degenerative spinal disease
Dental caries
Dysphagia
Epilepsy
Gastritis
Gastroesophageal reflux disease
Hearing impairment
Obesity
Osteoporosis and osteomalacia
Periodontal disease
Urinary retention
Visual impairment

Health checks increase the detection of serious conditions, improved screening for sensory impairments, and increased the immunization rate. Although many patients with IDD generally understand the need for a periodic health examination, physicians can enhance their experience by better explaining the rationale of the health check, providing a sufficient duration of the appointment, and discussing the value of laboratory testing and referrals to specialists.

TAILORING PREVENTIVE CARE

Many of the preventive services guideline recommendations typically utilized by primary care physicians, such as those developed by US Preventive Services Task Force, have been developed for the general population at average risk of conditions of interest. Adults with IDD, depending on the cause of their developmental disability and their behavioral risk profile, might be at significantly higher (or lower) risk of cancer, heart disease, and other conditions than the general population. To address these differences, preventive care guidelines tailored to patients with certain developmental disabilities have been developed, including guidelines specific to adults with Down syndrome, fragile X syndrome, Prader-Willi syndrome, Smith-Magenis syndrome, and 22q11.2 deletion (DiGeorge) syndrome.

Clarifying the molecular genetic etiology of many developmental disabilities has led to more precise understandings about physical and behavioral health issues associated with specific developmental disabilities. For that reason, patients without a known cause for their IDD might benefit from referral to a geneticist – even in early or middle adulthood. Features generally associated with a higher likelihood of an abnormal genetic test result include:

- *a family history of developmental disability*
- *a congenital malformation or dysmorphic features*
- *a dual diagnosis of developmental disability and co-occurring mental illness*
- *hypotonia*
- *severe or profound IDD.*

Successful implementation of preventive health screening tests often requires ingenuity and the collective creativity of patient, family members, staff, and physician to allay fears and anxieties. Two examples are: women who have been advised to undergo screening mammography might feel less anxious by undergoing tandem screening with their sister or mother, and colorectal cancer screening might be more easily accomplished using a fecal DNA test rather than by colonoscopy. Procedural desensitization strategies and preventive care instructional materials targeting persons with IDD are posted on YouTube and other websites.

WEIGHTY ISSUE: Youth with IDD tend to be less fit and have a higher prevalence of obesity.

MANAGEMENT OF CHRONIC DISEASE

Evidence of health disparities in patients with an IDD includes suboptimal management of chronic diseases, such as diabetes and hypertension, despite contact with a primary care physician. Nonadherence to a medication regimen might be more common in patients who live with their family or in a residential setting where there is less supervision.

ESSENTIALS OF MENTAL HEALTHCARE

It is estimated that one-third of adults with IDD have significant mental and behavioral healthcare needs. Patients with IDD are subject to the same psychiatric disorders that affect the general population; some also engage in problematic behaviors, such as self-injurious actions, physical or verbal aggression (or both), property destruction, and resistance to caregiving assistance.

Mental and behavioral health problems can have a profound impact on the quality of life of patients with IDD, their peers, and their families and other caregivers. If untreated, these problems can lead to premature institutionalization, loss of employment or desired program participation, fractured social relationships, and caregiver withdrawal and burnout.

Initial evaluation of suspected mental and behavioral health issues begins with careful assessment for medical conditions that might be causing pain and distress, stereotypies, and other problematic behaviors. Common sources of pain and discomfort include dental and other oral disease, dysphagia, gastroesophageal reflux disease, gastritis, constipation, allergic disease, headache, musculoskeletal pathology, lower urinary tract disease, and gynecologic disorders. Identification and optimal treatment of medical conditions might not eliminate problematic behaviors but often decrease their frequency and intensity.

Psychoactive medications are prescribed for many patients with IDD. Many drugs have behavioral adverse effects, such as akathisia, aggression, and disinhibition – leading to a prescribing cascade of psychoactive medication polypharmacy and escalating dosages. Antipsychotic medications are often initiated without a careful diagnosis, explicit outcome targets, or adequate clinical monitoring for effectiveness; in addition, they often lead to insulin resistance, metabolic syndrome, and massive weight gain. Even a physician who is not the prescriber can perform an important advocacy role by critically reviewing psychoactive medications, documenting adverse effects, insisting on a clear therapeutic target, and calling for discontinuation of medications that appear to be ineffective.

Evaluation of mental and behavioral health problems requires a developmental perspective to interpret specific, observable behaviors with a proper clinical lens. For example, many patients with IDD engage in self-talk *(soliloquizing)* as a means of processing the world around them. This practice might escalate during a time of physical or psychological stress, and the unwary clinician might misinterpret this behavior as psychotic, leading to inappropriate prescribing of antipsychotic medication. Other psychotoform behaviors that, superficially, mimic but are typically not truly psychotic, include talk with or about imaginary friends and repetitive retelling of sometimes elaborate or grandiose tales or assertions. The failure of clinicians to recognize developmentally-determined expressions of distress often leads to a misdiagnosis of schizophrenia or other psychotic illness and, consequently, inappropriate psychopharmacotherapy.

Primary care physicians, familiar with the use of psychiatric scales for diagnosis and treatment monitoring, should use similar scales that have been developed specifically for patients with IDD *(See Table 2)*. In addition, a psychiatric diagnosis manual, the *Diagnostic Manual—Intellectual Disability 2,* specific to individuals with IDD (and analogous to the *Diagnostic and Statistical Manual of Mental Disorders, 5th Edition*) provides modification of diagnostic criteria to account for patients who have difficulty with articulating their internal emotional states and inner thoughts.

Problematic behaviors that are not features of a bona fide psychiatric disorder are often best understood through functional behavioral analysis, which examines antecedents and consequences of problematic behaviors and identifies their predictable outcomes, such as attention, task avoidance, sensory stimulation, and securing of desired items. Rather than being given a prescription for one (or more) psychoactive medications, many adult patients with IDD and problematic behaviors might be best served by consultation with a certified behavior analyst, who will conduct an evaluation and, along with family or residential staff and the patient, craft a behavioral support plan to address core drivers of the undesired behavior. Behavioral support plans may be enriched by multidisciplinary input from a speech and language pathologist, habilitation professionals, occupational and physical therapists, a neuropsychologist, and others.

Resources to help address the physical and the mental and behavioral health problems of these patients are available online through Vanderbilt Kennedy Center's "Toolkit for primary care providers" (https://iddtoolkit.vkcsites.org).

WEIGHT MANAGEMENT

Patients with IDD are more likely to live a sedentary lifestyle. Compared to adults who do not have IDD, adults with IDD – especially women and patients with Down syndrome – are reported to have a higher prevalence of obesity. Health-promoting behavioral interventions that rely on a dyadic strategy, such as peer health coaches (i.e., people with IDD who have been trained as a health coach) or mentors (IDD staff trained as health coaches), might be more successful at changing health behaviors among patients with IDD compared to traditional office-based, individual patient education and counseling.

On the other extreme, undesired weight loss demands careful evaluation and management because such loss can reflect a medically significant condition, such as gastroesophageal reflux, constipation, dysphagia, neglect, and cancer.

Table 2. *Co-occurring mental and behavioral health problems and pertinent screening and monitoring tools*

Co-occuring problems:

- Anxiety disorders
- Attention deficit disorder
- Complicated grief
- Drug-induced movement disorders
- Dementia
- Mood disorders
- Posttraumatic stress disorder
- Rumination
- Stereotypic movements

Screening and monitoring tools:

- Abnormal Involuntary Movement Scale (AIMS)
- Antipsychotic Side-effect Checklist (ASC)
- Behavior Problems Inventory-Short Form (BPI-S)
- Dementia Screening Questionnaire for Individuals with Intellectual Disabilities (DSQ-IID)
- Glasgow Anxiety Scale for People with an Intellectual Disability (GAS-ID)
- Glasgow Antipsychotic Side-Effect Scale (GASS)
- Glasgow Depression Scale for People with a Learning Disability (GDS-LD)

BOOSTING THE AMOUNT AND EFFECTIVENESS OF PHYSICAL ACTIVITY

Youth with IDD participate in physical activity less often than their neurotypical peers; as a result, they tend to be less fit and have a higher prevalence of obesity. Interventions that focus on sport and movement skills training, such as soccer, basketball, and ball-throwing programs, might be more effective than general physical activity programs. In addition to year-round sports training and athletic competitions, Special Olympics conducts vital health screenings of athletes and supports community-based initiatives that address bias against patients with IDD, promote inclusion, and foster social relationships. In adulthood, fewer than 10% of patients with IDD exercise regularly. By participating in any type of physical activity, there is potential for considerable health benefit in reducing psychosocial stressors, improving mental health, counteracting metabolic syndromes, and, ultimately, reducing morbidity and mortality related to physical inactivity.•

Note: This article was adapted with permission from an article that originally appeared in *The Journal of Family Practice.* Tyler CV, McDermott M. Transitioning patients with developmental disabilities to adult care. *J Fam Pract.* 2021;70:280-288. doi: 10.12788/jfp.0232 The original article, with references, can be found at: www.mdedge.com/familymedicine/article/243139/diabetes/transitioning-patients-developmental-disabilities-adult-care

ABOUT THE AUTHORS:

Carl V. Tyler, Jr, MD, MSc; Molly McDermott, DO - Cleveland Clinic Lerner College of Medicine, Case Western Reserve School of Medicine, OH (Dr. Tyler); Cleveland Clinic Family Medicine Residency Program, OH (Drs. Tyler and McDermott)

The mission of CAA is exclusively lifelong education, but the vocational component is incorporated with the hiring of incredible and astute individuals who have had a hard time finding gainful employment in traditional workforce settings. CAA has also hired numerous students onto their CAA “Superstaff” as well to work as Associate Professors in multiple classes.

REINVENTING COLLEGIATE OPPORTUNITIES FOR ADULTS WITH SPECIAL NEEDS

BY DEANNA PURSAI

Many young people with special needs grow up seeing their friends and family graduate from high school and head off to college to get a degree and a diploma, but there is a stark contrast in educational opportunities for themselves, as most are mandated out of postsecondary programs at age 22.

PHOTOS PROVIDED BY LIZ ROSINSKI

If they are not able to keep up with the accommodations afforded them to access an .edu Associate's Degree, their educational opportunities essentially come to a grinding halt, and the focus shifts almost exclusively on independent living, vocational training, and traditional day program options. But all that is changing with College of Adaptive Arts (CAA), a 501 c 3 non-profit which provides an equitable, lifelong collegiate experience to adults with special needs who historically have not had access to college.

Co-founders DeAnna Pursai and Dr. Pamela Lindsay started College of Adaptive Arts in 2009 after both witnessing loved ones with special needs become marginalized and sidelined once they exited the public school system. They both knew how much more their loved ones were capable of achieving and saw the vast chasm between what was available educationally and what was possible for adults to achieve.

SHOWTIME: *(Opposite page)* Dr. Pamela Lindsay and CAA student & 2020 Valedictorian Oliver Motiee at a past CAA Film Festival. The 13th Annual Celebrating Abilities Virtual Film Festival featured films by, for, and about people with disabilities, showcased 50 films from nearly 2,000 entry submissions from around the world. *(Above left)* Associate Professor Bernard particpates in a Zoom class; *(Above right)* Curtis rehearses on a CreaTV set.

"When we first began, it was just one-musical theatre class and 12 adult students," said Dr. Lindsay, co-founder of the CAA. "As of Fall 2021, we are proud to report that we have nearly 80 course offerings, including around 1,000 available class seats and close to 160 adult students across four states each quarter."

What makes College of Adaptive Arts so different is that it focuses on person-centered, self-determination initiatives. The school accepts adults ages 18+ of all skill levels, and no prospective student is turned away. Some students are higher functioning while others are still learning how to read, write, and sometimes still learning how to speak. There are no tests, no papers to submit, and every student gets an A+ for the day if they want to be there and continue learning. Each course is one-hour long each week, and students only sign up for the classes that they are interested in.

According to CAA co-founder DeAnna Pursai, this new type of model provides a lifelong, articulated, equitable collegiate experience. "There are excellent collegiate models on institutions of higher learning – but nearly all these models are finite in design with a maximum of two to four years," said Pursai. "Other educational programs for adults have [maximum age limit guidelines] vs. age limits at 28 or 32 years of age."

"However," adds Dr. Lindsay, "adults with developmental disabilities do not experience a finite group of years during which they are able to capture concepts. They benefit from ongoing re-teaching and re-learning of skills, including reading and writing skills, over time. CAA's revolutionary model breaks the box, delivering courses personalized to each student's current needs at any point on their ongoing learning journey, plus expanded friendships and community engagement."

College of Adaptive Arts offers privately accredited, nontransferable diplomas with annual graduation ceremonies with keynote speakers, valedictorian/salutatorian, and other CAA performances. After they graduate, students are welcomed and encouraged to re-enroll and continue their educational journey for as long as they have an interest.

Bernard Smith has been a student at College of Adaptive Arts since its inception. Several years ago, Bernard was given the opportunity to become an associate professor, as well as a student at CAA. He assists in the choir class and is their piano accompanist.

According to his mother, Donna Smith, despite his autism, Bernard has grown tremendously and in many ways at CAA.

"He has grown in confidence, social skills, and in his ability to work with other teachers and students," said Donna. "He thoroughly enjoys his classes, friends, and teachers. CAA is really an integral part of his life."

While at CAA, Bernard has enjoyed a great variety of classes including art, reading, book club, science, math, nutrition, computers and more.

CAA has 10 Schools of Instruction – five in the arts and five in academics and health and wellness, rounding out a full liberal arts education that any adult would receive, whether they were enrolled in a community college, a state school, or an elite private university.

Over the years, the educators there listened to the requests of the adults, their parents, and care providers for more subjects they'd be interested in learning – classes like guitar, clay animation, computers, podcasting, voiceover, dance techniques, coding, and reading and writing.

The impact of this inclusive model on the students, their parents and care providers, and the CAA staff cannot be overstated. Students have made stunning leaps in developmental growth within such areas as new subject inquiry, confidence and advocacy ability, and development of lasting friendships.

Melissa Correa is another student who has been at CAA since the beginning. According to Melissa, part of what she likes about attending school is the social aspect. "I like seeing my friends and I have fun," said Melissa. "I am challenging myself."

Melissa has Down syndrome, and for most of her life, her mother Janice Correa had to be an advocate for her when it came to her education. But with CAA, Melissa was given the power to choose the classes she wanted and was interested in, instead of having them chosen for her. Melissa's mother, Janice Correa, said she is constantly amazed at how Melissa is able to grow and thrive.

CENTER STAGE: *(Above left)* Bernard prepares for his duties as piano accompianist; Melissa Correa *(Above, right)* has performed in many CAA productions since the founding of the school.

"She's 40 and is continuing to enrich herself," said Janice. "She has tried many different courses but has decided what she likes and what she doesn't."

CAA parents and care providers report resounding feelings of hope, relief, and astonishment of all the new skills, areas and interests they had no idea their adult children would explore. They also have found a rich network of camaraderie and support with other parents and care providers, as parents routinely stay on site and connect with each other as each class is just one hour long throughout the day. There is a constant flow of comings and goings, and for many, it is rewarding to see all of the positive synergy when students and their families connect around a like-minded course offering.

Another important component which sets CAA apart is that they strive to employ adults with differing abilities and complex backgrounds to be the front-line lead professors of this innovative collegiate model. The mission of CAA is exclusively lifelong education, but the vocational component is incorporated with the hiring of incredible and astute individuals who have had a hard time finding gainful employment in traditional workforce settings. CAA has also hired numerous students onto their CAA "Superstaff" as well to work as Associate Professors in multiple classes.

"Operationally CAA has grown more than 1,800% since inception and is well on the way to achieving a sustainable income stream of two million," said Dr. Lindsay. "Family and corporate patrons have routinely underwritten eight of the 10 schools, and CAA is always seeking more investors to inquire and engage in this innovative educational model of lifelong education and collegiate partnerships. One of CAA's strategic visions for the 2021 fiscal year is to actively partner with each of the 24 California Regional Centers and provide lifelong learning to adults with special needs across the state."

In July 2020, during the pandemic, CAA's physical building was sold and the West Valley Mission Community College District voted unanimously to welcome this equitable collegiate model onto their West Valley Campus in Saratoga, California. The partnership will allow CAA to be a living learning lab/work-study/leadership training lab for host campus students and staff whereby CAA adult students will have the integrity of learning on an authentic college campus.

CAA's ultimate goal is to show how this expanded collegiate model can be replicated on every campus of higher learning around the world for adults who are hungry to continue learning, growing, creating, connecting, and becoming the best versions of themselves. •

ABOUT THE AUTHOR:

DeAnna Pursai is the co-founder of the College of Adaptive Arts. She holds a Master's in Education Policy Analysis in the School of Education from University of Illinois at Urbana-Champaign and an undergraduate degree in Elementary and Special Education from Purdue University. DeAnna has been named an Architect of Change on the Maria Shriver blog and co-awarded the Delta Kappa Gamma State Distinguished Career/Professional Service Award with CAA's Co-Founder and Dean of Instruction, Dr. Pamela Lindsay. She is a big sister to Angel Ellenberger, who is an exquisite actress, entertainer and comedian who happens to have Down syndrome.

LJS Fac/X

WE CAN HANDLE YOUR PROJECT

HOME ELEVATORS • STAIR ELEVATORS • AUTOMATED SYSTEMS

Bring together more than thirty professionals, each a craftsman in his or her former industry, in one organization and no industry, situation, or challenge will be new to us. Not to say that we've seen it all. Technology adds novel challenges daily, making a flexible organization – one willing to grow in those new disciplines – invaluable.

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.

The staff forms two teams, each offering comprehensive expertise in one of the company's two main divisions of facility services. The “Electrical Team” and the “HVAC/Mechanical Team” can cope with any situation an client or homeowner might encounter.

Contact: Vice President of Operations
pmaloney@ljselectric.com
201-777-6625

LJS FAC/X, Inc.
430 Commerce Blvd, Unit C
Carlstadt, NJ 07072

LJS FAC/X, INC. I 430 COMMERCE BLVD, UNIT C I CARLSTADT, NJ 07072 I 201-777-6610

COMPETENT ■ PROFESSIONAL ■ COMPASSIONATE

LJS FAC/X

ERIK'S RANCH

OPERATED BY YOUNG ADULTS WITH AUTISM

BY KATHRYN NORDBERG

Erik's Ranch & Retreats, a non-profit providing living, working, social and recreational environments for young adults with autism is featured on the current season of "The World's Most Amazing Vacation Rentals." The hit Netflix series documents unique rental properties. In season two, streaming now on Netflix, Erik's Ranch & Retreats' Montana ranch is featured in an episode focused on philanthropic vacation destinations.

PHOTOS PROVIDED BY CHRISTINE LEKATZ

LIVE AND BREATHE: Young adults on the autism spectrum lead tours that they help create based on their passions and interests including trail rides, wildlife hikes, Native American artifact viewing, fly fishing, rafting – and more – where they are the stars, not the outcasts.

I founded Erik's Ranch & Retreats in 2008 as an avenue to provide my adult son, Erik, limitless possibilities in a safe and secure environment. As Erik was approaching adulthood, I quickly found that there were few good options for moderate to high-functioning young adults with autism, including those with Asperger's syndrome. Over the course of several years, I worked with a team of psychologists, attorneys, architects and marketing and business professionals to develop an innovative model for young adults with autism: Erik's Ranch & Retreats, with locations in Edina, Minnesota, a suburb of Minneapolis, and in Montana's Paradise Valley, not far from Bozeman.

Our model provides safe and unequaled living, working, social and recreational environments for young adults with autism, using our guiding principles of lifelong learning, individual community building, and bidirectional integration through "voluntourism." We're committed to giving these individuals a rewarding life on their own terms, experiencing dignity, compassion and the joy of continuing possibility.

OUR MODEL PROVIDES SAFE AND UNEQUALED LIVING, WORKING, SOCIAL AND RECREATIONAL ENVIRONMENTS FOR YOUNG ADULTS WITH AUTISM, USING OUR GUIDING PRINCIPLES OF LIFELONG LEARNING, INDIVIDUAL COMMUNITY BUILDING, AND BIDIRECTIONAL INTEGRATION THROUGH "VOLUNTOURISM."

Erik's Ranch & Retreats is not only home to young adults with autism, but these young adults also operate boutique- and ranch-style guest accommodations in two locations: Edina, MN and Livingston, MT. People from all over the world, and sometimes right next-door, stay in our one-of-a-kind guest accommodations.

Located just 45 minutes outside of Yellowstone National Park, Erik's Ranch offers guest accommodations, including two contemporary guesthouses, a secluded lodge, a creek-side cabin, and more. Young adults with autism are not only guests' personal concierges, but also lead experiential tours for guests that tap into their myriad abilities and passions, including trail rides, hikes, fly fishing, and rafting. Guests learn about all that those with autism can do while offering them a meaningful place in society. The program is a paradigm shift for the entire country that promotes the worldwide integration of those on the autism spectrum.

We were so excited that what we're doing at Erik's Ranch caught the attention of the production team of The World's Most Amazing Vacation Rentals. When we heard that they were looking to do an episode on philanthropic vacation destinations, we knew it was meant to be. That very concept was a big part of the vision and inspiration for our Montana location. Having the film crew and hosts so genuinely engaged with our members, and helping them to shine, was really fun to watch. Our members are amazing individuals and we're thrilled that they get to share this special place, and their many talents with an even wider audience. During filming, we were able to work with Megan, one of the hosts who specializes in DIY design, to help us with ongoing improvements and expansion on the property. Even before appearing on the show, we had an overwhelming amount of interest in the property and knew that our next move would be to add new guest houses to allow for more guests and, more important, more members.

Of course, renovations and new construction are very expensive, and current labor shortages make this a huge challenge. To complete our expansion, we need to raise $1.2 million. We are calling on our supporters and those interested in "voluntourism," to consider gathering a group

ABOUT ERIK'S RANCH

erik's
ranch & retreats
vision knows no bounds

Erik's Ranch & Retreats provides safe and unequaled living, working, social and recreational environments for young adults with autism, using its guiding principles of lifelong learning, individual community building and bidirectional integration through voluntourism. We're committed to giving these individuals a rewarding life on their own terms, experiencing dignity, compassion and the joy of continuing possibility. At Erik's Ranch & Retreats people from all over the world, and sometimes right next-door, stay in our one-of-a-kind guest accommodations for business and personal travel. It is our GOAL is to provide our guests with top-notch customer service, exceptional accommodations, and the unique touches that are only available in a smaller setting. Our members proudly live and work on site–offering boutique style accommodations in Edina, MN, and Ranch accommodations in Livingston, MT.

LIVE AND WORK: Young adults on the autism spectrum have the opportunity for employment at Erik's Ranch assisting with all guest services, the equestrian program and groundskeeping. The ranch offers an innovative living, working and social model for members and upscale volunteer guest accommodations at both the ranch in Montana, and the urban retreat in Edina, Minnesota. What sets Erik's Ranch & Retreats apart is that these unique destinations are run by the members who live there.

and take a mission trip to Erik's Ranch. Mission trip "voluntourists" work alongside the young adults on the autism spectrum that call Erik's Ranch & Retreats home, directly investing in their futures. Projects range from fence repair, to landscaping, and renovations. Booking fees are collected as a donation to cover lodging, meals, transportation from the airport, building materials, and recreation.

Another way we are looking to expand our offerings is by creating a "glamping" (glamour camping) experience by adding two new yurts to our property. With the help of many, we plan to start offering "glamping" experiences in the yurts by May of 2022.

More than 12 years have passed since we started this work, and I'm so grateful for where we are today. It's every parent's dream to see their child thrive. I hope my work toward making that dream come true for my son will create a path to help many more young adults with autism live their best lives.

Check us out on streaming, visit our website, or better yet, come see Erik's Ranch for yourself. •

ABOUT THE AUTHOR:

Kathyrn Nordberg founded Erik's Ranch & Retreat in efforts to provide her adult son, Erik, a young adult on the autism spectrum, with limitless possibilities in a safe and secure environment. Kathryn enjoys all things beautiful and elegant: people, wildlife, land/waterscapes, art, world travel, solutions and products that simplify and enhance the world. She is a tenacious creative solution provider that leads with courage and compassion. •

BRAIN RESEARCH
IES
FOUNDATION
Since 2004

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

THE IRENE AND ERIC SIMON BRAIN RESEARCH FOUNDATION IS LOOKING FORWARD TO A HEALTHIER AND HAPPIER 2021 FOR ALL.

www.iesBrainResearch.org

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

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

EP LOOKS BACK: OCTOBER 2008

Slilent Echoes

A young author rewrites the rules to transitioning

By Aaron Notariaani Stephens

> *"Brilliant, searing, insightful – important." That's what critics and experts have called the writings of Sarah Stup.*

A young woman with autism from Frederick, Maryland, Sarah made a choice to forgo traditional employment options for people with disabilities and to pursue the seemingly improbable option of becoming an author.

Becoming a successful writer can be a dubious prospect for people without disabilities. And yet with talent, passion, and collaboration, Sarah, 24, has managed to pave a way for herself as a poet, essayist, children's author, and advocate. She has been profiled in print and on TV and is the recipient of advocacy awards.

Sarah's silent yet powerful voice has begun to change the way teens with developmental disabilities look toward the future and employment. Sarah says that her speaking voice is broken but that on paper her words have broken barriers and carved out new pathways for herself and students who follow in her footsteps.

Sarah is a soft, gentle soul. When she greets people, she reaches out, and after a quick hand to hand connection, takes a delicate curtsy. She puts her hand to her nose taking in the person's aroma. "Smells and sounds stay with me long after the person is gone. It is part of my autism." Sarah explains in her writing.

Autism has a significant impact on Sarah's ability to control her body. She rarely speaks using her voice. She is ritualistic. When she walks into a room, she must find the light switch and turn the lights on and off several times. Her movements can be uncontrolled without the direct intervention of another person. Sarah needs support whether her task at hand is to take a walk, get a cup of coffee at

Author, Sarah Stup
Photo by Aaron Notarianni Stephens

Starbucks, or sit down in her home office to type. "My body edits not," she types.

Sarah's writing provides a fascinating insight into autism. She opens up a mysterious world, a world that many parents long to break into and understand. "A naughty beast called autism lives inside. protecting me from seeing and hearing too much. Autism acts rude, and people hate rudeness," Sarah muses in her book *Are Your Eyes Listening? Collected Works.*

Her mission as a writer is to entertain and to advocate. She leaped into advocacy as a young child. Until she was eight years old, Sarah attended a school for children with disabilities. Around that time. she began to communicate by typing. Before long, she used typed words to make her wishes clear.


Sarah and Taylor the Turtle from Sarah's book, *Do-si-Do with Autism.*

"Shortly after Sarah began communicating by typing, one of the first things she said was that she wanted to go to a regular school like her older sister, Janna," says Judy Stup, Sarah's mom. There is a humble pride in Judy's voice as she talks about her family's journey and her daughter's accomplishments.

With one finger and a lot of patience, Sarah painstakingly communicates and creates her stories using a portable communication device. "She occasionally uses a computer or laptop, but like other authors who may have a favorite pen, Sarah prefers her outdated typing device," Judy says.

Sarah's decision to become a writer was not greeted with overhelming approval. Like many students with disabilities. Sarah was encouraged by well-meaning advisers to choose a more "sensible" career path. There were philosophical disagreements among educators, service providers, and family members that needed to be addressed at the individualized education program (IEP) table.

"Sarah refers to the barriers as 'red stop signs on paths that could have crossed.' The Arc has helped us through many of the barriers along the way," Judy says.

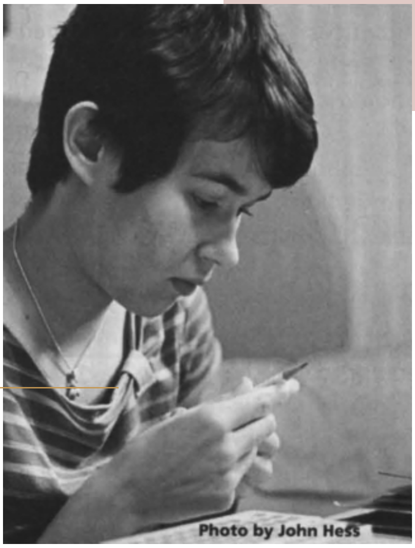


Photo by John Hess

Support coordinators from The Arc of Frederick County served as an ally to the Stup family as they approached many of the "stop signs" together. The Arc provided advocacy and supported Sarah and her famly at IEP meetings.

Karla Robeson, a senior support coordinator with The Arc. says Sarah expressed an interest in writing at a young age. She created the characters that would later be used in her children's book *Do-si-Do with Autism* when she was just 10. "Not only did she have an interest. but a true talent as well," Karla says.

Through a cooperative effort. Sarah's family, Frederick County public schools. and The Arc developed innovative supports to help Sarah pursue her interest in creative writing. "Sarah's combination of skills and needs led to a whole new perspective in program development," Karla says. "Part of advocacy is helping systems move forward and grow. The Arc was able to collaborate with our school system to leave a mark that continues to benefit transitioning students."

The Arc created a writing internship so Sarah would have time to solely devote herself to exploration and honing her craft. The agency provided office space and a writing mentor. and helped Sarah make connections to publish her work. The school system provided one-on-one staff Sarah needed throughout her day.

The partnership proved to be successful. Within a year, Sarah had published essays in several regional publications, including magazines, newsletters, and a newspaper, and her poetry was featured and displayed at a local coffee shop. Additionally, Sarah traveled to the state capital and presented written testimony opposing a bill that would have encouraged people to access respite services in state institutions instead of in the community.

Sarah's Suggestions for Transitioning Teams

"What I want you to know about me - and my autism"
By Sarah Stup
Excerpted from the book
Are Your Eyes Listening? Collected Works
www.SarahStup.com

- I am inside.
- The words are there; the voice is not.
- It is lonely and sad not to talk.
- We who are silent have our value.
- Being autistic is a battle that stays.
- Your world hurts me.
- Sounds pay me visits after I leave them.
- I need autism to breathe.
- Autism is awful, but I am not awful.
- I act dumb but am smart. Please be my friend.
- We can't be friends when you hate autism.
- Be an explorer who finds treasure beyond the strangeness.

Sarah's voice gained a strong state-widefollowing. In 2004, she was named The Arc of

9 ways to Interact with People with Autism

By Sarah Stup
www.SarahStup.com

1. Autism helps protect us from seeing and hearing too much. Please don't hate our shield.
2. Try not to stare. Sometimes we need to do unusual things.
3. We hear you when you complain about us. Find other times to talk mean.
4. Rudeness is not our intent. No sad faces please.
5. Real friends don't judge our actions. Please find us inside bodies that work differently.
6. See us as real. We are not shells with no inhabitants.
7. With too much asking us to be normal, we feel like impostors.
8. Try to help us, not control us.
9. Raise hope to give us better futures. We need to aim high.

Maryland Self-Advocate of the Year and received the Frances and Lease Bussard Award for Self-Advocacy. Upon graduation, she accessed state funding and business grants to publish her first book, *Do-si-Do with Autism*.

In the book, Sarah introduces readers to Taylor the Turtle and his friends. Taylor has autism and uses his shell to protect himself from the world. *Do-si-Do* teaches children the importance of seeing each others' similarities while respecting each others' differences. The book is in its fifth printing. Her *Taylor the Turtle Fun Pack CD* based on *Do-si-Do with Autism* uses interactive lessons to complement the book.

Beth Mende Conny, owner and founder of WriteDirections.com, has worked along with The Arc to help Sarah gear her portfolio toward different audiences. "The imagery in Sarah's work is particularly moving," Beth says. "I never saw Sarah as a person with a disability who writes. I see her as a strong writer with a gift."

Beth says she has grown as a result of their collaborations. "This is one of the most incredible projects I've worked on," she says. "I've learned how a support system can make things happen. The network of advocacy is impressive."

As part of Sarah's desire to serve as an advocate, she and The Arc developed a training curriculum called Hope's Ingredients for transitioning students. Through a person-directed approach. the training aims to ensure that students with developmental disabilities have the opportunity to incorporate their hopes and dreams into their plans for the future. Many students with disabilities have been told, subtly or overtly, that their hopes and dreams are silly or that they cannot accomplish things because of their disabilities.

Hope's Ingredients encourages students to look toward the future without constrictions. The training is intended to help students identify career choices as well as the support they need to make those choices a reality. It is opening up possibilities for students with disabilities to secure jobs with competitive wages in career fields that interest them. Sarah's silent voice echoes in the background of each student's accomplishments.

Tom Oden is one such student. After taking part in Sarah's Hope's Ingredients curriculum, Tom identified computer work as his area of interest. Staff from The Arc and Frederick County public schools supported Tom to interview and land a job assembling computers at Best Buy. Tom has held his job for over two years. He is a member of Best Buy's Geek Squad and a valued employee.

"Sarah's Hope's Ingredients training helps people focus on their passions," says Penny Jurchak, a teacher with Frederick County Public Schools. "Prior to the training, Tom was working in lawn service – not necessarily because he wanted to, but because it was available. I don't know if Tom would have reached the kind of job he did without The Arc partnering with us," Penny says.

Building on her success as an author and advocate, Sarah published *Are Your Eyes Listening? Collected Works* in 2007. The compilation of poetry and essays candidly and poignantly conveys the sights, sounds, and experiences of autism.

"Her wrenching language reveals 'the beast that is autism but also the special gifts it imparts, gifts that make her the unique person she is," Beth Mende Conny says. "This book is about more than autism, however. Ultimately, it is a book about life."

Sarah's career continues to blossom. This year, she has published the first of *Sarah's Keepsake Collection*, a line of gift books that reveal the essence of life, love, family, nature, and autism Additionally, she is working on a novel for middle-school students tentatively titled *Paul's Beast*.

Bringing her autism with her has been key to Sarah's hope and dreams becoming reality. Embracing it. Not hiding it. Not being ashamed of it. Realizing that success can be found within her autism.

Sarah wants other students to be afforded the dignity of bringing their disabilities with them. And she wants the world to know about her autism.

"Autism is not about good or bad manners. Autism is part of us, a shield that we need and not a manner we are choosing. We need to bring autism into your spaces without your being sad," Sarah says. •

Sarah's books and blog postings are available at amazon at **www.amazon.com/Sarah-Stup/e/B00J6SZH0K**

Aaron Notarianni Stephens an assistant director with The Arc of Frederick County. Aaron has served as a writing mentor to Sarah since 2003. He can be reached at astephens@arcfc.org

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

ADVERTISERS: *Reach a growing audience on EP's all-new website and strategically target your consumers. Our competitive advertising rates offer top-quality results for an excellent value. Our team of designers and developers are ready to create digital marketing campaigns that effectively communicate your brand's message to our dedicated online audience.*

CONTACT: Faye Simon at epmagazinevp@gmail.com

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

ONE SINGULAR – BUT COLLABORATIVE – SENSATION

POSITIVE EXPOSURE'S 2021 CHANGE HOW YOU SEE CELEBRATION

BY LIZ MATEJKA-GROSSMAN

It was a night of all nights – the Positive Exposure 2021 Change How You See Celebration, which aired virtually on September 22, and is still available for streaming, free of charge. This magical, harmonious and inclusive event, chockful with a spectacular blend of performances, tributes, ambassadors, advocacy organizations, physicians and honorees, was masterfully crafted by Nick Corley.

Corley, a beloved Broadway actor, director and producer, whose credits include *She Loves Me, Mary Poppins, You Can't Take It with You,* and *A Christmas Carol,* also served as Associate Director on the recent revivals of *Burn This* and *Plaza Suite.* Currently, Corley is Associate Director of Candace Bushnell's *Is There Still Sex in the City,* opening at NYC's Daryl Roth Theater this fall. Corley, who also directed Positive Exposure's first virtual celebration in 2020, was initially introduced to the organization through his friend and Positive Exposure's Director of Development, Lisa Johnson.

PHOTOS PROVIDED BY RICK GUIDOTTI

“In putting together this year’s Change How You See Celebration, it was important to me that it reflect the commitment and emotion of the organization and that everyone had ownership of the event – and that we were not just ‘performing for’ but rather ‘engaging with’,” Corley explains. “I love that through this celebration, the medical world, the disability human rights activist world, parents, performing artists, and the inclusion community itself were all interacting together. The celebration reflects not just Positive Exposure, but their worldwide goal. The celebration is truly about connection and working together.”

> *“Having grown up with a younger deaf sister, I have been aware of disability inclusion for a long time. I remember how hard my mother fought to see that my sister had equal opportunities and was included in everything growing up. I find this same passion and mission at Positive Exposure. Rick Guidotti and the entire staff are tireless in their pursuit of a wonderful positive global shift of inclusion.”*
>
> ~ Nick Corley

“On a personal artistic level,” Corley continues, “I love bringing together people who may have different areas in the performing arts, discover what magic can happen when they work together, what new and impactful opportunities arise – and I am so lucky to have such great help to pull this off!”

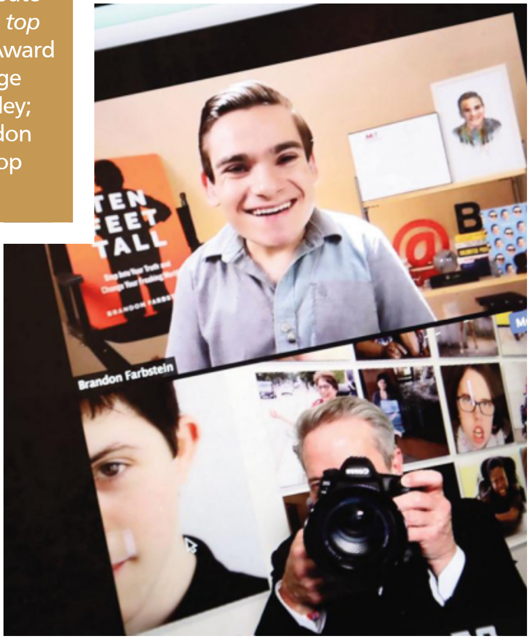
“Everyone at Positive Exposure pitches in to make this happen. All the amazing performers who said ‘yes’ and lent us their time and boundless talent. The incredible choreographer, James Kinney, who made our dream of honoring the late Positive Exposure supporter and friend, Ann Reinking, happen in such a beautiful way. All the fantastic film makers who helped create impactful mini movies. The amazing community from around the world who sent in toasts and heartfelt testimonials. And lastly our tireless editor, Matt Axel, who beautifully pulls everything together, making sure it was also accessible for all.”

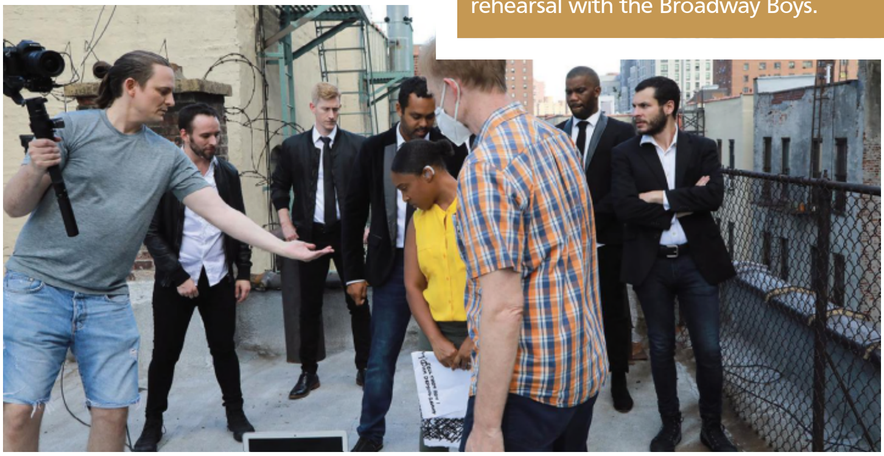
“‘It takes village’ as they say but in a way that’s the point – We can be one big supportive global village, if we simply embrace the beauty of all humanity,” reflects Corley. “I love that Positive Exposure reminds us of that simple truth every day.”

This sentiment was reiterated by Positive Exposure’s Director and co-host for the evening, Rick Guidotti, who founded the 501(c)3 organization nearly 25 years ago and is dedicated to promoting a more equitable and inclusive world through award-winning photography, films, lectures and educational programs.

“There is such amazing beauty and grace in every single person

BEHIND THE SCENES: *(Opposite page)* A tribute to Ann Reinking in dance; *(Clockwise from top left)* 2021 Positive Exposure Rising Leader Award winner Xian Horn with Rick Guidotti; Change How You See Celebration director Nick Corley; Rick photographing program co-host Brandon Farbstein; and Treshelle Edmond in a rooftop rehearsal with the Broadway Boys.





on this planet and we are here to celebrate everything that makes us unique," Guidotti exclaimed in the opening to the celebration. "The more we include everyone as part of our global community and embrace the gifts that each of us have to offer, the richer and fuller all of our lives will be – together we have the power to effect social change by the very celebration of our individual humanity."

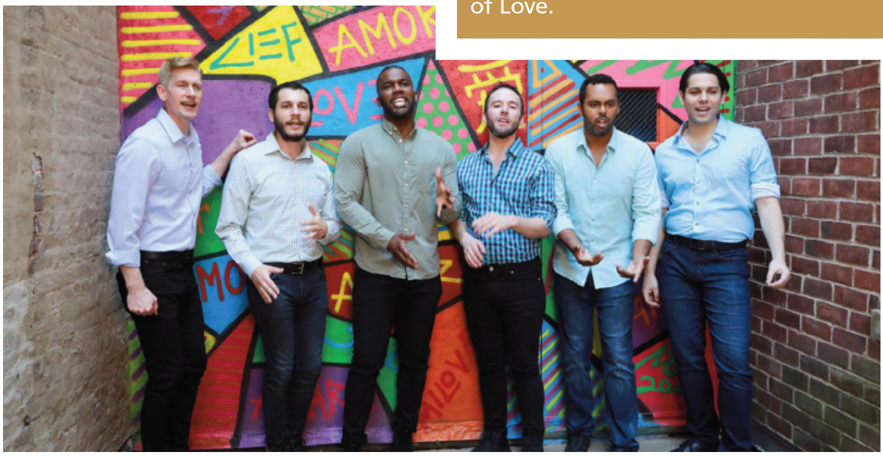
Artist Marco Santini's Wall of Love, a four-story mural in the courtyard that Positive Exposure shares with The Church of St. Edward the Martyr and the New York Common Pantry served as a backdrop for many of the performances as did NYC's Central Park, Duke Ellington Circle, Museum Mile, and the rooftops and fire escapes of East Harlem where the Positive Exposure Gallery is located.

> **Positive Exposure has continued its work to transform public perceptions in which individuals and communities at risk of stigma and exclusion are understood, embraced and celebrated.**

Performances included The Broadway Boys (Jesse Nager, Artistic Director, Jamison Scott, J Daughtry, Michael Linden, Jordan Ellis and Gabe Violett) filmed and edited by Nolan Doran, Treshelle Edmond (Broadway's *Spring Awakening*), Mandy Harvey (*America's Got Talent*) with Warren "Wawa" Snipe, Christopher Corsini and Shaheem, Lachi (PBS), Portia Cina, The Merry Rockers with Aaron Nigel Smith and Tubby Love, David Lutken, David Finch, Spiff Wiegand, Brittany Brook, Robin Skye, Peter Boynton, Mike Lusk, Deb Thomas and Brandon Kazan-Maddox, GODA, or grandchild of deaf adults. And serving as co-host, 21-year-old Brandon Farbstein, a global empowerment speaker, GenZ activist and author.

In remembrance of the late, legendary performing artist, Ann Reinking, Rick Guidotti recounted the 2001 premiere of his photographic exhibition for the Human Genome Celebration at the Smithsonian's Museum of Natural History. Among the images featured was a young boy named Christopher living with Marfan syndrome who was also the son of Ann Reinking. Christopher was the first person living with Marfan syndrome that Guidotti ever photographed and it was also a pivotal moment in the making of what Positive Exposure is today.

In tribute to Ann Reinking, whose talents extended into the depths of disability rights and inclusion activism, choreographer James Kinney (*Fosse*) in collaboration with cinematographer, Pierre Marais, created a Fosse-style reimagining complete with tilted bowler hats, shoulder rolls, splayed fingers and laybacks. Featured dancers included Heidi Latsky Dance Core Company Member, Donald Lee with Broadway dancers, Ashley Blair Fitzgerald, Yesenia Ayala and Arisa Odaka. As actress, dancer and singer, Bebe Neuwirth remarked about her special friend, "Like her fierce indomitable spirit, Annie lives on



ANTICIPATION BUILDS: *(Clockwise from top left)* Treshelle uses ASL to make a suggestion to the Broadway Boys; The Positive Exposure team gathers for an evening of celebration; James Kinney demonstrates a Fosse-inspired move for a student; and the Broadway Boys practice a verse in front of artist Marco Santini's Wall of Love.

in the work she created and in the legacy of her inclusion advocacy. Annie saw dance in everything and everyone. To her, it was the expression of the human soul and the celebration of our bodies."

Judith Heumann, an internationally recognized leader in the disability community and lifelong civil rights advocate for disadvantaged people, presented the 2021 Positive Exposure Rising Leader Award to Xian Horn who describes herself as a joyful half-Asian woman with cerebral palsy, a beauty and accessibility advocate, speaker, instructor, Forbes contributor, and founder of the nonprofit Give Beauty Wings.

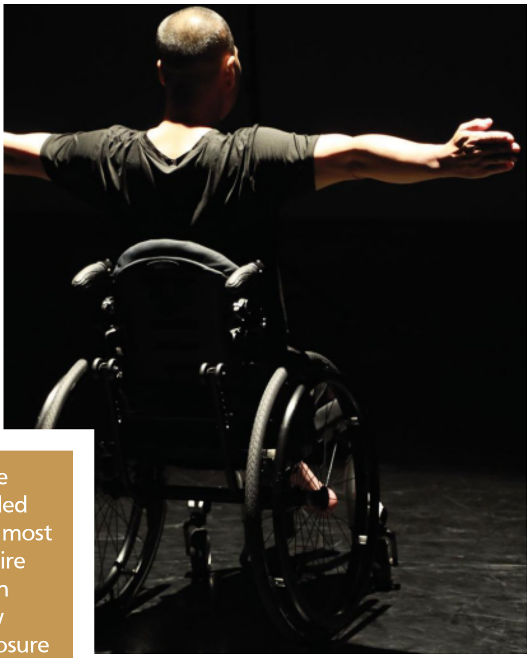
Tim Shriver, Dr. Rick Rader and Special Olympic athlete, Kathleen Maggi, presented Steven Perlman, DDS, MScD, DHL with the 2021 Positive Exposure Spirit of Change Award for creating Special Olympics Healthy Athlete, currently the largest global, public, health program for people living with intellectual and developmental disabilities. He is also the founder of Special Olympics, Special Smiles, an oral health initiative of Special Olympics International and integral component of bringing healthcare services to athletes. "There are 5 million athletes in Special Olympics and the fact that I could do something to impact those children and adults living in 150 countries was an incredible thing," Dr. Perlman explained. "Working with Positive Exposure has been so amazing to me because we have to educate the next generation whether it be physicians or nurses, or occupational therapists, or physical therapists, or speech and language, or nutritionists."

Next year will mark the 25th Anniversary of Positive Exposure working collaboratively with global organizations, hospitals, medical schools, educational institutions and advocacy groups to promote a more inclusive and compassionate world, impacting millions. Positive Exposure has continued its work to transform public perceptions in which individuals and communities at risk of stigma and exclusion are understood, embraced and celebrated.

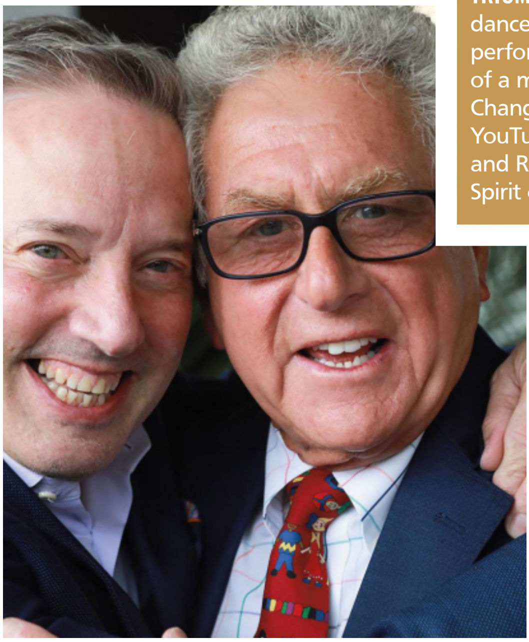
A special thanks to Chef Gregg Brackman, owner of the G Bar and Little G Bar in Swampscott, MA for hosting a pre-party livestream cooking class via the Chefsfeed by Tastemade platform.

Enormous gratitude to Paul Taylor Dance Studios and to the following artistic unions: SAG-AFTRA (New Media Agreement); ASCAP – The American Society of Composers, Authors & Publishers; BMI – Broadcast Music Inc.

To learn more about Positive Exposure, please visit **www.positiveexposure.org** *Want to visit? Positive Exposure is scheduling "in-person" appointments. To schedule a visit, please email* **liz@positiveexposure.org** •



TRIUMPHANT: *(Clockwise from top left)* The dance team in preparation of their Kinney-led performance; Dancer David Lee makes the most of a moment in the spotlight; View the entire Change What You See 2021 Celebration: on YouTube at https://youtu.be/e7B5jwv0Lcw and Rick with one of the 2021 Positive Exposure Spirit of Change honorees, Steven Perlman.



ONE MORE FIGHT

FOR THE DOWN SYNDROME COMMUNITY

BY HAMPUS HILLERSTROM

GONNA NEED A BIGGER POOL: Oskar cools off with a midday dip. LuMind IDSC's position is that a larger number of research participants is required in order to achieve a new level of health and independence for our loved ones with Down syndrome.

PHOTOS PROVIDED BY HAMPUS HILLERSTROM

Like many parents, I have two full-time jobs: "Dad," and my professional career. I am the proud father of seven-year-old Oskar, who has Down syndrome. He lights up every room, is starting to read, and loves puzzles, hugs, and ice cream. Oskar and his younger brother, Sebastian, are a dynamic duo, perfecting the best kind of brotherly mischief, who keep my wife and I fully employed at every hour of the day.

For most families, the parents' daily work – the paycheck-generating work - doesn't have a direct impact on their family. Not so at the Hillerstrom house, where Down syndrome is also my career. I lead LuMind IDSC Foundation, a national non-profit organization that accelerates Down syndrome research and empowers families through resources and connections to address the unmet medical needs of people with Down syndrome. October is Down Syndrome Awareness Month and so, at the intersection of family life, non-profit work, and daily adventures with Down syndrome, I offer my perspective on the vibrant and diverse Down syndrome community with an important call to action: join the battle for increased research participation.

The Down syndrome community in America has already fought, and won, many significant battles. It is because of thousands of previous victories - in public policy, in doctors' offices, in school districts, in the media, and in our own lives – that people with Down syndrome live more independently and longer than ever before. Those battles were fought before my son Oskar was born, and our family will forever be grateful to those who went before and paved the path for us.

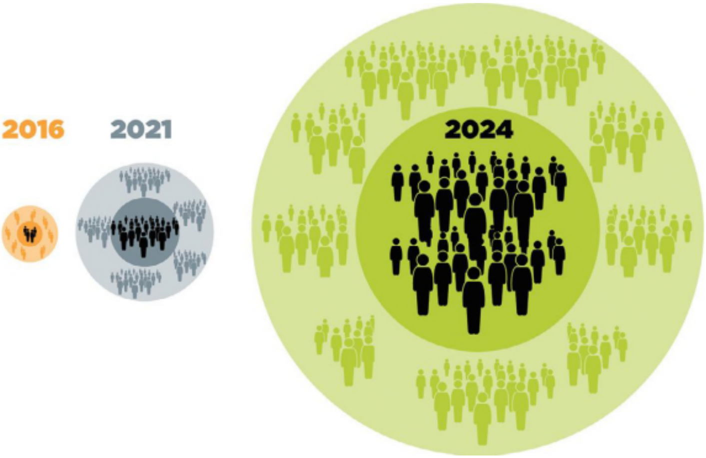
Today, I see in our community an opportunity to engage in one more battle: the fight for better research and research participation. Although my personal area of expertise is Down syndrome research, I know other intellectual disabilities communities find themselves in similar circumstances. We are all looking for the science and solutions that will enable our loved ones to live longer, healthier, and more independent lives.

There are many critical medical conditions that affect people with Down syndrome. Alzheimer's disease (AD) and sleep apnea, for example, require improved treatment options, diagnostics, and medical care solutions. Researchers estimate the lifetime risk of Alzheimer's disease (AD) is more than 90%, and AD is the leading cause of death for adults with Down syndrome. Compounding the prevalence of AD in the Down syndrome community is the shockingly early onset of dementia symptoms, typically around age 55.

Obstructive sleep apnea, a condition where a person's breathing temporarily stops while asleep, affects between 50-75% of children and adults with Down syndrome. Speech capability is also a common concern for people with Down syndrome, as speech is often delayed and sometimes impaired.

Related to all the medical issues listed above is the overarching issue of personal independence. LuMind IDSC Foundation recently surveyed 400 parents of people with Down syndrome, and nearly 90% of those parents listed "independence with daily living activities" as one of their primary concerns.

While those statistics may seem shocking and depressing to some, I see them as challenges that are possible to overcome. "Possible," because, in addition to having a child with Down syndrome, I also have a front-row seat to the latest developments in Down syndrome research. For me, research in this field is vitally important on both the personal and professional levels.



EXPANDING THE FIELD: In 2016, there was only one clinical trial involving 16 participants that took place in the United States. This year, four clinical trials and observational studies with more than 800 participants are ongoing.

LuMind IDSC works at the crossroads of science and the Down syndrome community by taking a "venture philanthropy" approach to our initiatives, focusing on translational research – the kind that focuses on unmet needs and turns successful laboratory and data discoveries into clinical best practices and new treatment options at local doctors' offices.

At the core of our research initiatives are individuals with Down syndrome, their caregivers, and loved ones. We directly serve the community by offering a wide range of multimedia health, wellness, parenting, and support resources on our free digital library platform, myDSC. We also provide the means for families to be heard in research matters by soliciting input from them and bringing that "family voice" to researchers, pharmaceutical companies, and policymakers.

Beyond these community resources, the three corners of LuMind IDSC's current research activities are: the Down Syndrome Clinical Trial Network (DS-CTN), the LuMind IDSC Research Consortium, and the Longitudinal Investigation for the Enhancement of Down Syndrome Research (LIFE-DSR). To date, LuMind IDSC has been involved in 19 clinical trials and observational studies in the past 15 years. We currently collaborate with major pharmaceutical companies to gather important biomarker samples (like brain imaging, spinal fluid, and blood samples) in order to bring Down syndrome data to their work. In addition, LuMind IDSC currently coordinates a multi-year, multi-site research study to track and analyze the medical and physical data of 270 adults with Down syndrome (LIFE-DSR).

THE BIG PICTUURE: LuMind IDSC Foundation is a national non-profit organization that accelerates Down syndrome research and empowers families through resources and connections to address the unmet medical needs of people, Like Teresa F., with Down syndrome.

Having now established a multi-tiered infrastructure for clinical research, LuMind IDSC turns to the overwhelming need for people with Down syndrome and their caregivers to participate in research studies. Studies can only move forward when the community responds and participates. Family participation is the key!

To illustrate the growing need for research participation, we can look at studies focused on Down syndrome-associated Alzheimer's disease. In 2016, there was only one clinical trial involving 16 participants that took place in the United States. This year, four clinical trials and observational studies with more than 800 participants are ongoing. In the next few years, with the increasing interest from National Institutes of Health (NIH) and pharmaceutical companies to find Alzheimer's treatment solutions for people with Down syndrome, experts expect three to five new clinical trials starting. An average trial requires between 75 and 500 participants. Because these study trials will have strict qualifying parameters, we estimate that we need a ten-fold increase in research participation by individuals with Down syndrome and their caregivers over the next five years.

Meeting a challenge of this magnitude is a battle our community must fight together. As Oskar's father, and as a leader in Down syndrome research, I call on families to consider participating in research studies and clinical trials. I realize research participation is a lot to ask, especially for those parents, now in their retirement years, who are veterans of the early fights, and whose children blazed a trail for Oskar's generation. But I appeal to the parents and siblings of adults with Down syndrome: please join us for one last battle.

Working together, we can achieve a new level of health and independence for our loved ones with Down syndrome and for the generations that come after us. Community readiness and participation in research are the key to achieving therapeutic, medical, and diagnostic advances for all.

You can read more about LuMind IDSC at **www.lumindidsc.org** and you can request information, or register for our newsletter, here: **https://www.lumindidsc.org/s/1914/20/interior.aspx?sid=1914&gid=2&pgid=609** •

ABOUT THE AUTHOR:

Hampus Hillerstrom is President/CEO of LuMind IDSC Foundation. Previously, he co–founded and served in executive roles at biotech company Proclara Biosciences. He also worked at venture capital firm HealthCap, pharma company AstraZeneca, and investment bank Lazard. Hampus holds a master's degree in economics from University of St. Gallen, MBA from Harvard Business School, and MSc in Health Sciences and Technology from MIT/Harvard. Hampus lives in the Boston area with his wife and children. Their oldest son, Oskar, has Down syndrome.

EP FOR FREE!

RECEIVE *EXCEPTIONAL PARENT eMAGAZINE* AT NO COST!

Exceptional Parent Magazine, a 47-year-old award-winning publication, provides practical advice, emotional support and the most up-to-date educational information for special needs families.

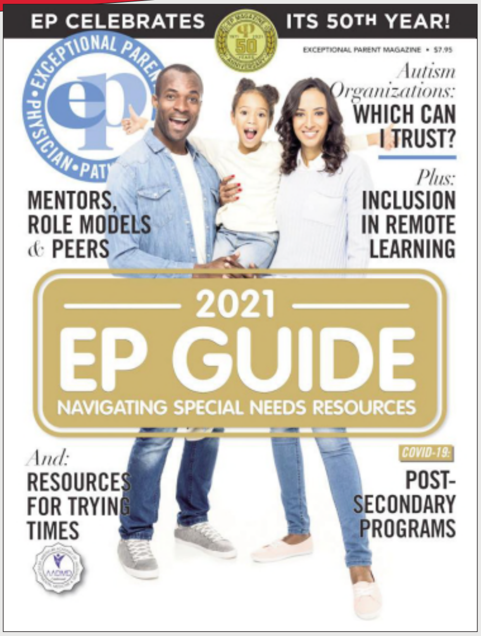
IT'S EASIER THAN EVER!

Simply visit us at
www.epmagazine.com
and click
"SUBSCRIBE"
and you will receive a link
to the magazine every month.

Print subscriptions: $95 a year;
email ***subscriptions@ep-magazine.com***

Empowering the
Special Needs
Community
since 1971

Subscribe Today at www.epmagazine.com



EP CELEBRATES ITS 50TH YEAR!

EXCEPTIONAL PARENT MAGAZINE • $7.95

Autism Organizations: WHICH CAN I TRUST?

Plus: INCLUSION IN REMOTE LEARNING

MENTORS, ROLE MODELS & PEERS

2021 EP GUIDE
NAVIGATING SPECIAL NEEDS RESOURCES

And: RESOURCES FOR TRYING TIMES

COVID-19: POST-SECONDARY PROGRAMS

AN AMAZING ADVERTISING OPPORTUNITY

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

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

For more advertising opportunities, email us at
epmagazinenews@gmail.com

EP MAGAZINE: THE JOURNAL FOR SPECIAL NEEDS FAMILIES AND PROFESSIONALS

LOVING MY BROTHER WITH A DISABILITY

BY IAN CHEN

Having a brother with disabilities isn't easy for my family and for me. I feel a jumble of emotions. There is a lot of drama, pain, and sadness. But there is also hope that he will get better. I am 12 years old and my brother is 14. I hope this essay will enhance your knowledge and when you see a disabled person, I want you to know how hard it is on their families.

My brother was diagnosed with Lennox-Gastaut Syndrome (LGS) when he was two-and-a-half years old. It is a rare epilepsy syndrome and there is no cure for it. According to the LGS Foundation, about 48,000 children and adults in America, and about one million worldwide have been diagnosed with this form of epilepsy. It is one of the worst seizure disorders to have. About 70% of patients have cognitive impairments and about 50% have bad behavioral issues like my brother. In his life, he will need a caregiver and supervision at all times.

I am filled with sadness when I think of the things that he does that creates drama. For starters, he throws huge tantrums frequently. He bangs his head forcefully to the walls and slaps everyone that he can reach. Going to stores, we always try to avoid the wine aisle because he tries to break every wine bottle even though he is in a wheelchair. Sometimes, my brother gets his hands on toys, batteries, and DVDs, and he holds them so tight so as not to hand them over. We would then have to buy them because my mom does not want to create a scene. Eating at restaurants is not easy either. Everything within his reach he would grab and throw it wildly on the floor. One time, we were at a restaurant for Christmas dinner with my cousins, and my mom explicitly told the waiter not to serve next to my brother. Nevertheless, he did and my brother's head bumped the plate of spaghetti and meatballs. He hurt his head and the sauce was splattered all over the floor and the table. Everyone at the restaurant was shocked. The incident ruined the good vibes and the mood.

When it comes to traveling, nothing is easy, from departure to arrival. My brother falls onto the ground and starts screaming at the top of his lungs at the gift shop. He would do that if we didn't buy something for him or if we have to leave the gift shop. When flying, my brother throws up because of motion sickness and the stress of a new environment. When we land, it's a struggle to get to his wheelchair because we have to carry him all the way to the front of the plane. At a hotel my brother would have special meals that would have to be blended because he cannot chew. When I was nine, I often got very frustrated when he slapped me, and I used to yell at him for doing that. But now I have learned that he cannot control what he does. He is non-verbal and therefore he cannot express his feelings. Even if my brother seems very lovable on the outside, I can assure you that he has the eye of a tiger.

> THERE IS A LOT OF UNCERTAINTY ABOUT WHETHER MY BROTHER WILL GET BETTER. BUT I KNOW ONE THING FOR SURE, WE CANNOT LIVE WITHOUT HIM BECAUSE WE LOVE HIM TOO MUCH. SO, THE NEXT TIME YOU SEE A DISABLED PERSON, MAKE SURE TO BE KIND AND THOUGHTFUL TO THEM AND THEIR FAMILIES.

It's very painful to see my whole family worried about his seizures and get injured from helping him with daily activities. My family feels upset because they cannot control his seizures. When I see him having a seizure, it leaves a permanent scar on my heart. When he is having a seizure, it looks like he is being possessed. His eyes roll up into his upper sockets and his whole body starts cramping up like he is being electrocuted. His lips start to turn blue

PHOTOS PROVIDED BY ALLEN WONG, DDS

the longer he is in a seizure. He starts screaming in pain. His face and body turn as pale as a ghost. His face starts tightening and it looks pretty unnatural. After that, he is limp and has recurring spasms for about 10 minutes. While he is having a seizure, the oxygen tank comes out and his nose is instantly plugged with a nasal oxygen straw.

It is also causing me agony to see my family physically drained. My dad endures back pain and meanwhile, my mother frequently has arm injuries. These injuries are mostly caused by lifting him out of the bathtub. My grandma always gets whacked by my brother. And I get slapped on the face. Now that he is well over one hundred pounds, one person cannot lift him up anymore. I try to help but I am in no shape to lift him. Therefore, I want to get stronger in order to help them out. Sometimes I just feel like, "Why does it have to be our family to have a brother who is disabled?" But to that, I have learned the answer, "Why not?" The physical struggles make my family stronger, and that is what we need to take care of him.

TOUGHER TOGETHER: "The physical struggles make my family stronger, and that is what we need to take care of my brother."

Even though there is a lot of uncertainty about my brother getting better, I still try to believe he will get better. My brother has been on lots of medical diets and trials. For instance, my brother did the Ketogenetic diet which is a low-carb and high-fat diet. His body burns fat instead of carbs which helps some people not have as many seizures. My brother has also been on two medical trials. The first is the Epidiolex, which is based on cannabidiol, or more commonly known as marijuana. The second is a medication called Fenfluramine, which was used as an appetite suppressor, but in 1997 it was banned because of cardiotoxicity. Therefore, my brother always has to go to the hospital to monitor his heart. He also has done surgery to implant a Vagus Nerve Stimulation (VNS), which basically is a device that sends mild electrical pulses into the brain via the neck. I am hopeful that one day there will be a new medication that can cure him.

Having a disabled brother is not easy for any family, especially dealing with emotions of everyday drama. There is a lot of uncertainty about whether my brother will get better. But I know one thing for sure, we cannot live without him because we love him too much. So, the next time you see a disabled person, make sure to be kind and thoughtful to them and their families. •

ABOUT THE AUTHOR:

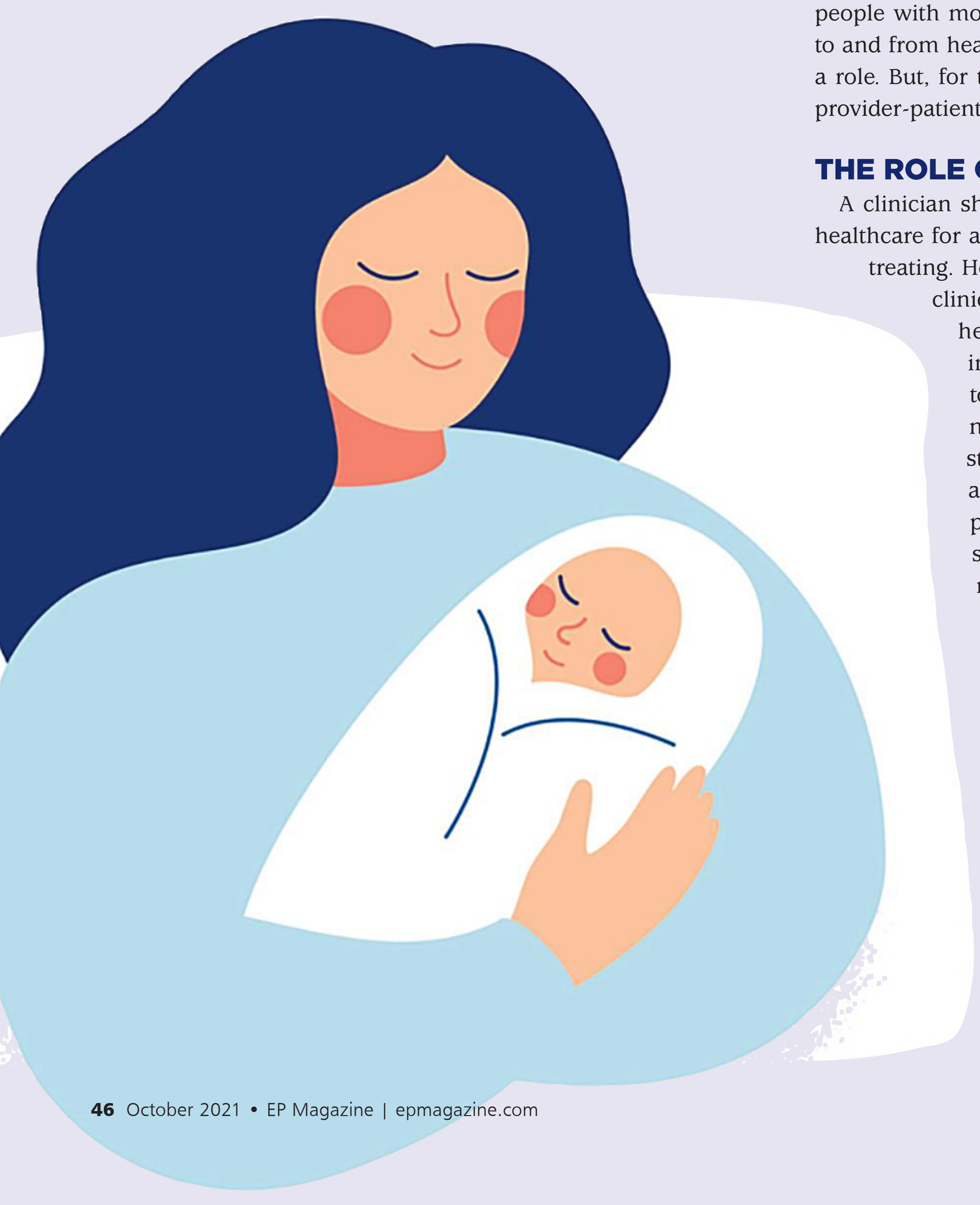
Ian Chen: "I am currently a seventh grader attending Cathedral School for Boys. During my spare time, I love to socialize and play video games with my friends. A sport that I like to play is basketball. I am addicted to the longest running prime time sitcom, *The Simpsons*."

STARTING A FAMILY IS RISKIER FOR WOMEN WITH IDD

BY CRAIG ESCUDÉ, MD, FAAFP

Most people with intellectual and developmental disabilities (IDD) want what everyone else does—the opportunity to live life to its fullest. For some, this includes having a family. For anyone, the decision to start a family is usually a big one. However, people with IDD, their families, and supporters have additional factors to consider. They are at greater risk for poor pregnancy outcomes.

We know that there are health disparities in many areas relating to people with IDD. There are lower rates of health screening for diseases like diabetes, prostate cancer and breast cancer. People with IDD are more likely to have chronic health conditions, to have undetected poor vision, and to have limited access to quality healthcare and health promotion programs, according to the Center for Disease Control (CDC). Women with IDD are less likely to have cervical and breast cancer screenings and less likely to have ever visited a gynecologist. Studies have also shown that women with IDD have increased risk of pregnancy complications and adverse outcomes, including gestational hypertension and gestational diabetes. They are also shown to have a higher rate of caesarean delivery compared to women without IDD. Other noted increased risks include early labor, pre-term birth, and preeclampsia, which is a serious and potentially deadly condition associated with pregnancy.



IMPROVING THE SITUATION

Enough about the negatives. How do we make this better? Having access to quality healthcare is a good place to start. There are a number of factors that come into play when working to create a healthcare environment where everyone can receive quality care. Things like having a physical environment that facilitates access for people with mobility limitations, the availability of transportation to and from healthcare visits, and financial considerations all play a role. But, for this discussion, I'd like to focus on the healthcare provider-patient interaction.

THE ROLE OF THE CLINICIAN

A clinician should have the knowledge and training to provide healthcare for any given condition which they are responsible for treating. However, it is widely known that many, if not most, clinical training programs provide little IDD-specific healthcare training for their students. Besides improving clinical competency, education can help to reduce inaccurate stereotypes and preconceived notions about people. The CDC notes that there are stereotypes that exist in the healthcare world with assumptions being made that the quality of life of a person with IDD is poor or that they are unhealthy solely based on their disability or level of impairment. There is also stigma associated with having a disability that shapes attitudes and expectations and can also shape outcomes. These assumptions and stigmas are certainly not limited to the healthcare world. They permeate throughout society.

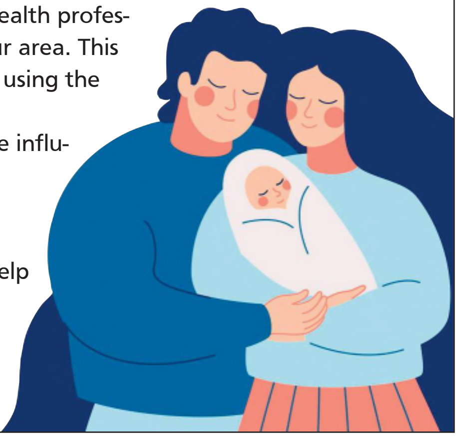
BETTER TRAINING LEADS TO BETTER OUTCOMES

There is no doubt in my mind that if you came to see me to have cataract surgery, you would have a very poor outcome. Why? Because I am a family physician, not a trained ophthalmologist. As a family physician and knowing my lack of training in this procedure, I would refer you to someone who has expertise in the field. This

HELPING CLINICIANS UNDERSTAND : WHAT ROLE CAN FAMILIES AND SUPPORTERS PLAY?

There is an opportunity here. An opportunity to work with clinicians to help them improve their skillset and provide better care. What role can families and supporters play?

- **Know that most healthcare providers want to provide good healthcare.** Starting with this understanding may help alleviate the thoughts that clinicians just do not care.
- **Help clinicians to see the person with IDD as a person, first:** someone with interests, likes, hobbies, friends, and activities. This helps clinicians understand that their patient is a person like everyone else, with a quality of life that can be improved with good healthcare, and that helping them resolve or better manage their clinical issues can help them resume their normal life activities.
- **Increase the awareness of clinicians' knowledge** about organizations and resources that can help them gain knowledge in the field of IDD healthcare. Here's a few of them:
  - The American Academy of Developmental Medicine and Dentistry: **AADMD.org**
  - The Developmental Disabilities Nurses Association: **DDNA.org**
  - The book, *Clinical Pearls in IDD Healthcare:* **https://replacingrisk.com/product/clinical-pearls**
  - The eLearn Course, "Curriculum in IDD Healthcare:" **https://replacingrisk.com/academy/idd-training-curriculum**
- **Be as prepared as possible** for healthcare appointments, having up-to-date health information readily available along with concise medical history, medications and social information as well. Utilizing a Health Passport document can be very helpful. Here's an example of one: **www.replacingrisk.com/downloadables/HRST-Health-Passport-Fillable-PDF.pdf**
- **Advocate for incorporation of formal training about IDD** healthcare into medical, dental, nursing and allied health professional schools in your area. This training can include using the **Curriculum in IDD Healthcare.** Use the influence you may have through advocacy organizations and with legislators to help ensure that future clinicians can meet the needs of everyone.



makes perfect sense, right? But for people with IDD, especially adults, clinicians with training and experience in providing healthcare for people with IDD are few and far between. Don't get me wrong, there are indeed clinicians and clinics that do a wonderful job of providing healthcare for people with IDD, however, sometimes people have to drive hours to get to them. In some communities, when word gets out that a particular clinician does a great job providing healthcare to people with IDD, they get overloaded with patients who are desperate to find good healthcare. We must do better as a healthcare profession to ensure access to quality healthcare for all.

IDENTIFYING THE ISSUES

One of the ways to make thing better is to study in more detail exactly what the problems are that contribute to the issues. The Administration for Community Living's National Institute on Disability, Independent Living, and Rehabilitation Research division has just awarded a three-year grant to the Lurie Institute for Disability Policy at Brandeis University to support research toward advancing pregnancy experiences for women with disabilities. The goals are to address gaps in knowledge about pregnancy and disability, to develop interventions to support and enhance the pregnancy experience, and to ensure optimal pregnancy related outcomes. This is certainly good news! One of the ways that they plan to ensure optimal outcomes is through active dissemination of findings and trainings for stakeholders. Training is the key.

THE PROVIDER-PATIENT RELATIONSHIP IS A TWO-WAY STREET

There is a great responsibility on the part of health professional training programs to educate clinicians on providing healthcare to people with IDD. There is also a great opportunity for people with IDD to foster the growth of clinically competent and compassionate clinicians. What I am about to say may certainly add to the frustration of people with IDD and their supporters in terms of not being able to find clinicians to meet their needs, but if we view it as an opportunity, we can make it a win-win situation.

I've heard from countless people with disabilities, their supporters and nurses about the frustration they experience when looking for good healthcare. I've also heard from many that they should not have to train clinicians. They want clinicians that are already trained in this area. First, let me say that I could not agree more. But, the reality is that this is not the world in which we currently live. But, sharing the resources above can help make it so.

I believe that anyone, with or without a disability, should be able to present to any clinician's office, emergency room or hospital and receive a basic level of competent and compassionate healthcare. Improving clinician education and fostering better clinician-patient communication will certainly work to make this ideal a reality.•

ABOUT THE AUTHOR:

Craig Escudé, MD, FAAFP is a board-certified Fellow of the American Academy of Family Physicians and the American Academy of Developmental Medicine and is the President of IntellectAbility (**www.replacingrisk.com**). He served as medical director of Hudspeth Regional Center in Mississippi and is the founder of DETECT, the Developmental Evaluation, Training and Educational Consultative Team of Mississippi. He has more than 20 years of clinical experience providing medical care for people with IDD and complex medical conditions and is the author of "Clinical Pearls in IDD Healthcare" and the "Curriculum in IDD Healthcare."

GUARDING YOUR CHILD'S MENTAL HEALTH DURING THE SCHOOL YEAR

BY SUSAN L. READ

Young people dealing with mental health issues is not something new. As an educator for over 40 years, I can recall many students over the years who were dealing, with varying levels of success, with a wide range of mental health conditions. The problem was, until recently, there was a lack of recognition by parents, teachers, and even healthcare professionals that these were issues that affected young people. This resulted in a lack of appropriate resources to assist these students, as well as a lack of reading materials which reflected their struggles.

Our children, whether they are in our class or our family, need our time and attention. They need to know we care about their best interests, and that we will always have time for them if they need to talk about something that is concerning them. This may seem obvious but, without meaning to, parents and teachers can often be so busy with everyday family or classroom life issues that they can become blinded to the needs of their children as individuals. It is important for adults to make time for their children every day. A good way to do this is to ask them about their day. Have there been any challenges? Perhaps sharing a challenge you have had in your day to encourage them to see that openness is valued in the class or the family. Have there been any successes worth celebrating, and what are they looking forward to tomorrow?

Celebrating success does not have to mean a focus on grades. Our children and our students should never be compared to each other. As we all know, everyone has different talents and interests, and we all develop at different rates. Praise can be given for a wide variety of things, such as for working hard and putting in their best effort, or mastering a new skill or meeting a new goal. All of this will lead to a healthy self-esteem, which is essential for positive mental health. These are good things to focus on.

If you do discover that your child's grades are slipping, it is important to find out why. A great first step is to talk to your child, followed by a talk to their teacher. Both parents and teachers are in a great position to offer support and to work together to offer help if there is a problem. From my years of experience as an educator, I know that the child always benefits when all the important adults in their lives can come together to provide support.

EXPERT CLASS: Teachers, principals, parents may notice a change in typical behavior. Parents are the ones who are the best experts on what is typical for their child.

Sometimes, our children may behave in a way that is out of character for them. Teachers, principals, parents (or perhaps all of them) may notice a change in typical behavior. “Why did you do that?” is a great question to ask when this happens. Parents are the ones who are the best experts on what is typical for their child. Speak with your child’s Guidance Counsellor if necessary to get to the root of the problem. Children should be encouraged to understand that it is okay to feel anger, frustration, and other negative feelings, but it is so important to talk about why they are feeling this way. Let’s all be that person our children can talk to, whenever they need to, and about anything they need to talk about.

It is also incredibly important for children to have strong relationships with both family and friends. Learning to form friendships, as well as to work together with classmates who are not friends, are both important life skills. Developing the ability to work through the inevitable conflicts within these relationships will allow children to develop positive conflict resolution strategies, rather than to allow these situations to be the cause of withdrawing from social situations. Both parents and teachers these relationships, particularly when there are changes evident.

The global COVID-19 pandemic, and the stresses which have been created and magnified by it, has thrown a spotlight on the issues of the mental health of our young people. The pandemic has changed our world. Much of this change has been negative. However, by highlighting how much our pre-teens and teens are struggling in many ways it is possible, I believe, to bring a positive twist to this situation. As parents and educators, we have been made more aware of their struggles. The conversation has begun. How can we help? How can we model to our pre-teens and teens that there is a way forward? How can we show them that they are not alone, and that asking for help has positive results?

> **THE CONVERSATION HAS BEGUN. HOW CAN WE HELP?**
>
> **HOW CAN WE MODEL TO OUR PRE-TEENS AND TEENS THAT THERE IS A WAY FORWARD?**
>
> **HOW CAN WE SHOW THEM THAT THEY ARE NOT ALONE, AND THAT ASKING FOR HELP HAS POSITIVE RESULTS?**

As an educator I know how important it is for students to be able to see themselves in literature. By writing Mermaid Tears, a middle-grade novel which addresses the topic of mental health in children of that age, I hope to be able to reach out to the readers who are suffering, as well as to their parents, caregivers, and teachers, and to show them that there is a way forward. Other books I have recommended to students in the past include Finding Perfect by Elly Swartz, Fish in a Tree by Lynda Mullaly Hunt, and Counting by 7s by Holly Goldberg Sloan. Seeing how other children, even those who live in fictional worlds, have dealt with mental health issues, healed, and moved forward with their lives is an important step in overcoming obstacles.•

ABOUT THE AUTHOR:

Susan L. Read is a school librarian in Massachusetts and the author of Mermaid Tears. She was born and raised in New Zealand. During that time, she was an elementary school teacher and principal, a writer, and an avid reader of any books she could get her hands on.

PART V: EP MAGAZINE SLEEP SERIES

THE ROLE SLEEP PLAYS IN PEOPLE WITH DISABILITIES AND THEIR FAMILIES

BY DR. EMILY SINGER

This article focuses on the important role sleep plays in people with disabilities and their families. As anyone that has had a bad night of sleep can relate, the consequences of poor sleep are often felt immediately the next day. Particularly, in families with a child with a disability, quality sleep can be elusive.

Children with developmental disabilities are more likely to have sleep problems compared to their typically developing peers.[1] Many neurodevelopmental disorders are associated with certain pediatric sleep problems. Children with Down syndrome commonly have obstructive sleep apnea and screening for this disorder is important for their health.[2] Children with autism spectrum disorder can have a wide variety of sleep problems, including problems falling asleep and staying asleep. Studies have shown that children with attention-deficit/hyperactivity disorder can have worsening of those symptoms around bedtime, which leads to increased bedtime resistance and trouble falling asleep.[3] These sleep problems can have daytime consequences such as inattention, behavioral dysregulation and school difficulties.[4] Frequently, these children have pre-existing difficulties with behavior or social interaction and a poor night's sleep exacerbates these issues.[5] Thus, you can see the importance of screening children with disabilities for sleep problems.

The effects of poor sleep can ripple out to the entire family. We know that sleep can have a large impact on an individual or families' overall sense of wellness.[6,7] As discussed in an earlier article in this series, sleep is a restorative process that allows us to consolidate memory, regulate emotions and be alert during the day. Importantly, when we have disrupted or inadequate sleep there are effects on how we are able to process events and store memories. Studies have shown that poor sleep leads to more negative associations of memories. Furthermore, poor sleep can lead to emotional dysregulation, lowering our threshold to tolerate stressors.[8] We can all recall a time when we became irrationally upset about a minor stressor in the face of sleep deprivation! This exemplifies how sleep problems can be a predictor of our daily mood, but even more importantly, chronic inability to sleep can lead to future depression.[9] This finding underlies the importance of establishing better sleep to promote mental health.

Our sleep inevitably changes as we age. From the tendency to wake up and go to sleep earlier to the amount of time spent in different sleep cycles, the differences abound when comparing children to older individuals.[10] By studying people over age 85, researchers have made connections between regular, quality sleep and longevity.[11] On the other hand, poor sleep habits can impact our physical health in myriad ways. Sleep problems have been linked to chronic medical problems like heart disease and diabetes, just to name a few.[12]

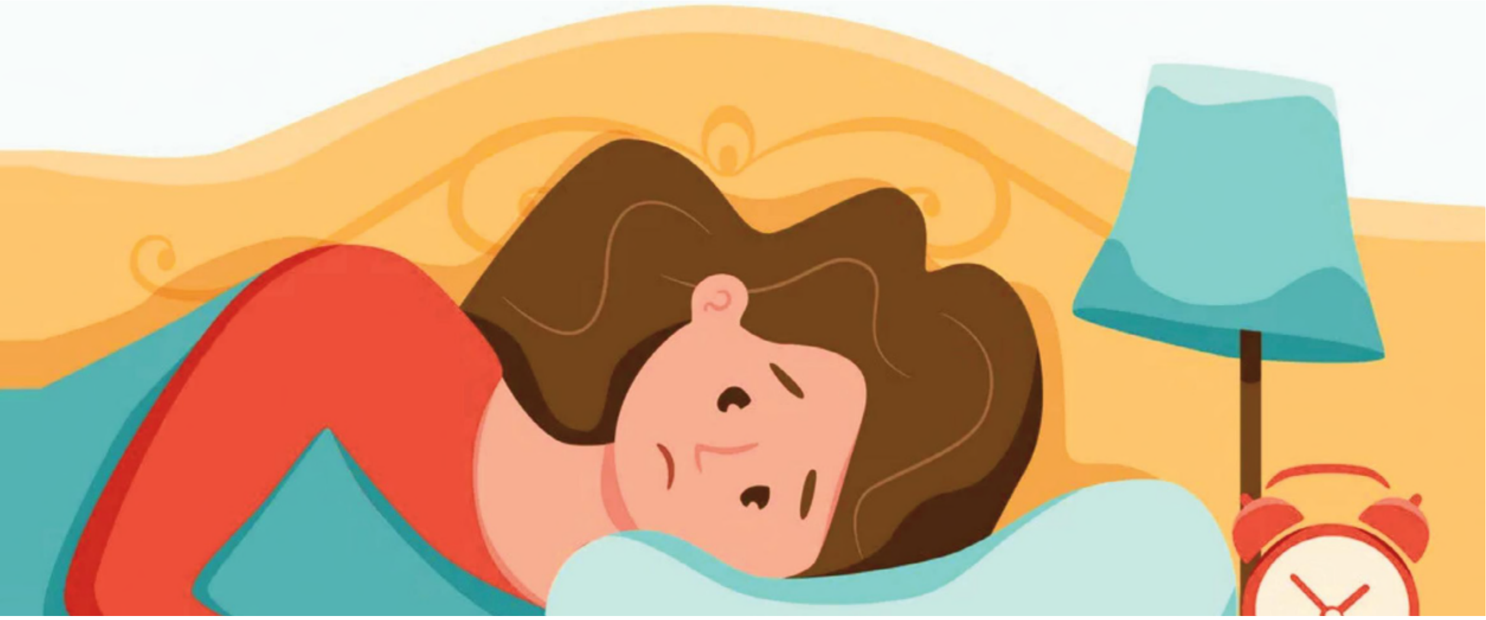
So, in our busy, modern society, what can we do to mitigate these risks? Promoting healthy sleep throughout the entire family should be of utmost importance. Families should be encouraged to discuss their children's sleep issues with their health provider. Studies have shown that targeting poor sleep can lead to better daytime behaviors. For example, parents of children with autism reported improvements in hyperactivity and restricted behaviors after implementing strategies learned from sleep education workshops.[13] Family-focused interventions can be most helpful when addressing pediatric sleep problems. This is especially true with younger children and children with developmental delay. Often, a family's attitudes and beliefs towards sleep need to be evaluated before changes to behavior can be undertaken.[14] Parental education to common pediatric sleep problems can empower families to implement the changes necessary to find solutions.

---

1. Reynolds et al., "Sleep Problems in 2- to 5-Year-Olds With Autism Spectrum Disorder and Other Developmental Delays."
2. Horne et al., "Sleep and Sleep Disordered Breathing in Children with down Syndrome."
3. Owens, "A Clinical Overview of Sleep and Attention-Deficit/Hyperactivity Disorder in Children and Adolescents."
4. Malow et al., "Characterizing Sleep in Children with Autism Spectrum Disorders."
5. Mazurek and Sohl, "Sleep and Behavioral Problems in Children with Autism Spectrum Disorder."
6. Varma et al., "Examining Sleep and Mood in Parents of Children with Sleep Disturbances."
7. Estrela et al., "Chronic Parenting Stress and Mood Reactivity."
8. Worley, "The Extraordinary Importance of Sleep."

9 Baglioni et al., "Insomnia as a Predictor of Depression"; Varma et al., "Examining Sleep and Mood in Parents of Children with Sleep Disturbances."

10. Edwards et al., "Aging and Sleep."
11. Mazzotti et al., "Human Longevity Is Associated with Regular Sleep Patterns, Maintenance of Slow Wave Sleep, and Favorable Lipid Profile."
12. Buysse, "Sleep Health."
13. Reed et al., "Parent-Based Sleep Education Workshops in Autism."
14. Tikotzky and Sadeh, "The Role of Cognitive–Behavioral Therapy in Behavioral Childhood Insomnia."



Bedtime resistance, a child's attempt at stalling the inevitable bedtime (one more book, another hug, a sip of water!) can be ameliorated by parents setting clear limits. A concrete way to do so is with a bedtime pass. Providing a child with a pass to get out of bed for one or two last "curtain calls" before being told that they are out of passes and must go to bed. Emphasis should be placed on the rewards that could be earned if a child keeps their pass for the night by staying in bed. Sleep-onset association is another common problem that children face when trying to fall asleep. Sleep-onset association occurs when children become dependent on the presence of a parent to fall asleep. Gradually promoting independent settling and ability to fall asleep can help children wake less frequently at night.[15]

When thinking about sleep problems, considering the developmental age of the child is important. In contrast to younger children, adolescents may need more active participation in their own sleep education. A study of adolescents with autism showed that an individualized sleep plan based on both the adolescent and parents' identified problems improved sleep and daytime behaviors like impulsivity and anxiety. The adolescents were engaged to complete sleep diaries and track rewards and roles for the adolescent and their parent were clearly defined.[16]

As you can see, there are many different ways to improve sleep for children of different developmental stages. We suggest families start with one or two interventions and expand from there. Making sleep a priority can provide lasting benefits for mood, health, and longevity! •

ABOUT THE AUTHOR:

Dr. Emily Singer has research and clinic interests in pediatric neurology and sleep medicine, especially in children with neurodevelopmental disorders and epilepsy.

---

[15] Anders, Halpern, and Hua, "Sleeping Through the Night."

[16] Loring et al., "Impact of a Brief Behavioral Intervention for Insomnia on Daytime Behaviors in Adolescents with Autism Spectrum Disorders.

References

Anders, T. F., Halpern, L. F., & Hua, J. (1992). Sleeping Through the Night: A Developmental Perspective. Pediatrics, 90(4), 554–560.

Baglioni, C., Battagliese, G., Feige, B., Spiegelhalder, K., Nissen, C., Voderholzer, U., Lombardo, C., & Riemann, D. (2011). Insomnia as a predictor of depression: A meta-analytic evaluation of longitudinal epidemiological studies. Journal of Affective Disorders, 135(1–3), 10–19. https://doi.org/10.1016/j.jad.2011.01.011

Buysse, D. J. (2014). Sleep Health: Can We Define It? Does It Matter? Sleep, 37(1), 9–17. https://doi.org/10.5665/sleep.3298

Edwards, B. A., O'Driscoll, D. M., Ali, A., Jordan, A. S., Trinder, J., & Malhotra, A. (2010). Aging and sleep: Physiology and pathophysiology. Seminars in Respiratory and Critical Care Medicine, 31(5), 618–633. https://doi.org/10.1055/s-0030-1265902

Estrela, C. da, Barker, E. T., Lantagne, S., & Gouin, J.-P. (2018). Chronic parenting stress and mood reactivity: The role of sleep quality. Stress and Health, 34(2), 296–305. https://doi.org/10.1002/smi.2790

Horne, R. SC., Wijayaratne, P., Nixon, G. M., & Walter, L. M. (2019). Sleep and sleep disordered breathing in children with down syndrome: Effects on behaviour, neurocognition and the cardiovascular system. Sleep Medicine Reviews, 44, 1–11. https://doi.org/10.1016/j.smrv.2018.11.002

Loring, W. A., L. Johnston, R., Shui, A. M., & Malow, B. A. (2018). Impact of a Brief Behavioral Intervention for Insomnia on Daytime Behaviors in Adolescents with Autism Spectrum Disorders. Journal of Contemporary Psychotherapy, 48(3), 165–177. https://doi.org/10.1007/s10879-018-9381-3

Malow, B. A., Marzec, M. L., McGrew, S. G., Wang, L., Henderson, L. M., & Stone, W. L. (2006). Characterizing Sleep in Children with Autism Spectrum Disorders: A Multidimensional Approach. Sleep, 29(12), 1563–1571. https://doi.org/10.1093/sleep/29.12.1563

Mazurek, M. O., & Sohl, K. (2016). Sleep and Behavioral Problems in Children with Autism Spectrum Disorder. Journal of Autism and Developmental Disorders, 46(6), 1906–1915. https://doi.org/10.1007/s10803-016-2723-7

Mazzotti, D. R., Guindalini, C., Moraes, W. A. dos S., Andersen, M. L., Cendoroglo, M. S., Ramos, L. R., & Tufik, S. (2014). Human longevity is associated with regular sleep patterns, maintenance of slow wave sleep, and favorable lipid profile. Frontiers in Aging Neuroscience, 6, 134. https://doi.org/10.3389/fnagi.2014.00134

Owens, J. A. (2009). A Clinical Overview of Sleep and Attention-Deficit/Hyperactivity Disorder in Children and Adolescents. Journal of the Canadian Academy of Child and Adolescent Psychiatry, 18(2), 92–102.

Reed, H. E., McGrew, S. G., Artibee, K., Surdkya, K., Goldman, S. E., Frank, K., Wang, L., & Malow, B. A. (2009). Parent-Based Sleep Education Workshops in Autism. Journal of Child Neurology, 24(8), 936–945. https://doi.org/10.1177/0883073808331348

Reynolds, A. M., Soke, G. N., Sabourin, K. R., Hepburn, S., Katz, T., Wiggins, L. D., Schieve, L. A., & Levy, S. E. (2019). Sleep Problems in 2- to 5-Year-Olds With Autism Spectrum Disorder and Other Developmental Delays. Pediatrics, 143(3). https://doi.org/10.1542/peds.2018-0492

Tikotzky, L., & Sadeh, A. (2010). The role of cognitive–behavioral therapy in behavioral childhood insomnia. Sleep Medicine, 11(7), 686–691. https://doi.org/10.1016/j.sleep.2009.11.017

Varma, P., Conduit, R., Junge, M., & Jackson, M. L. (2020). Examining Sleep and Mood in Parents of Children with Sleep Disturbances. Nature and Science of Sleep, 12, 865–874. https://doi.org/10.2147/NSS.S271140

Worley, S. L. (2018). The Extraordinary Importance of Sleep. Pharmacy and Therapeutics, 43(12), 758–763.

IS YOUR FAMILY
CYBERFIT?

Protect your family. Protect your country.
Teach your kids online safety.
TRICARE.mil/CyberFit

EXCEPTIONAL PARENT • PHYSICIAN • PATIENT • PEOPLE

FROM OUR FAMILIES... TO YOUR FAMILIES

MILITARY

TION

MILITARY LIFE

PUZZLES AND CAMO

MOVING WITH AN INDIVIDUALIZED EDUCATION PROGRAM

If you have a child with an individualized education program, don't be nervous about moving schools.

The Individuals with Disabilities Education Act, or IDEA, (**www.militaryonesource.mil/family-relationships/special-needs/special-education-and-childcare/an-overview-of-special-education**) ensures that all children with special needs have access to a free, appropriate public education and the tools needed to meet their educational goals — no matter where or how often your family moves.

The IDEA governs how states and public agencies, including the Department of Defense, provide early intervention, special education and related services to eligible children with disabilities from birth through age 21. Department of Defense Instruction/Manual 1342.12 "Provisions of Early Intervention and Special Education Services to Eligible DoD Dependents" (**www.esd.whs.mil/Portals/54/Documents/DD/issuances/dodm/134212m.pdf**) published on June 17, 2015 interprets IDEA for the Department of Defense.

When a student with an individualized education program transfers, the new school must:

- *Provide free and appropriate public education. This principle makes sure every child, regardless of disability, has the right to a free public education tailored to achieve his or her highest potential.*
- *Include services comparable to those in your child's current individualized education program. The new school provides interim services until the IEP team adopts the incoming IEP or develops and implements a new IEP.*

Comparable services are provided if the child is identified as having a disability under the Individuals with Disabilities Education Act at the time of the transfer, the IEP was in effect at the previous school, or if the transfer was in the same academic school year.

You may be able to get a head start on registering your child in a new school and coordinating their IEP through the Advance Enrollment Initiative (**www.militaryonesource.mil/education-employment/for-children-and-youth/changing-schools/advance-school-enrollment**). This policy, in place in a number of states, waives the residency requirement for military families, allowing them to pre-enroll their children before arriving at the PCS destination.

The Interstate Compact on Educational Opportunity for Military Children (www.militaryonesource.mil/education-employment/for-children-and-youth/changing-schools/interstate-compact-for-military-children) eases relocation issues by calling for the new school to provide special education services comparable to the previous school's until it can create a new IEP. Contact your EFMP Family Support provider (https://installations.militaryonesource.mil/?looking-for-a=program/program-service=16/focus=program) to request a warm hand off to the gaining installation prior to a PCS. Your EFMP Family Support provider can provide information, resources, and referrals even before you've arrived at your location.

> REACH OUT TO THE NEW SCHOOL AND REMAIN AN ACTIVE ADVOCATE FOR YOUR CHILD IN DEVELOPING THE NEW INDIVIDUALIZED EDUCATION PROGRAM.

Your school liaison (https://installations.militaryonesource.mil/search?program-service=12/view-by=ALL) can help pave the way for your child's transfer to a new school and assist with any other issues that arise with your child's IEP or education in general.

It may take your child awhile to get used to the new surroundings and people, but over time, they will. Reach out to the new school and remain an active advocate for your child in developing the new individualized education program. As a member of your child's IEP team at both the losing and gaining school, you play an important role in helping your child thrive.

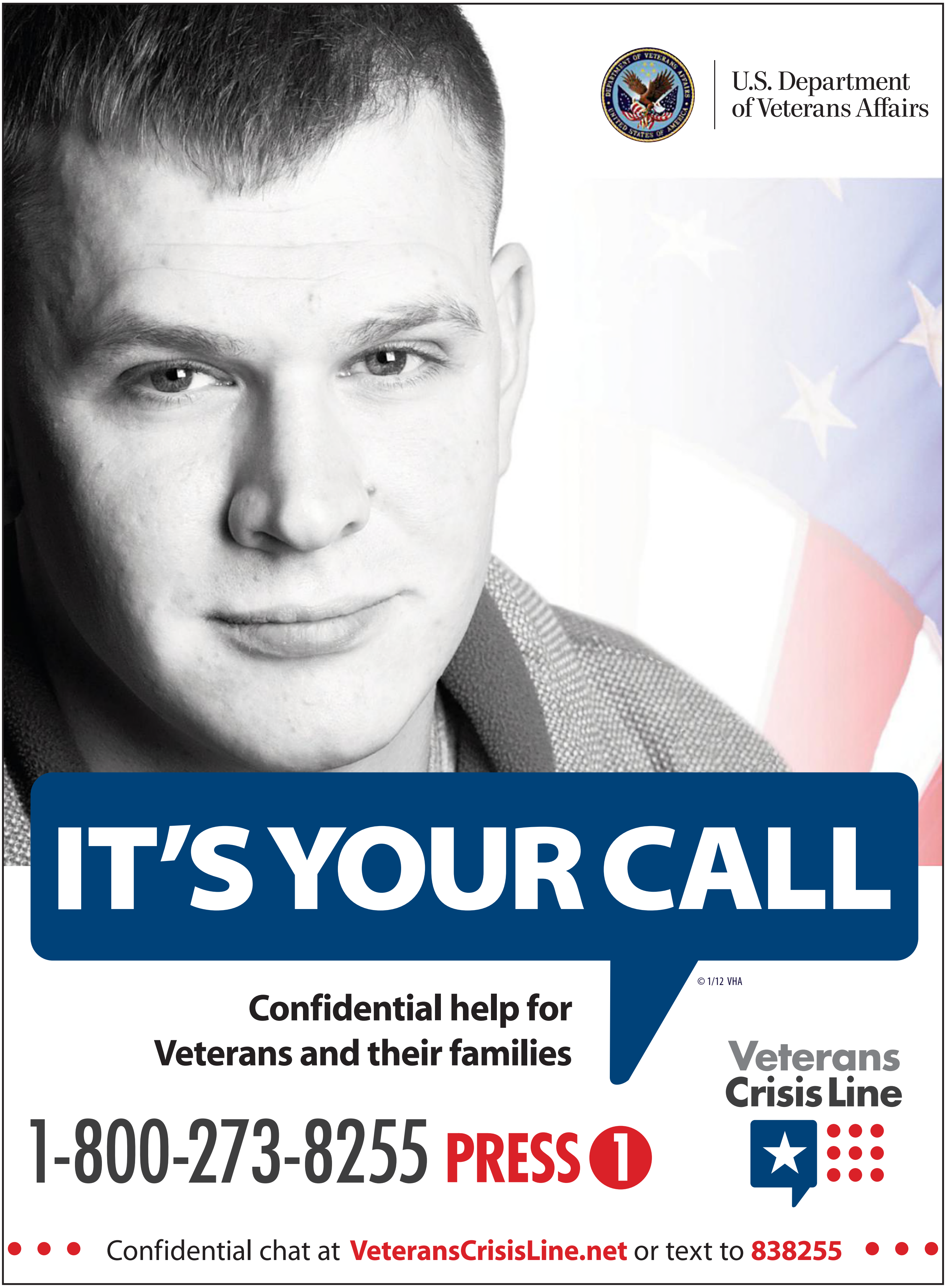
Take advantage of available services offered by EFMP Family Support on your installation. Or, call Military OneSource at 800-342-9647 or use live chat to schedule an appointment with a special needs consultant. Appointments are available seven days a week.

– Military OneSource

MOVERS AND SHAKERS : RESOURCES FOR PORTABLE IEPs

Military OneSource offers a number of resources to help your family move successfully with an IEP.

- Download the **Preparing for Your Move fact sheet** for suggestions to consider before, during and after a move: https://www.militaryonesource.mil/products/preparing-for-your-move-fact-sheet-923/
- Visit the **EFMP & Me tool** to create a customized checklist for your family. Review the Education checklist to learn more about IEPs and transferring schools: https://efmpandme.militaryonesource.mil
- View the Military OneSource **Facebook Live Special Education Discussion** to hear two Exceptional Family Program representatives discuss ways to ensure a smooth transition in both special education and health care services: www.facebook.com/military.1source/videos/483249362415028
- **The EFMP podcast series**, Episode 3, is another resource for tips on easing your medical and educational transitions when you move: www.militaryonesource.mil/training-resources/podcasts/osn-efmp-podcast-series/
- **The Education Directory for Children With Special Needs** provides information to make informed decisions about your child's education and early intervention services: https://efmpeducationdirectory.militaryonesource.mil/
- **The Directory of Early Intervention, Special Education and Related Services in OCONUS Communities** identifies military communities in OCONUS locations with programs or services for children with special needs: www.militaryonesource.mil/products/directory-of-early-intervention-special-education-and-related-services-in-oconus-communities-300/
- The **Special Care Organizational Record for Children with Special Health or Educational Needs** (www.militaryonesource.mil/products/special-care-organizational-record-for-children-with-special-health-or-educational-needs-downloadable-143) and **The Special Care Organizational Record for Young Adults With Special Needs** (www.militaryonesource.mil/products/special-care-organizational-record-for-young-adults-with-special-needs-downloadable-881/) can help you keep track of contacts, resources and your child's progress and plan.
- Take the **Moving With an Individualized Education Program** MilLife Learning course to learn how to help make sure your child gets comparable services wherever you go: https://millifelearning.militaryonesource.mil/f?p=332:8:::NO



10 QUESTIONS TO ASK CHILD CARE PROVIDERS FOR YOUR CHILD WITH SPECIAL NEEDS

Finding a great child care provider is like finding a new member of your military family. After all, your child will spend a significant amount of time there each week, and what happens at day care can impact what happens at home. This connection makes it even more important for families when looking for a child care provider for a child with special needs.

GETTING ANSWERS : QUESTIONS FOR POTENTIAL CARE PROVIDERS

Here's a list of 10 questions for you to ask potential care providers in your community before enrolling your child with special needs in a new child care program.

1. **Is your child care program nationally or regionally accredited?** With an accredited child care facility, you're more likely to get the best possible care for your child.
2. **Do you hold regular staff training or educational opportunities?** The answer to this question not only tells you how highly the child care provider values its staff, it also offers a glimpse into how receptive staff will be to learning new ways to care for your child and their special needs.
3. **What is your current staff-to-student ratio?** The more staff a child care provider already has, the more likely it is your child with special needs will more easily fit in with the current classroom environment.
4. **How do staff discipline children, if necessary?** Look for providers who would reinforce the discipline strategies you use at home in order to create a more consistent and predictable experience for your child.
5. **What are the age ranges of children at your program?** If you know you're going to stay in an area for a while, do your best to pick a child care provider that will be able to take your child on for the length of your stay at this latest PCS.
6. **May I see your parent handbook or a copy of your policies?** Reading through a provider's parent handbook or policies will tell you how organized a child care provider is, what situations may have occurred previously and what your family can expect.
7. **What would you consider 'special needs'?** Just as there is a range of special needs a child could have, there is a range of what child care providers consider to be special needs, which may impact your child's subsequent care. Getting everyone on the same page before your child participates will help avoid confusion and misunderstandings.
8. **Has your child care program ever cared for a child with this need before?** This question offers background on how the child care provider handled your specific need in the past, and how they may approach future accommodations. Bear in mind that under the Americans with Disabilities Act, child care providers are not allowed to assume what care your child needs based on their previous experience or personal understanding of the special need (www.ada.gov/childqanda.htm). Instead, they must evaluate your child as an individual to see what they need to thrive in the program and if such accommodations can be offered without posing a fundamental change to the nature of the program.

9. **How do you introduce new children to your child care program?** A proper introduction of a newcomer into the program can make a significant impact on the child's experience.
10. **How involved are the families in your child care program?** Some child care providers expect little outside involvement from the families; others expect regular volunteering and contributions from parents. Know what expectations the provider has for you as the parent before you commit to a child care program.

In the end, everyone – you as a parent and the child care provider staff as a whole – wants what is best for your child. By asking these questions, you can make sure they and you are ready to make your child's time at their day care or other child care program a success.

Use the EFMP & Me tool (https://efmpandme.militaryonesource.mil) to help organize your child care and other needs for your family. Review the Child Care section for tips and resources. And if you ever need extra help, you can always reach out to your installation EFMP Family Support provider (https://installations.militaryonesource.mil/?looking-for-a=program/program-service=16/focus=program), call Military OneSource at 800-342-9647 or use live chat to schedule an appointment with a special needs consultant. Appointments are available seven days a week.

– Military OneSource

He's Got a Job

EMPLOYMENT & TRANSITION

In the last few months, we've seen a change in Broden. He's happier. He's initiating social interaction to communicate his needs in a way we have never seen before.

Years ago, I remember sitting in an office of an ABA clinic where my son used to be a client. Broden was not himself. I felt like we were losing him. After digging around and asking questions, I soon realized that he had so many programs that inhibited him from self-regulating, he had completely shut down. It was as if he didn't know how to live in his body. After questioning the therapists' vision on what they wanted to focus on with our son, one therapist turned to me and said, "Well Shelly, he has classic autism. He's not responding to the programs the way we'd like him to at this point." After leaving the office, in so many words, it was communicated that Broden wasn't going to amount to much due to his level of severity so they were still going to focus on preschool level skills and not consider looking outside the box on what he could do.

COPY THAT: "If I told anyone that my 15-year-old son was the designated 'copier' for a clinic, there would be little fanfare, but the point is that the staff that works with my son saw his worth. They gave him a job to do each day, a task to complete that contributed to the overall mission of the clinic."

Mark and I eventually pulled him from that clinic. For the first time since Broden was diagnosed at 26 months old, Broden did not have any services and there wasn't a plan on what to do next. All I knew then was that the clinic he was attending at that time did not deserve him. Fortunately, weeks later, we were able to find a better fit and we started to see our Broden slowly come back to us. He was with staff that saw his potential, and later, I realized that Broden was self-aware. He knew when he was working with people who saw him for who he was and accepted him, as opposed to staff who were not only teaching him, but who were trying to change his core being of who he was as a person. I finally connected the dots last week when visiting the clinic where he is currently receiving services.

During my parent's visit, we went on a tour of the facility to see the new changes that were taking place. I had been on a tour a few weeks prior and I assumed that it would be specifically for my parents, but I realized that although I had been there before, I still learned something new. I learned that Broden had a job.

During the tour, I pulled my parents over to the copier and told them that Broden had learned how to make copies. The staffer who was conducting the tour motioned for us to come into a room that contained administrative items. There were several small shelves with slots to slide documents into for staffers. Our tour guide patted her hand to the bottom right slot and said, "This is Broden's job. A couple times a day, Broden will come in here and check to see if there is anything that needs to be copied. If so, he makes the copies and puts them in the appropriate slot."

With my mask on my face, our guide could not see my bottom jaw drop in amazement. If I told anyone on the street that my 15-year-old son was the designated "copier" for a clinic, there would be little fanfare, but that's not the point. The point is that the staff that works with my son saw his worth. They gave him a job to do each day, a task to complete that contributed to the overall mission of the clinic.

In the last few months, we've seen a change in Broden. He's happier. He's initiating social interaction to communicate his needs in a way we have never seen before. Last Sunday, I was laying down for a short nap since I had an early morning. I was woken up by someone poking my shoulder. It was Broden, “Hamburger? French fries?” I rolled over and looked at the clock. It was 4 pm, “Dinner is going to be round 5:30 pm. Do you want some popcorn?” Broden started to walk away, but turned around and answered, “No.” I countered with the idea of him having a bowl of chips. He stuck his head back in the room and declined my offer. Once I knew he was in his room, I yelled out, “How about some gummies?” Broden walked out of his room and into the hallway, “Gummies!” Instead of me jumping out of bed and tending to his request, I told him to go downstairs in the pantry and get some gummies for a snack to hold him over for dinner. Soon after, I heard his feet skip down the stairs and Broden tell Mark what he wanted for his snack. I laid on my back in bed for a moment to process what had happened. Broden and I had just had a conversation about him being hungry before dinner. I laid there for a few minutes to take it in and to enjoy the feeling of connection to my son.

> “When I look back and remember the challenges with autism, I appreciate the triumphs even more. Working with a team that sees Broden for who he is and working with us to envision his productive future matters.”

When I look back and remember the challenges with autism, I appreciate the triumphs even more. Working with a team that sees Broden for who he is and working with us to envision his productive future matters. When describing our son, the term “classic autism” does not come to mind. Broden is a teenager that loves music and goes for walks with friends. Our son is still continuously learning new things every day and who now has a job. He's come so far and he's not done yet. Not even close. •

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.

PRODUCTS AND SERVICES

ADAPTIVE/SPECIAL NEEDS BEDS

KAYSERBETTEN

P: 800-574-7880
E: ruthann@kayserbettenus.com
W: www.kayserbettenus.com
Designed to allow the child to be part of the surroundings while being safe and secure in their bed.

CLEANING/SANITIZING SOLUTIONS

BANTEC SANITIZING

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

EDUCATION

OLS BELLEVUE COLLEGE

W: bellevuecollege.edu/ols
E: ols@bellevuecollege.edu
An associate degree for adults with learning disabilities.

UI REACH AT UNIVERSITY OF IOWA

Iowa City, IA
W: education.uiowa.edu/reach
P: 319-384-2127
E: reach@uiowa.edu
A 2, 3 or 4 year certificate, on-campus, Big 10 college experience for students with diverse learning challenges.

FINANCIAL PLANNING/ ESTATE PLANNING/ INSURANCE

MASS MUTUAL SPECIALCARE

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

THE AMERICAN COLLEGE OF FINANCIAL SERVICES

www.theamericancollege.edu
A private college focused on professional training for financial practitioners

HOME ADAPTATION/DESIGN

LJS ELECTRIC

www.ljselectric.com
Home automation products and devices professionally installed.

NON-PROFIT

IRENE AND ERIC SIMON BRAIN RESEARCH FOUNDATION

www.iesbrainresearch.org
Helping to further research and find answers to addiction, pain and other brain diseases and disorders.

SCHOOLS/CAMPS/RESIDENCES

THRESHOLD PROGRAM AT LESLEY UNIVERSITY

Cambridge, MD
W: www.Lesley.edu/threshold
P: 800-999-1959 ext. 8181; or 617-349-8181
E: threshold@lesley.edu
A two-year, on-campus college experience for students with diverse learning challenges.

Your VA & DoD Benefits. Online.

Register Now

www.**ebenefits**.va.gov

“I just checked my VA disability claim status. Online.”

Whether you are a Wounded Warrior, Service member, Veteran, or family member, eBenefits is your online source for VA & DoD benefits information and service. Get personalized VA & DoD information, manage your benefits claims and much more. Register for a Premium eBenefits Account at **www.ebenefits.va.gov**.

eBenefits
www.**ebenefits**.va.gov