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MAGAZINE
SEPTEMBER 2019
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FIX THE SYSTEM, NOT THE CHILD

AND:

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BACK TO SCHOOL

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Without the structure of school or a job during the summer, students may lapse into a more relaxed routine, making the transition back to school all the more difficult. *EP*'s Annual Back to School Issue advises parents on how to ease the transition back to a post-secondary program or college. Several other pertinent topics, including bullying prevention, are addressed. *Coverage begins on page 20.*

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Information and Support for the Special Needs Community

VOLUME 49 ISSUE 9 ▪ ESTABLISHED 1971

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

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or toll free: 800-372-7368 ext. 234

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.ep-magazine.com. All rights reserved. Copyright ©2019 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@ep-magazine.com or call toll free: (800) 372-7368 extension 119. Back issues incur a charge of $10.00 each and depend upon availability, call (800) 372-7368. Agreement #1420542

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— Rick Rader, MD

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On Being Able to See Right Through You

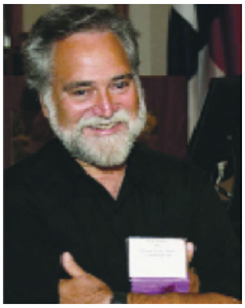
A study demonstrated that radiologists who read images, X-rays, MRIs and CT scans did a better job if they saw a picture of the face of the patient. The radiologists in the study said they read CT scans more meticulously and felt more empathy when they saw a patient's face.

The report of one of the several X-rays that were ordered over the weekend came back and landed on my desk.

"Hands and wrists, two views of the right and left hand and wrist were obtained. There is generalized osteopenia. There are OA changes seen at the first CMC joint with subchondral sclerosis and joint space narrowing. Ulnar styloids appear intact. There is no chondrocalcinosis. There are some degenerative changes seen at the carpus but without any obvious erosive changes. There are no erosions seen at any of the MCP or PIP joints. There are scattered areas of joint space narrowing at the PIP and DIP joints."

To the layperson it might as well been written in ancient Egyptian hieroglyphics. But to the radiologist, the doctor who "read" the X-ray, it was sheer poetry. It explained exactly what was going on with these two hands and wrists. What was observed, what was normal, and what was out of whack. To the primary care physician, it provided a guide to assisting in what might have been the problem and what was needed to address the problem.

I know that this was just one of perhaps hundreds of X-rays that the radiologist studied and reported on in the previous week. And while the X-ray revealed much of everything, the radiologist needed to know to provide the report there was something missing; something that the radiograph did not reveal, announce or describe.



While the patient referral did indicate that there was a three-week history of wrist pain, nothing about the patient, nothing "really" about the patient was revealed by either the referral-slip or the X-ray.

The radiologist never actually saw the patient, talked to the patient, or understood the patient. In the world of radiology, it probably didn't matter. Radiologists do not treat patients, they simply describe parts of them. They are almost like the bombardiers in World War II. They put the "target" in their cross hairs, identify them (factory, airfield, railroad lines, bridges) and then watch and describe what's left after

PHOTO CREDIT RICK RADER COLLECTION

•the bombs were released. In this metaphor, the bombs are the trauma, the disorders or the disease.

Had the radiologist faced the patient, touched the patient, or found themselves in the same room with the patient, he or she would have understood that the wrist pain was not allowing the 44-year-old Special Olympic athlete to enjoy his favorite sport of bocce ball. How the pain had kept him from practicing Saturday afternoons with his Special Olympic buddies. How the wrist pain kept him from issuing a meaningful "high five" to his friends. But with no face, no soul, no expressions, there was simply a part that needed to be compared and described.

There was a study that demonstrated that radiologists who read images, X-rays, MRIs and CT scans did a better job if they saw a picture of the face of the patient. The radiologists in the study said they read CT scans more meticulously and felt more empathy when they saw a patient's face, although it's not clear whether the photo actually improved their accuracy in interpreting the test results.

> "Groups like school boards or employment departments, policy makers, insurance agents, biostatisticians, city planners, admissions officials, housing authorities and public officials often make decisions about people without seeing people. You don't have to be a radiologist to be able to see right

Dr. Yehonatan Turner, an Israeli radiologist, came up with the idea as a result of being a frustrated radiology resident. He realized that without ever meeting the patient he knew more about the patient's liver and spleen than he knew about the patient. Turner shared that he was influenced by the twentieth-century philosopher Emmanuel Levinas' idea that seeing another person's face instills a series of responsibility for that person.

In the study, it was found out that the scans that included photos of the patients had more incidental findings provided by the examiner than the scans without the photos. So the conclusion was that if you saw (and felt you "knew") the patient, you might be more motivated to do a more comprehensive assessment. The radiologists reported that being able to have a look at the patients, it made them feel more like "physicians" than technicians. This approach could have some positive impact on both radiologists and pathologists, who also never see their patients but simply their "specimens".

This study could have similar positivity to others who "assess" people with disabilities without ever actually "seeing" them. People like those in school boards or employment departments, policy makers, insurance agents, biostatisticians, city planners, admissions officials, housing authorities and public officials. These groups often make decisions about people without seeing people. You don't have to be a radiologist to be able to see right through them.

Perhaps they should read the observations of Levinas (with or without seeing a picture of him) to better understand his teachings: "Among all the organs of the body, the face is the one which stays most naked…In front of the face of the other, silence is impossible." •

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

A NEW PICTURE BOOK FOR SIBLINGS OF KIDS WITH DISABILITIES

Author Jessica Leving remembers clearly the night her brother, Billy, was diagnosed with autism. She was eight years old and recalls coming home from school to find her mom crying in her room with the door closed. It was days before anyone would tell her why.

Title: **Special Siblings: Growing up with a sibling who has special needs**

Author: **Jessica Leving**; Illustrator: **Ian Robertson**

Publisher: **Independently published**
Publication Date**: August 16, 2019**
Paperback: **33 pages**
ISBN-13: **978-1686677328**
Available at amazon.com

"Everything was different after Billy's diagnosis," says Leving. "Our lives started revolving around his doctor appointments and therapy sessions. It was all very hard for me to understand at that age."

Now an adult, Leving has written and published a picture book geared toward helping other young siblings feel less alone and discover the joy in their special sibling relationships.

Though the book is geared toward children 3-8, siblings of all ages seem to finding that the message still resonates.

"The loving and honest portrayal of Jessica and Billy's life together will let other children know they are not alone," said reviewer Suzanne Aaron. "While there may be frustrations, there is also lots of love."

For more information, e-mail specialsiblings@gmail.com •

WHAT'S HAPPENING

SMITHSONIAN DINOSAURS ACCESSIBLE VIA AUDIO DESCRIPTION, TACTILE MODELS

GOING DEEP: Demonstrations at the Deep Time exhibit will feature touchable objects that will enlighten visitors on the topics of fossil dating, fossilization and evolution.

BY MEG RIVERS
AND SAMANTHA BARRY

This October, the Smithsonian's National Museum of Natural History will launch a new mobile app with audio description for our new fossil hall: the David H. Koch Hall of Fossils – Deep Time.

The app is designed for visitors who are blind or have low vision to access key content in this new exhibition. This new offering, combined with tactile components and robust volunteer engagement throughout the hall, is a direct result of a collaborative, intentional effort to make the new hall something that all visitors will enjoy.

Working as part of a team of hundreds of scientists, educators, artists and designers who contributed to the Deep Time exhibition, one of our roles is to consider accessibility in the space. We want all dinosaur-enthusiasts, and everyone who's curious about the natural world and science, to be able to experience the new 31,000 square-foot permanent exhibit, home to more than 700 fossils and the nation's T-Rex.

Early on in the exhibition development process, we looked across the board at what accessibility meant for our visitors and how we could improve our approach to access in this very unique and much awaited gallery. We knew Deep Time would be filled with dynamic specimens in really wonderful activated backdrops, so ensuring all our visitors are able to experience that sense of awe and engage with our content was a priority. With so many specimens behind glass, a key aspect of this initiative was identifying how we could ensure our visitors who are blind or have low vision could engage with everything the Museum has to offer.

MOBILE APP/AUDIO DESCRIPTIONS

As part of a suite of accessibility offerings, we're very excited to be able to offer audio descriptions via a downloadable mobile app. Users are able to use a menu to select the content they want to explore based on the main graphics and content in the gallery. Since this is downloadable, users can access the content before their visit or discover more after their visit.

To make the app as intuitive as possible, it was designed so users can use their phone's accessibility features, such as screen readers, to access the stories, specimens and images on iOS and Android. At the same time, users who do not use screen readers

PHOTOS COURTESY SMITHSONIAN INSTITUTE

can view all text on screen. This kind of universal design offers a shared experience, while at the same time, all users are able to independently choose which exhibit components they'd like to explore.

While audio descriptions are commonly used in art museums, natural history museums are exploring how best to describe our spaces with content in mind. The way you describe an art piece or an object, for example, is different from how you describe a scientific specimen. Through intensive prototyping and user testing, we're learning and defining good audio description for our space, which will inform future projects here.

We also know that some visitors may choose not to use the mobile app. The app is one option; with advanced notice we can arrange audio described tours of the exhibit for visitors who are blind or have low vision. Led by specially trained volunteers, visitors can receive one-on-one descriptions of our exhibit specimens and tactile objects.

AN EARLY START: Families can sign up on a first-come, first-served basis to experience the Museum before it opens to the general public and explore with a limited number of visitors.

TACTILE MODELS

While wandering through the Jurassic and other time periods in Deep Time, visitors engage with a number of bronzes, 3-D printed or actual fossils. Touchable specimens add to the immersive, interactive experience of a museum visit for all visitors. We witnessed first-hand the impact of the tactile components this summer during user testing. One example involved a couple – where the wife has been blind since birth and her husband lost his sight at age 18. As he was touching the Triceratops, he was astonished by the sensation of remembering in that moment what a Triceratops looked like. This kind of feedback is invaluable and accentuates our hope is that all of our visitors can utilize the exhibits tactile models to have their own memorable and educational experiences.

ACCESSIBILITY BEYOND DEEP TIME

In addition to what we're providing for the new Deep Time exhibition, we offer quiet spaces, recognizing that there's a need, particularly for visitors who are on the autism spectrum or with other cognitive disabilities. Through a Smithsonian Institute initiative, we also offer sensory-friendly activities and early entry to the museum through the Morning at the Museum program. Families can sign up in advance (first-come, first-served) to experience the Museum before it opens to the general public. These times are quite popular because you're able to explore the museum with a limited number of visitors so it's a much quieter experience. We recommend that families who are interested sign up early for these spaces.

More than ever, museums are exploring the best way to provide access to everyone in a way that meets their needs. For the National Museum of Natural History, Deep Time is a great catalyst to constantly improve and to continue to incorporate accessibility early on in the exhibit design and development process. The accessibility of Deep Time will influence future projects here and will be shared with colleagues at other museums at the Smithsonian and beyond. By sharing with each other, we can build on each other's experiences to provide the best experience for our visitors.

Without a doubt, Autumn is one of the best times to visit the nation's capital. The summer crowds are gone, and the weather is cooler for long days of touring D.C. sites and museums.

ABOUT THE AUTHORS:

Meg Rivers is an exhibit developer and project manager, Smithsonian Institution, National Museum of Natural History.
Samantha Barry is the visitor experience and accessibility manager, Smithsonian Institution, National Museum of Natural History.

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WHAT'S HAPPENING

SENSORY-FRIENDLY EXPERIENCES AT WONDERS OF WILDLIFE

Johnny Morris' Wonders of Wildlife National Museum and Aquarium consists of an all-new 1.5-million-gallon Aquarium Adventure showcasing 35,000 live fish, mammals, reptiles, amphibians, and birds, and immersive Wildlife Galleries that bring visitors eye-to-eye with the greatest collection of record-setting game animals ever assembled.

Created by conservationist and Bass Pro Shops founder/CEO Johnny Morris, the 350,000-square-foot experience celebrates those who hunt, fish, and act as stewards of the land and water. Located next to Bass Pro Shops National Headquarters in Springfield, Missouri, the campus is a centerpiece of America's Conservation Capital in Missouri's Ozark Mountains.

IMMERSIVE EXPERIENCE: The Out to Sea Shark Dive lets guests come face-to-face with sand tiger sharks, brown sharks, barracuda and Atlantic goliath groupers.

Since opening in 2017, Wonders of Wildlife has been delivering unforgettable experiences for all families. The attraction has intentionally made every effort to accommodate all type of visitors and has recently made enhanced accommodations to serve individuals with autism and other sensory needs. In April 2019, the International Board of Credentialing and Continuing Education Standards (IBCCES) designated WOW a Certified Autism Center (CAC).

As a part of the new designation, the staff at Wonders of Wildlife is committed to providing a positive experience for all visitors by learning to recognize, welcome and accommodate guests with autism spectrum disorder and other sensory needs. Additionally, adaptations have been made to exhibits and activities around Wonders of Wildlife to ensure that every guest can experience the immersive aquarium and museum.

OUT TO SEA SHARK DIVE

Out to Sea Shark Dive is Wonders of Wildlife's most immersive experience – and the only place to dive with sharks in the Midwest. State-of-the-art air helmets allow guests to comfortably submerge under the water without diver certification and experience sand tiger sharks, brown sharks, barracuda, Atlantic goliath groupers and dozens of other colorful reef fish face-to-face.

AMAZON RAINFOREST

This exhibit is wilder than ever before with the recent addition of several new animals including a two-toed sloth and marmoset monkeys. The charismatic two-toed sloth has quickly become a guest favorite. One of the world's slowest mammals, two-toed sloths spend nearly all their time hanging from tree branches thanks to the powerful grip of their long claws. Wonders of Wildlife is also adding primates to its lineup of animals. The 4D gallery promotes up-close encounters to some of the Amazon's most amazing species, inspiring guests to get involved in the conservation of the planet's most precious natural resources.

While Wonders of Wildlife offers plenty of activities for visitors of the heartland, it also provides conservation learning opportunities for children across Missouri. Visit: https://wondersofwildlife.org •

PHOTO COURTESY WONDERSOFWILDLIFE.ORG

NEW PRODUCTS SOUND IDEAS

MUSICAL INSTRUMENTS SOUND PUZZLE

The Musical Instruments Sound Puzzle is an audio stimulation aid designed for children with autism and sensory processing disorder to reinforce cause and effect relationships, early vocabulary, and matching skills. Each musical instrument plays a snippet of Old McDonald Had a Farm. Features eight musical instrument wooden puzzle pieces. As puzzle pieces are placed correctly in the puzzle board, matching the instrument on the pieces with the instruments on the board, the puzzle makes the realistic sounds of the specific instrument! The puzzle teaches the association of the particular sound with the instrument that makes it. In addition to teaching instrument sound association, this puzzle also helps build fine motor skills, problem-solving, and independent play. The puzzle may also be used as a silent peg puzzle if used without batteries. Uses two AAA batteries (not included). Ages 2 and up.

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The ABLEDATA database of assistive technology and rehabilitation equipment contains information on more than 30,000 products for persons of all ages who have a physical, cognitive, or sensory disability. Products are chosen for these pages by the ABLEDATA staff based on their specific applicability to or design for children who have disabilities. ABLEDATA, operated by New Editions Consulting, Inc., is funded by the National Institute on Disability and Rehabilitation Research (NIDRR) under contract number ED-OSE-13-C-0064.

For more information on these and other assistive devices, or to submit product information for the database (and possible inclusion on this page), contact: ABLEDATA, 103 W. Broad Street, Suite 400, Falls Church, VA 22046; phone: 1-800-227-0216; TTY – 703-992-8313; website: www.abledata.com; email: abledata@neweditions.net; twitter: https://twitter.com/AT_Info; Facebook: https://www.facebook.com/abledata.

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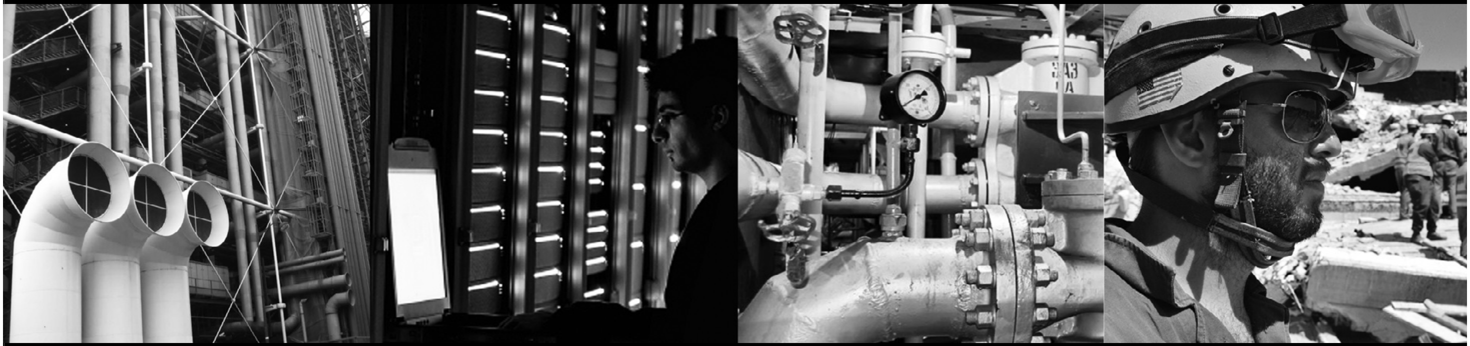

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Concern for Parents of Children with Special Needs

BY H. BARRY WALDMAN, DDS, MPH, PHD, JEFFREY SEIVER, DDS
AND STEVEN P. PERLMAN, DDS, MSCD, DHL (HON)

> *“Caring for a child with activity limitations affects the health, mental health, and … it can place tremendous physical, financial, time and psychological burdens on the family and may present substantial additional risk for family dysfunction and adverse personal health, mental health and work related outcomes…caring for multiple children with activity limitation was predictive of adverse parental mental health outcomes.”* [1]

> *“Over time, if these circumstances are not addressed and relief is not found, a cognitive and, sometimes, biological change may start to take place. Chemicals in the brain such as Serotonin and Dopamine regulate our responses to pleasure, hurt and help us navigate our emotions/perceptions of the world around us begin to decrease as we chronically experience negative emotions and/or situations. The longer we’re exposed to stress or negative emotions and thinking, the less able we become at coping with those feelings.”* [2]

A report from a national study of a representative sample of the civilian noninstitutionalized population of the country indicated that 15.6% of parents had a child aged 0-17 years with a disability. Compared with parents of children without disabilities, parents of children with any activity limitation were more likely to be between the ages of 35 and 44, white (non-Hispanic), less educated, single parents, living in larger families, and living below 200% of the poverty threshold. Specific findings included:

- *Parents who were employed full-time and have children with disabilities had a significantly higher number of workdays lost than parents of children without limitations.*
- *Parents of children with ongoing disabilities had a significantly-increased probability of poor mental health compared with parents of children with resolved activity disabilities.*
- *Caring for multiple children with activity limitations was predictive of adverse mental health outcomes beyond those experienced by parents of a single child with a limitation.*
- *The impact of childhood disabilities on parents’ work can have lasting effects on family socioeconomic status.*
- ***“…healthcare providers need to follow parents of children with limitations over time to ensure that their health and mental health needs are addressed.”*** [1] (emphasis added)

“Researchers … found that the physiological and psychological toll on mothers raising autistic children is significantly

AMERICAN ACADEMY OF DEVELOPMENTAL MEDICINE AND DENTISTRY

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

IN THE MOMENT: It's important to make the time to play, laugh, be silly and just enjoy your kids. Untold numbers of other families have come together and learned of the joy that these youngsters can bring to the lives of their parents and other family members.

greater than that on mothers of children who with no disabilities, and **that the chronic stress experienced by mothers of autistic children is similar to that of combat soldiers** (emphasis added)… Parents of children with disabilities, for example, face a host of questions that most parents never have to address: Should I set up a special needs trust? How can I help my son or daughter navigate the confusing world of dating? Will my daughter ever be able to live on her own?" [3]

And then there are the everyday needs, "Between PTO meetings and work deadlines, it can be hard for any parent to find 'me' time. Magnify that 10 times for parents of children with special needs who must also add IEP (Individualized Education Program) meetings, therapy appointments, and multiple doctor visits into the mix. Add challenges such as driving 50 miles to get to the **only dentist who will work with your child,** (sic) only to learn that you'll need to come back next week to fill that cavity." [4]

HELPING PARENTS: GETTING STARTED

One psychologist suggested an array of approaches for the stressed parents:

1) **You are not alone.** There may not be anyone else with the same constellation of symptoms as your child, but there are people with similar challenges. Find those people.
2) **You, too, deserve to be cared for.** Whatever makes you feel special and taken care of, take the time to enjoy it. You are worth it!
3) **You aren't perfect - and that's ok!** No one is perfect. But beating yourself up isn't going to change the situation, so try to move on.
4) **You are a superhero.** You are a therapist, nurse, doctor, friend, teacher and confidante. You are no regular parent.
5) **Therapy is play.** The best therapists find ways to make our child engage in challenging activities that they otherwise would have balked at, by making it a game that they wanted to play. We took a page from their book and did the same at home.
6) **Play is therapy.** He played sled hockey, runs on a track team, learned to shoot archery and takes swim lessons. All of this is therapy. He's learning what fun is and getting stronger.
7) **Make time to enjoy your kids.** It's important to make the time to play, laugh, be silly and just enjoy your kids.
8) **You will be obligated to make heart-wrenching decisions.** You will have to make painful decisions that hurt your heart and leave you questioning everything you thought you knew or understood. Make them, move on and once it's made don't rethink it.
9) **You won't always get it right.** You will do your best, but you won't always get it right, no matter how many sleepless nights you spend agonizing over how to handle a situation.
10) **Forgive yourself.** Remember many of the toughest decisions have no right answer.
11) **Being a parent is hard work.** With the challenges come the rewards. Sometimes, you have to search your heart for the rewards, but they are there if you look for them.
12) **Parenting a child with extra needs is like running a marathon.** So remember, you don't need to win, just make it to the end.
13) **Don't lose yourself.** Don't let being the parent of a child with special needs create or reshape your identity. Find things in your life you enjoy doing, a glass of wine, a hobby, shopping for yourself.

14) **Keep your sense of humor.** If you're not careful, you can become overly sensitive to so many things that people will start to avoid your company.

15) **Celebrate the little things!** Brag about those accomplishments that might seem small to others but are huge for our kids!

16) **Don't let typical parents get you down.** I know how hard it is to hear from parents that their child six months younger than yours is walking and yours isn't.

17) **Don't compare.** All kids are different, typical, or with extra challenges and they will grow and develop at their own pace.

18) **You don't have to be "THAT" parent.** I have found that there are always enough of those moms in my kid's classes to keep them in cute snacks and treat bags. Since I have bigger fish to fry, I let them have all the glory!

19) **Make time for your marriage.** Marriage is hard work, period. Parenting is hard work, period. Parenting a child with special needs, is especially hard work, period!

20) **Trust your instincts.** Don't be afraid to fight for your child and their needs. While the professionals are experts in their areas, you are the expert on your child. [5]

THE KIDS HEALTH ORGANIZATION ADDED ANOTHER PERSPECTIVE:

If you are the parent of a child who is sick or has special needs, your schedule likely involves doctors' visits, therapy sessions, and waiting for doctors and insurance companies to return your phone calls. And then there's the exhaustion and endless worry.

1. **Accept help from friends and family.** Everyone's busy and that makes it hard to ask for or accept help. For some, it's difficult to let your kids or partner help because they may not do things the same way you do them. Or maybe letting other people know you feel stressed or over-

TAKING CARE : CAREGIVER SUPPORT RESOURCES

There are support groups that can provide needed community and fellowship.

MOMMIES OF MIRACLES

www.facebook.com/MommiesofMiracles

The mission of Mommies of Miracles is to eliminate the isolation mothers of children with complex medical needs experience daily by providing an extended network of resources, grief support, and hope.

DIFFERENT DREAM

www.differentdream.com

This website provides resources and literature, with a blog that addresses what parents of special needs children often encounter.

5 MINUTES FOR SPECIAL NEEDS

www.5minutesformom.com/category/special-needs

A website for special needs puts parents in touch with other parents raising children with complex medical needs.

THE GLOBAL TRACHEOSTOMY COLLABORATIVE

www.globaltrach.org

A non-profit collaborative with a mission to increase awareness of tracheostomy care and quality of life for those in need.

NANCY'S HOUSE

www.nancys-house.org

A support resource for *all* caregivers, not just parents raising children with special needs. They are a non-profit organization for caregivers to find respite and support.

THE ARC

www.thearc.org

An advocacy organization to promote and protect the human rights of people with intellectual and developmental disabilities and actively support their full inclusion and participation in the community throughout their lifetime.

COMPLEX CHILD E-MAGAZINE

www.complexchild.com

Online-only magazine is free and written solely by parents of special needs children.

THE CAREGIVER ACTION NETWORK

www.caregiveraction.org

Gives you access to forums, information, and a large community of caregivers.

whelmed is just not your style.

2. **Be honest about what you need.** By letting people know how hard your situation is, you're allowing them entry into your world. How many times have you heard someone say, "Let me know if I can do anything?" And how many times have you said, "I will" – and then didn't? People want to help but they don't know how. Make a list of the things that would make your life easier.
3. **Enlist other caregivers.** Parents of children with special needs often feel that they are the only ones who can handle their child's care. This is certainly true to an extent but that doesn't mean that you can't get away for a few hours every now and then. By leaving your child with a trusted sitter or family member, you are teaching your child to handle change.
4. **Consider home health care.** Some insurance companies will cover the cost of an in-home health aide or visiting nurse for a few hours a week if your child's medical problems are chronic or severe.
5. **Seek companionship.** Seeking help doesn't always mean asking someone to do something. Often, what a caregiver needs most is to maintain contact with friends and family. Take time to connect and laugh with others and free yourself from your usual worries. Support groups, both online and in-person, can be helpful, too. [6]

PARENTS VS. CHILDREN?

Assuring the care of children with special needs is not a question of the needs of parents vs. those of their children. The necessity is to develop working arrangements for members of the family; including mom, dad, siblings, (and if possible) relatives and friends to provide youngsters with special needs what appears to be seemingly endless assistance. Can it be done? Absolutely; untold numbers of other families have come together and learned of the joy that these youngsters can bring to the lives of their parents and other family members. •

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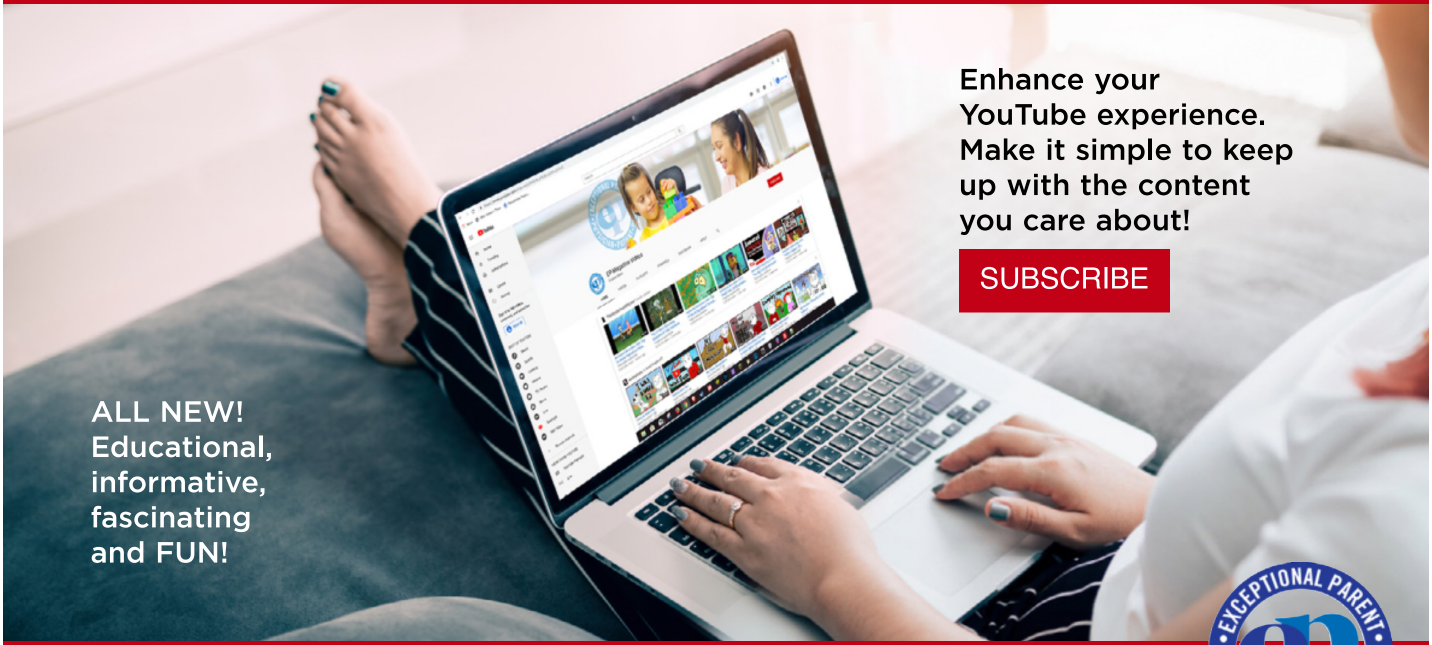


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USE AN ABLE ACCOUNT FOR QUALIFIED DISABILITY EXPENSES

LEARN HOW TO USE AN ABLE ACCOUNT AS AN ALTERNATIVE OR COMPANION TO A SPECIAL NEEDS TRUST (SNT) FOR DISABILITY-RELATED EXPENSES LIKE FOOD, HOUSING, TRANSPORTATION AND MORE.

Manage your spending without impacting your government benefits with an ABLE account. ABLE funds can pay for education, housing, transportation, employment, assistive technology and adaptive equipment, health, prevention and wellness, legal and financial services, funeral and burial, basic living expenses and more.

Be sure to keep good records of all your spending, because the IRS has the right to ask for verification for each expense. An expense is qualified if it meets all 3 requirements:

- *It was incurred at a time the individual was eligible for an ABLE account.*
- *It relates to the disability.*
- *It helps to maintain or improve health, independence or quality of life.*

EXAMPLES OF QUALIFIED EDUCATION EXPENSES

• School tuition – pre-school through post-secondary • School supplies • Other educational materials • Text books • Certification • Trade school • Attendant fees

EXAMPLES OF QUALIFIED HOUSING EXPENSES

Qualified housing expenses make an ABLE account different from a Special Needs Trust (SNT), since distributions to pay for housing costs are not counted as income for SSI qualifications, if spent in the month received.

• Rent • Purchase of a primary residence • Mortgage payments • Real property taxes • Utility charges

EXAMPLES OF QUALIFIED EMPLOYMENT EXPENSES

• Job-related training • Tools of the trade • Certification and licensing fees • Work-related uniforms • Job coaching • Start-up fees for entrepreneurs • Moving expenses

EXAMPLES OF ASSISTIVE TECHNOLOGY AND ADAPTIVE EQUIPMENT

• Hearing aids • Wheelchairs • Transfer devices • Walkers • Prosthesis • Screen readers, magnifiers and magnifying software • Braille • Tactile keyboards • Wearable technology • Accessibility software and computer devices • Personal emergency response system (PERS) • Alerting Devices • Memory Aids • Educational Software • Home automation • Augmentative and Alternative Communication Devices (AAC)

EXAMPLES OF QUALIFIED HEALTH, PREVENTION AND WELLNESS EXPENSES

• Health insurance • Mental health, medical, vision and dental expenses • Habilitation and rehabilitation services • Durable medical equipment • Therapy • Personal assistance • Respite care • Long-term services and supports • Nutritional management • Communication services and devices

Non-qualified expenses: If ABLE account funds are used on non-qualified expenses, regular income taxes plus 10% additional tax on the earnings portion of those non-qualified distributions will need to be paid. And, those distributions may impact your eligibility for federal benefits, like Medicaid or SSI.

IMPACT ON FEDERAL BENEFITS

Most federal benefits disregard or favorably treat ABLE assets – so you have a better chance of becoming and remaining eligible for them.

Supplemental Security Income (SSI): SSI disregards up to $100,000 in ABLE account assets. SSI payments will be suspended if the beneficiary's account balance exceeds $100,000, but SSI eligibility will not be terminated. ABLE funds used for housing expenses will not affect SSI payments, as they're not counted as income or in-kind support maintenance. ABLE distributions intended for housing must be spent in the month they are taken.

Medicaid: Medicaid disregards ABLE assets when determining eligibility, and Medicaid benefits are not suspended if the ABLE account balance exceeds $100,000.

At the end of the designated beneficiary's life, the ABLE account becomes part of the estate and is subject to Medicaid payback. Each state's Medicaid payback policy may differ, and some choose not to recapture at all. Medicaid may become a creditor of the account but is not the beneficiary, so Medicaid can only ask for payback for expenses incurred while the account was open.

Executors can pay outstanding (QDE) bills and funeral and burial expenses from the ABLE account prior to Medicaid payback. There is no "named beneficiary," so a will, executor, and the probate process will dictate where any remaining funds go.

ACTION STEPS

- *Check your eligibility and open an ABLE account.* (www.ablenrc.org).
- *Save for your goals and Spend ABLE funds on qualified expenses.*
- *Maintain your means-tested government benefits.* (www.voya.com/articles/laying-foundation-government-benefits).
- *Talk to a financial advisor to get started.*

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CHRISTINA LLANES MABALOT

Lessons from My College Days

Educational institutions are known for specializing in particular areas of study. Don't get intimidated by discouraging rumors about low acceptance rates, strict entrance examinations, and high standards of education.

"But a diploma is just a piece of paper!" were my famous words as an impetuous junior college student. I wanted to quit college. A national magazine bought two of my articles so I thought I'd write full time. Besides, I submitted my application as a copywriter to a publication in Hong Kong. They were interested in reading some of my work, so I thought I'd go there to hand them my portfolio personally.

"You won't succeed without a diploma. Failure will teach you this lesson," my wise father conceded after an intense argument.

I started as an English major. However, I was discouraged by the dean because my course entailed intense and abundant readings. He thought that my condition would hinder me from pursuing my study path. Remembering the career test results in high school, I shifted to Industrial Psychology but couldn't pass the Natural Science and Math General Education courses.

"These difficult courses are unnecessary anyway," I justified my failure. I searched the university's course catalog for an area that required the least credits in Math and Science. I found myself pursuing a Mass Communication degree, majoring in Communications Research. However, midway through the course, I found myself failing my Statistics courses due to, of course, my visual limitations. I felt as though I had returned back to square one, dropping subjects that I expected to fail then shifting courses, wasting semesters. My visual impairment was the wall that blocked my progress in my pursuit of a fulfilling career, containing me in mediocrity and failure. I didn't muster the courage and mental strength to break through, nor did I seek support to overcome it. I skirted around my individual needs as if it would magically disappear. I was focused on failing and quit without finishing the fight.

If there's anything good that resulted from the good and the bad of my college experiences, it's the privilege to share my lessons with you today.

Don't settle for a diploma. Aim for your dream! Every student, with or without special needs, must have a dream. If you don't have one, start dreaming now. Set your educational goals to make your dream a reality and fight for that dream. Never allow what you or society think your limitations are to customize your educational purposes. I conveniently chose Communications Research to stay clear of math and science courses which, at that time, I thought I couldn't handle. I chose the path of least resistance and compromised my dream of becoming a lawyer or a writer. Don't get me wrong. I like my chosen field of study, but not enough to get me excited every morning.

SPEAKING UP: "Inclusive education means that a student with special needs can participate fully, reciprocate, and enjoy in the classroom as well as in the entire learning environment in a regular school."

Take advantage of career guidance integrated into the Individualized Educational Program (IEP). I advise family members to keenly observe what their children love to do, as well as what they excel in. Set them on the right educational path accordingly and choose course electives and extra-curricular activities that will hone their skills. Stir them towards their passion at a young age until they learn how to fight for their dream despite challenges.

Opt for the best university or college for your chosen field of study. Educational institutions are known for specializing in particular areas of study. Don't get intimidated by discouraging rumors about low acceptance rates, strict entrance examinations, and high standards of education. When I told my family that I was aiming for the premiere state university in the Philippines, they thought I was out of my mind. Only my father, also an alumnus of the University of the Philippines, encouraged me and even met with the Board of Regents to accommodate my particular needs for the entrance exam.

Advocate for real inclusive education. There could be a difference between being "integrated" in mainstream education and being "included." Integration is when the student with special needs attends general or mainstream educational institutions, as opposed to residential or special schools. However, some schools might not have a system to address the diverse needs of students with special requirements, resulting in probable exclusion in some components of education. Inclusive education, on the other hand, means that a student with special needs can participate fully, reciprocate, and enjoy in the classroom as well as in the entire learning environment in a regular school. I was integrated into a mainstream university but not "included." I was the square peg and often felt like an outsider in the classroom, primarily when all my classmates were engaged in visual activities. Support and resources for students with special needs were inadequate in my time. I didn't know how to communicate how my visual limitations could be accommodated since my mother advocated for me in elementary and high school. When I finally spoke up, I realized that my professors and classmates were more than willing to help me if only I asked.

I advise parents of young students with disabilities to advocate for full inclusion so that their children will enjoy the total learning experience like their non-disabled peers. If necessary, talk to authorities about conducting disability sensitivity sessions in the classroom and for the school personnel for smooth interactions.

It is never too late to pursue an educational goal that will lead to a rewarding career path. Let me tell you the ending of this particular rebellious segment of my educational life. The publication where I applied to liked my writing but required, as my father warned, a diploma! I finally understood that while a college education does not provide a student precisely what he needs for a fulfilling career, it gives them the raw materials and the disciplines.

I came back to my father's house, a miserable failure, but was ready to take another try at my college education. My gracious father forgave his prodigal daughter. He facilitated my re-admission to the university. He pleaded with the Board of Regents to give one last chance to his daughter who had been “absent without leave.” The conditions were harsh, but I psyched myself to gain the mental strength to persevere – and then I finally graduated.

What revived my spirit, you might ask? In the darkest tunnels of my journey as a person with special needs, I always looked up to my hero, Helen Keller. I'm not close to being half as brilliant as this woman, but I always ask myself, "What would Helen do in this situation?"

“Helen might scale the dead-end wall, or find a crack where she could chip through, or probably dig underground to the other side,” I figured. Whatever happens, Helen would not quit, so, why would I? Remembering Helen Keller brings me to my last tip:

Always have a hero or champion you can emulate. At your moments of defeat, recalling their heart of courage will spur you to get back on the race and run to the finish line.•

MY ROLE MODEL : HELLEN KELLER, THE MIRACLE WORKER

Anne Sullivan was initially the miracle worker who pierced the darkness that wrapped Helen Keller's life and being. In Helen's words, she was “less than an animal” at six years old, unable to see, hear, or speak, stubborn and full of aggression. No individual had been able to connect with her until, one day, Anne led Helen to an epiphany. She prompted Helen to feel water coming out of a pump as she showed her the word for water in sign language. Helen's mind opened to the most excellent learning adventure. Since then, their souls linked together, and Helen's brilliance illuminated.

VISION AND PURPOSE: Helen Keller *(left)* and Anne Sullivan visit the set of a Charlie Chaplin film in 1918.

The first student with visual and hearing impairment to graduate from college, with cum laude honors, Helen shattered all the limiting stereotypes about persons with disabilities. Anne, who committed her life to Helen, likewise exceeded all the stereotypical expectations of a teacher. She persevered to communicate to Helen every lesson in sign language.

These revolutionary milestones blow my mind. When conversing with a friend with hearing impairment who's not yet able to speak, fingerspelling is our medium to communicate. I, being blind, hold my hands over his to understand what he's saying. I can't imagine the scene in a regular classroom setting, much less, in the early 1900s.

Helen wrote her first book, *Story of My Life,* while in college. Since then, she had been a mover and shaker not only for the sector of persons with disabilities, but also for women and children, in politics and the Humanities globally. Helen, the embodiment of a miracle, had become a “miracle worker” and continues to transform people into wonders. We, the persons with disabilities, can be productive in society as a result of her legacy.

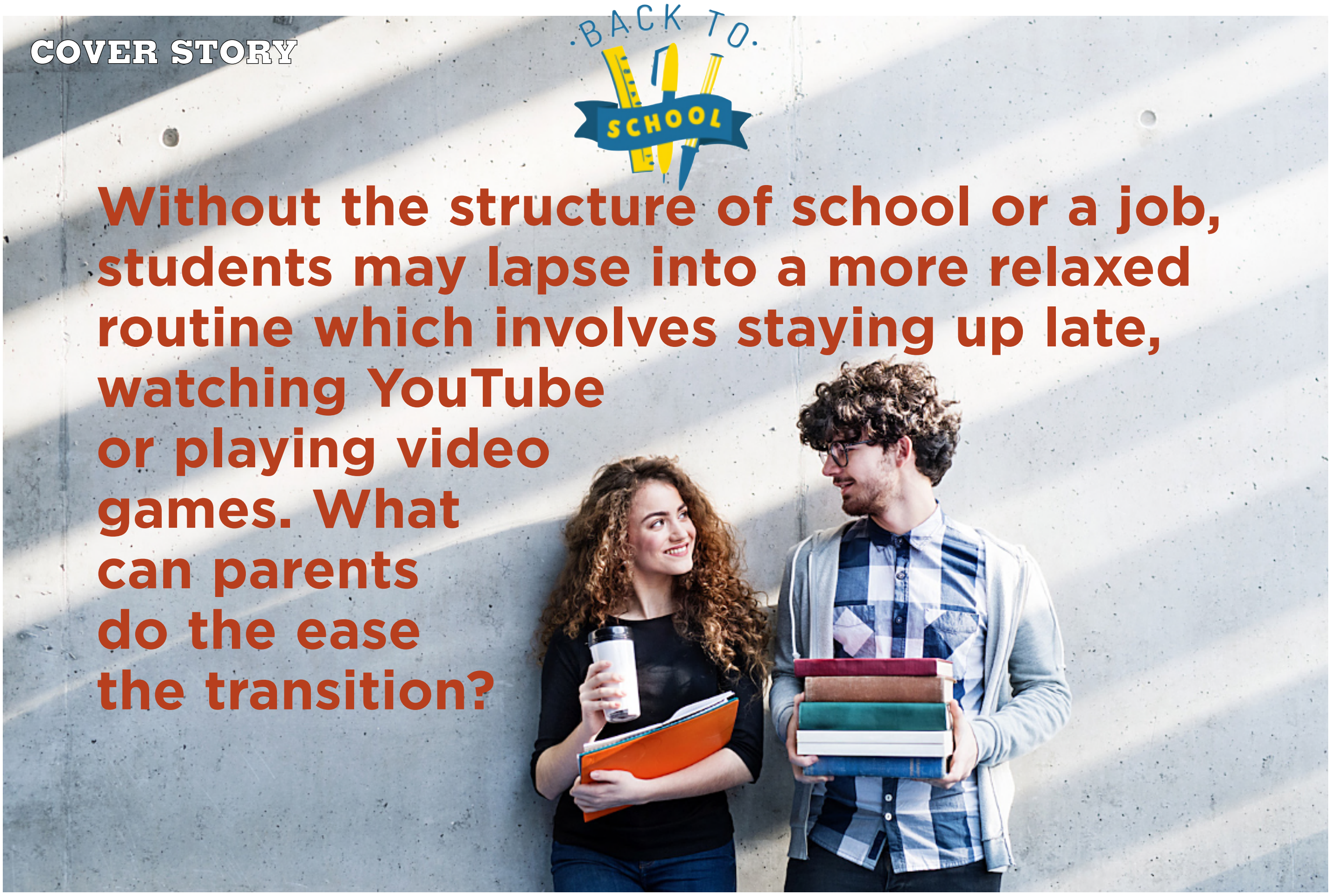
Mass media, including print, Broadway, film, and television have immortalized the legacy of the Anne Sullivan and Helen Keller tandem. The movie *The Miracle Worker* won the Oscars in 1962, and to this day to bear on the torch of victory and courage that our obstacle-ridden contemporary society calls for.

The story of Anne Sullivan and Helen Keller is living evidence that teaching is the noblest vocation because a teacher's influence lasts for eternity.

HEARTSIGHT

Christina Llanes Mabalot is physically blind from aniridia, but has a vision. She enjoys touching people's lives to bring out the best in them. “Heartsight” explains her ability to see with her heart. Christina earned her B.A. degree and Masters in Education from the University of the Philippines, Diliman, specializing in Early Intervention for the Blind. She later received Educational Leadership training through the Hilton-Perkins International Program in Massachusetts, then worked as consultant for programs for the VI Helen Keller International. She has championed Inclusive Education, Early Intervention, Capability Building and Disability Sensitivity programs. She was twice a winner in the International Speech contests of the Toastmasters International (District 75) and has been a professional inspirational and motivational speaker. Christina is blissfully married to Silver Mabalot, also physically impaired, her partner in advancing noble causes. Their children are Paulo and Jem, who has aniridia. Visit leadershiptovision.com

PHOTO COURTEY BISON ARCHIVES



Without the structure of school or a job, students may lapse into a more relaxed routine which involves staying up late, watching YouTube or playing video games. What can parents do the ease the transition?

TRANSITIONING BACK TO POST-SECONDARY ENVIRONMENTS AFTER A LONG SUMMER BREAK

BY ERNST VANBERGEIJK, PH.D., M.S.W.

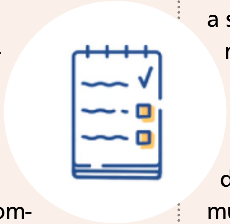
Summers change after a young adult with an autism spectrum disorder leaves high school and attends a post-secondary program. For starters, the summers are generally longer. Most colleges and universities are only in session for two 15-week semesters.

This means they often end school in early May and do not return until after Labor Day. Without the structure of school or a job, students may lapse into a more relaxed routine which involves staying up late, watching YouTube or playing video games. Consequently, they wake up later and later as the summer progresses. This makes the transition back to school all the more difficult. The question is, what can a parent do ease the transition back to a post-secondary program or college?

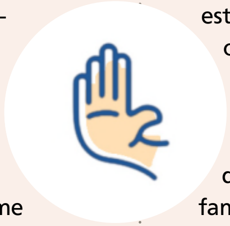
EASING THE TRANSITION BACK TO A POST-SECONDARY PROGRAM OR COLLEGE

1. Prevent the lapse or loss of routine.

How can a parent prevent this? Find summer activities that provide structure. Summer employment provides that structure. Getting up and going to work each day during the summer will help the student when they return to school, plus it gives the added benefit of giving them practice with their employment skills, the sense of pride from earning a paycheck, and will help build their resume. It also increases the likelihood that they will be employed for pay after completing the post-secondary program. If your student cannot find paid employment, then volunteering for an organization can be an excellent place where your student not only has structure and routine, but can still practice important pre-employment skills like arriving on time, dressing appropriately for work, collaborating with supervisors and colleagues, etc. Make sure your young adult gets a favorable letter of recommendation from his or her supervisor at the end of the summer. This will help build their portfolio and can lead to future employment. Check with your local civic center, food bank, hospital, senior center, or community garden for volunteering opportunities.



If paid employment or volunteering are not options, then consider summer camps. There are many special needs summer camps across the country. Colleges and universities have specialized summer camps that often have a theme or special interests like marine biology, computers or astronomy. Summer camps need counselors or counselors in training (CIT). If your son or daughter was a camper at a particular camp as a younger child, then the camp may be inclined to hire them as a CIT or as a counselor. Generally, camps are highly structured with planned activities from sunup to sundown. The structure of working at a summer camp will help ease the return to college.



Some colleges and college-based transition programs offer summer semesters. Here, students on the autism spectrum or other types of learning disabilities may continue to take college classes for credit which can help lighten the student's course load during the academic year. The caveat is that these summer semesters tend to be accelerated. The classes meet more often each week, for a shorter number of weeks, and assignments are often due back to back. Missing classes or falling behind on assignments can happen easily and quickly during a summer session with devasting results. Selecting this option must be done with careful consideration. Most students will take only one or two classes during a summer session.

For those students who attend a college-based, post-secondary transition program during the academic year, check to see if the college offers a summer program. There may or may not be an opportunity to take credit-bearing classes. However, the certificate-based programs will offer opportunities for these students to practice their pre-employment skills though internships. They also will provide opportunities for the student to practice their independent living and social skills which can regress over the summer if a student goes home. This option provides a student with the easiest transition back to a post-secondary environment in the fall. Typically, the students will live in the same residence halls and eat in the same cafeterias as they do during the academic year. The familiarity of the surroundings and routine can be very comforting to young adults on the autism spectrum.

2. Expect push back.

When your son or daughter returns from their first year of post-secondary education, you may be surprised at their new-found level of independence and confidence. They are used to living on their own and have perhaps given little thought about curfews and letting anyone knowing their comings and goings. This will need to be a negotiated process that both parties are comfortable with. In the long run, this is what we want for our children with disabilities; we want them to be independent. Establish minimum standards for safety, communication, and acceptable behavior in public and at home.

3. Have them practice their activities of daily living (ADLs).

The successful daily completion of activities of daily living is a better predictor of employment post-high school than I.Q. or academic ability. ADLs provide structure, routine, and predictability and will ease their return to school. Setting alarms on smart phones or alarm clocks is an important life skill and pre-employment skill. It will be tempting to fall back into old habits of expecting mom or dad to wake them up in the morning. Resist the urge. Being in the habit of cleaning up one's room and making one's bed is something many young adults fight, whether or not they have a disability. For students on the autism spectrum, this can be especially difficult as their impairment in executive functioning can inhibit their ability to organize. However, by continuing this habit during the summer, it will help them when they return to college and have to share a dorm room with a roommate. Cleanliness of a shared room is a frequent source of disagreements between roommates. Establishing this habit is also a life-long skill that will help your student when they move into an apartment after college. Make sure your son or daughter continues to do their laundry once they return home. When he or she returns to school, no one will do his or her laundry. This can be a tough transition back. They put off doing laundry upon their return until they no longer have any clean clothes to go to work or school. The pile can be so high that he or she becomes overwhelmed, and this creates a crisis.

Establishing a summer laundry day that is the same day as when he or she would do laundry at school just makes the return that much easier. Having a personal hygiene schedule that mirrors the academic year will also ease the transition back to school. Meal preparation and planning is another habit to continue during the summer. Having them make their own breakfasts and pack their own lunches helps promote independence. Occasionally, have them make the family dinner. Better yet, if they are able, have them grocery shop for the meal. This will give them the added practice of navigating to the store, using checklists for the groceries, and money management skills. Practicing these skills will help them ease back to school.

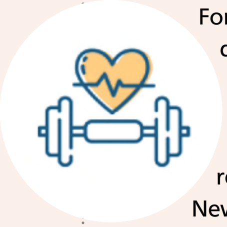
4. Establish good sleep hygiene behaviors.

Students on the autism spectrum need their sleep. Vacation can lead to variable bedtimes and waking times. Good sleep hygiene is more than simply going to bed and waking up at the same times and ensuring that a young adult gets 8-10 hours of sleep a night. It also means limiting screen time on computers, iPads, smart phones, and gaming devices before bedtime. Experts recommend stopping usage of these devices two hours before bedtime in order to not interfere with REM sleep which is associated with deep sleep (Chang, Aeschbach, Duffy, & Czeisler, 2015). The use by adolescents of electronics at night is also linked to depression (Lemola, Perkinson-Gloor, Brand, Dewald-Kaufmann, & Grob, 2015). The negative effects on electronic media at night has a significant effect upon children and adolescents on the autism spectrum (Mazurek, Engelhardt, Hilgard, & Sohl, 2016). Likewise, people should limit caffeine in-take, hours before bed (Drake, Roehrs, Shambroom, and Roth, 2013). Also, students should not exercise less than two hours before bedtime.

5. Exercise regularly during the summer break.

The benefits of exercise are well documented. What most Americans don't realize is that the average American gains one to two pounds a year after college. This means the average American will have a Body Mass Index (BMI) that places them in the overweight and obese range in middle age, even if they are in the normal BMI range during college. Establishing an exercise routine during the summer not only helps with the transition back to school in the fall; it also helps to develop a lifelong habit that will help stave off weight gain.

The benefits do not end there. Most people know that exercise improves cardiovascular health and that heart disease is the leading cause of death in the U.S., but perhaps not many know that exercise before learning academic material also leads to better concentration, better retention of the material, and higher test scores. This is true for both students with and without disabilities. It also leads to better sleep, reduced symptoms of anxiety and depression, as well as less reliance of psychotropic medication. In fact, the Boston Higashi School incorporates regular exercise into their daily curriculum for their students, all of whom are on the autism spectrum. They report their students are medication free as a result.



For an entertaining and wonderfully written synthesis on the benefits of exercise for both general education and special education students, readers should refer to the New York Times Best-selling book, *Spark: The Revolutionary New Science of Exercise and the Brain* by John J. Ratney, M.D.

Children with autism and other developmental disabilities are more likely to be diagnosed as obese (Egan, Dreyer, Odar, Beckwith, & Garrison, 2013). They are also less likely to participate in team sports due to problems with fine and gross motor coordination issues, proprioception, and understanding the complex social and nonverbal communication that often accompanies team sports. Think about how complex a behavior of performing an alley-oop in basketball, or stealing a base in baseball can be.

Alternatively, there are a number of adaptive sports leagues across the country that take the students' disabilities into account. Running, swimming, hiking and biking are excellent physical activities that can be done individually or in groups, and do not necessarily require a high degree of non-verbal social communication. Additional research shows that spending time in nature exercising leads to a plethora of physical and mental health benefits (Barton, Bragg, Wood, & Pretty, 2016; Barton & Pretty, 2010; Gladwell, Brown, Wood, Sandercock, & Barton, 2013). It can also lead to exercising more than simply hitting the gym with less perceived exertion (Lahart, Darcy, Gidlow, & Calogiuri, 2019; Rogerson, Gladwell, Gallagher, & Barton, 2016).

6. Have the students practice their social skills.

Help them stay in contact with new friends from school and arrange their own social get-togethers over the summer. This enables them to practice their chit-chat skills and strengthen the friendships they made during their previous academic year. This will help with decreasing the anticipatory anxiety they may face about re-integrating into the social scene back at school. It could also help build excitement for the upcoming year.

7. Travel skills are essential to practice over the summer.

Being a little rusty at using public transportation can undermine a student's confidence in being independent and returning to school. Have the student practice trips at home using public transportation. If possible, a field trip mid-summer to rehearse travel to a new internship site or class location will help immensely with the transition back to school. Furthermore, the lack of reliable transportation and the inability to use mass transit severely limits the employment opportunities of an individual with a disability (Belgrave, & Walker,1991; Lindsay, S., 2010; Magill-Evans, Galambos, Darrah, & Nickerson, 2008).

Even if your family did not start the summer with some of these structured activities, it is not too late to begin. Institute what you can, when you can, to make the transition back to college or a college-based post-secondary transition program easier for your student with a disability.

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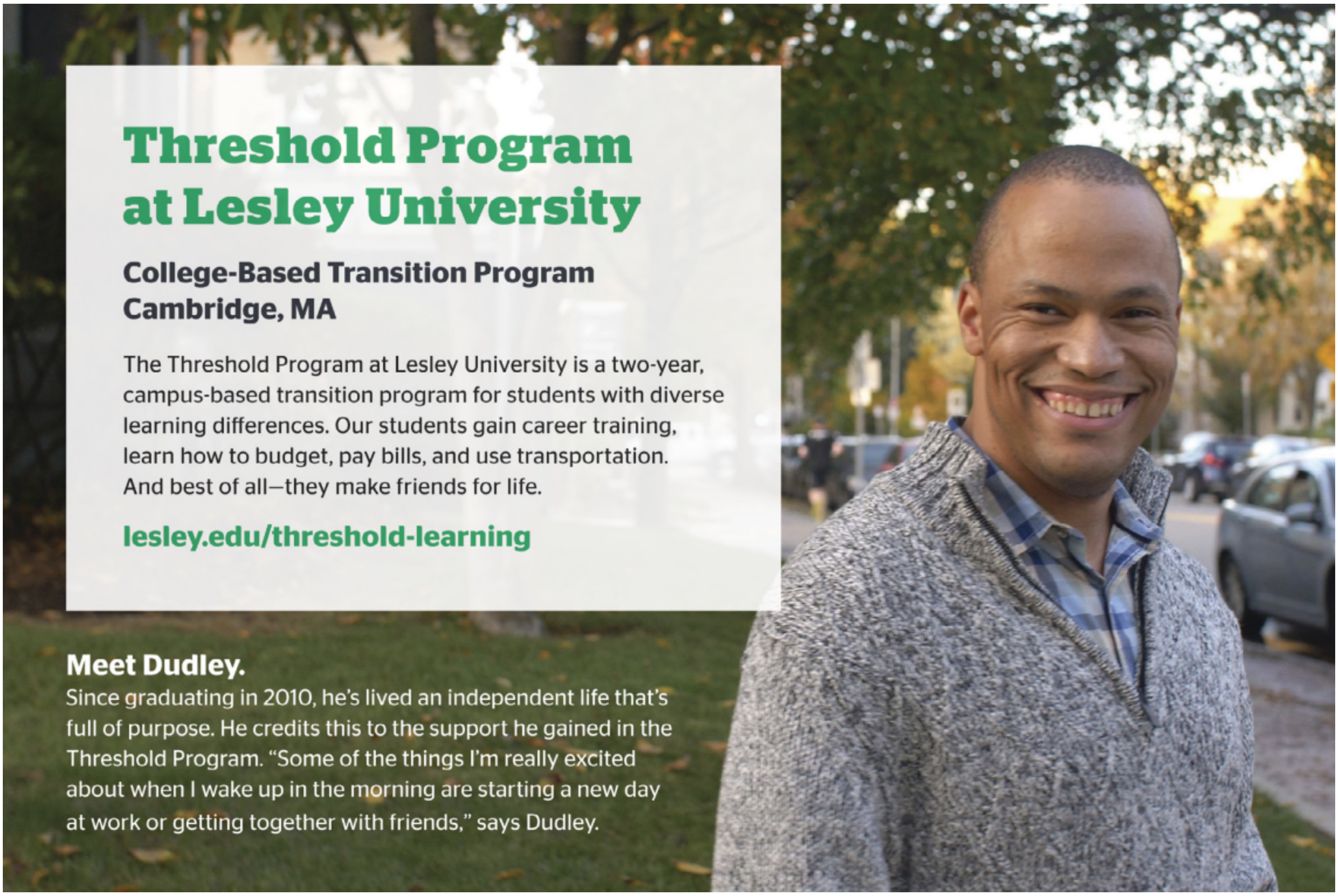

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EP MAGAZINE: THE JOURNAL FOR SPECIAL NEEDS FAMILIES AND PROFESSIONALS

Normal's time is up. It has got to go. In truth, the only normal people are people you don't know very well. The moment you get to know another human being – really know them, see them, not how they should be, but how they actually are – it is not their normality that matters. It's their differences, eccentricities, fallibilities, strengths, and weaknesses that constitute their humanity.

FIX THE SYSTEM NOT THE CHILD

BY JONATHAN MOONEY

When I was a kid, I was the round peg that did not fit in the square hole that is school. I was the kid who had such a hard time sitting still in elementary school, I grew up chilling out with the janitor in the hallway; I couldn't keep my mouth shut so I grew up on a first name basis with Shirley the receptionist in the principal's office. I also had such a hard time with reading, specifically reading out loud, that I spent most of the day hiding in the bathroom with tears streaming down my face. I did not learn to read until I was 12; I was diagnosed in third grade with a whole bunch of language-based learning disabilities and attention disorders. I left school for a time in sixth grade. I struggled with anxiety, depression, and had a plan for suicide.

Like many young people who don't fit a narrow definition of "the normal student" or human, I faced a lot of low expectations. I was told I would never graduate from high school, would be unemployed, and even at one point was told I would end up incarcerated. I beat those odds. Opposed to being a high school dropout, I became a college graduate. Opposed to being unemployed, I ended up writing books, the first of which I wrote as an undergraduate in college. Instead of being an inmate, I became an advocate on behalf of people with atypical brains and bodies.

This journey of transformation often raises a valid question in people's minds. I'm asked all the time by parents, teachers, and people with differences how did I do it? What drugs did I take and where can they buy some? While the answer to that question is multifaceted and complicated, I do know that I transcended these low expectations in large part because of my mom. To give you a mental image of Colleen Mooney: my mom is not a tall woman. On a good day in high heels on her tippy toes, she is 4' 11". My mom also has a very high-pitched voice like Minnie Mouse. And, by the way, she curses like a truck driver. So if you were a teacher, principal, or a counselor not doing right by her son, you did not want cursing Minnie Mouse in your office! But when I was having a hard time in school that's where my mom was every day. How did I know she was in that office? Because every dog in the neighborhood was running away! Glass was shattering! Only bats could hear her high-pitched obscenities.

My mom understood that I didn't need somebody in my life to fix me; I needed somebody in my life to fight for me. There is a deeply held cultural belief that has become institutionalized in schools and the helping professions, that people with atypical brains and bodies are deficient and in need of fixing. This belief stems directly from the myth that there is a normal brain or body that everyone should have and if you deviate from this mythical human something is wrong with you. My mom fought against the relentless focus on my deficits and the relentless emphasis on fixing me.

When I was a kid, like many people and atypical brains and bodies, I had many variations of an individualized education plan or IEP. The NSA, the KGB...they got nothing on the IEP. They did deep intel on me, flew drone missions over my house, and it wasn't good news in that file. Many researchers, including Thomas Hehir, Director of Special Education at the U.S. Department of Education, and now a professor at Harvard, have shown that these documents are relentlessly deficit oriented. For every strength or talent cataloged there are often 20 weaknesses. This systems orientation to what's wrong with atypical children leads to a pedagogical and "rehabilitation" practices and interventions that are all about fixing them.

RETROFIT: My mom fought for the idea that if a student doesn't learn the way they are taught, then it's the school's obligation to teach the way they learn. It's not the person that should change but the environment around them. It is wrong to ask anyone to be different than who they are.

My mom fought against this fix-the-kid mentality in every way but nothing was a bigger fight then spelling. Every Friday when I was in elementary school was spelling test day. What a wonderful way to end the week. Every day, leading up to Friday, was fix-my-spelling day. What a wonderful way to spend the week. I got my words on Monday and did two hours of flashcards; Tuesday I drew the words in the sand; Wednesday I built the words with blocks; and Thursday… I did interpretive dance to get the words in. Come Friday… I failed the test. My mom constantly advocated for me to have accommodation on these tests. It did not happen. So on Friday we ditched school and went to the zoo because I loved animals, to construction sites because I loved building, and to the movies because I loved stories. She called this focus-on-what-is-wight-with-you day. Cumbersome title, I know, but it saved my life.

My mom rejected this medical deficit model. My mom fought for the idea that if a student doesn't learn the way they are taught, then it's the school's obligation to teach the way they learn. It's not the person that should change but the environment around them. It is wrong to ask anyone to be different than who they are. It is an act of violence to work to make the round peg fit the square hole. Every human being has the right to be different. We should demand that our systems and institutions include not just some human beings, but all.

My mom was fond of saying to me "normal sucks." She was right, because what is normal anyway? Look up normal in any English dictionary and the first definition is "usual, regular, common, typical." How did *this* become something to be aspired to and have the cultural force it has? Normal has a history and it is not a history of discovery, but a history of invention. It was born in the mid-1840s with the rise of standardization, industrialization, and statistics. I didn't do too well on my AP statistics class (ok, didn't even take it!) but I do know that averages are by definition abstractions. A statistical norm doesn't exist in the world—it is an aggregation of multiple differences on a curve. The normal or average birth rate for women in

America: 2.5. Haven't seen many half babies in my life. Ian Hacking summed it up when he wrote, "The normal whispers in your ear that what is normal is also right."

Normal has been responsible for a great number of social injustices. Because of this idea, whole groups of people have been labeled as abnormal or sick and their subjugation justified as "treatment." In the 19th century, black folks who were enslaved and ran away to escape this injustice were diagnosed with "slave running away sickness." Up until the mid-20th-century, actual doctors and psychiatrists diagnosed women as suffering from hysteria and this diagnosis was used to justify their disenfranchisement; and homosexuality was listed in the DSM as a personality disorder until the 1970s. Oh yeah – one more – let's not forget eugenics. In the early 20th century a bunch of scientists, geneticists, doctors, and social workers were so enamored by the idea of normal that they decided to rid the world of "defectives."

Normal's time is up. It has got to go. In truth, the only normal people are people you don't know very well. The moment you get to know another human being – really know them, see them, not how they *should* be, but how they actually *are* – it is not their normality that matters. It's their differences, eccentricities, fallibilities, strengths, and weaknesses that constitute their humanity.•

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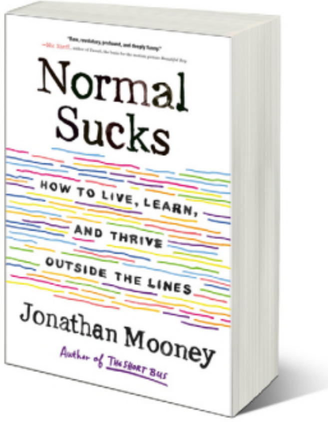
Jonathan Mooney's work has been featured in The New York Times, The Los Angeles Times, The Chicago Tribune, USA Today, HBO, NPR, ABC News, New York Magazine, The Washington Post, and The Boston Globe, and he continues to speak across the nation about neurological and physical diversity, inspiring those who live with differences and advocating for change. His books include *The Short Bus* and *Learning Outside the Lines.*



Title: **Normal Sucks: How to Live, Learn, and Thrive Outside the Lines**

Author: **Jonathan Mooney**

Publisher: **Henry Holt and Company**
Publication Date**: August 13, 2019**
Paperback: **233 pages**
ISBN-13: **978-1250190161**
Available at amazon.com and barnesandnoble.com

Safety is the Number One Priority for Children with Food Allergies Heading Back to School

BY MICHAEL MANNING, MD FACAAI, FAAAAI

It is that time of year again: summer is ending, camps are coming to a close, and students across the country are getting ready for their first day of school. It's an exciting and potentially stressful time for families, young children or teenagers starting the next chapter in their lives. But for families with children who have – or suspect they have – food allergies, this time of year can be particularly stressful as they are at higher risk of accidental exposure away from home.

According to Food Allergy Resource & Education (FARE), (https://www.foodallergy.org/life-with-food-allergies/food-allergy-101/facts-and-statistics) a food allergy reaction sends someone to the emergency room every three minutes. Although a person can develop an allergy to just about anything, the most common food allergies are milk, eggs, peanuts, tree nuts, wheat, soy, fish and shellfish.

Although a food allergy can develop at any time in a person's life, including infancy, they are more common in children born into families with a history of allergies, according to Kid's Health. Here a few tips parents and guardians, teachers and administrators should keep in mind to recognize food allergy reactions and help prevent accidental exposure in the classroom.

- ***Understand what causes a reaction.*** *Food allergy symptoms can occur from eating the allergen, or if the allergen enters the body through the eyes, mouth or nose. Any contact with a food allergen has the potential to result in an allergic reaction.*
- ***Learn what a reaction looks like.*** *Allergic reactions to food can range from mild (e.g., a few hives, tingling around the mouth) to moderate (e.g., multiple hives, wheezing, stomach discomfort or vomiting) to severe (e.g., throat or airway closing, low blood pressure), with the most severe being anaphylaxis. Signs of anaphylaxis include vomiting, chest pain, fainting/unconsciousness, shortness of breath/wheezing, swelling of the lips, tongue or throat, trouble swallowing and changes to skin tone, according to FARE (*https://www.foodallergy.org/education-awareness/community-resources/your-back-to-school-headquarters/managing-food-allergies-in*).*

- ***Set up a meeting with appropriate school administrators before the first day of class.*** *Parents and guardians – especially those with children entering preschool – should ask to meet with the director or principal, along with their child's teacher and school nurse. An in-person discussion with these key people in your child's life before class begins can create a foundation of positive communication and help ease anxiety for everyone.*
- ***Know how to identify and treat allergic reactions.*** *Teachers and school employees should learn how to follow the student's Food Allergy Action Plan, developed by a board-certified allergist. This includes understanding the student's allergies, how to identify symptoms of a reaction and how to treat it. It is especially important for teachers to understand (and practice) how to administer epinephrine – a shot of adrenaline that counteracts symptoms of anaphylaxis – in case of a reaction.*

If a student does have a food allergy, it's important for teachers to educate classmates (and classmates' parents) about how to help keep the student safe at school. This can be done without sharing the identity of the student with the allergy. Parents of classmates can help prevent accidental exposure by not including allergens in their own child's lunches and treats brought to the classroom. Parents and guardians of students with allergies can also learn more about oral immunotherapy (OIT), an investigational desensitization treatment for people with food allergies, on the American Academy of Allergy, Asthma and Immunology (AAAAI)'s website at www.aaaai.org.

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4

SNEAKY WAYS TECHNOLOGY IS AFFECTING YOUR FAMILY'S HEALTH AND MAY AFFECT YOUR CHILD'S NEW SCHOOL YEAR

We as parents have to lead by example and show our kids healthy lifestyle habits by following our own advice. Turn your off WiFi at night, set your phone's display to night mode in the evening, minimize time in front of the television and get outside with your children.

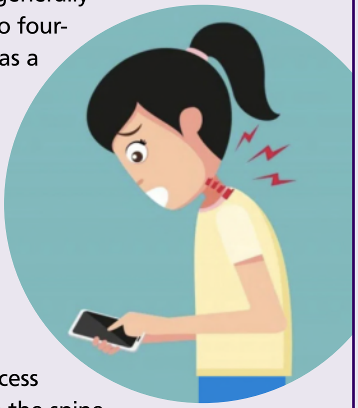
BY DR. NATHALIE BEAUCHAMP
B.SC., D.C., I.F.M.C.P.

Advancements in technology within recent years have come with many benefits. There is a world of information and entertainment conveniently located at our fingertips. The development of the smartphone alone has revolutionized the way we function, consolidating all of our needs into one small device. Even kids at school are now able to complete and submit their homework on tablets rather than carrying papers around. However, these technological advancements have also come at a cost for our health. From poor posture, nervous system functioning, attention, sleep, memory, and even learning, this article dives into the challenges caused by our uber-connected world. Here are four ways technology may be affecting you or your child's health:

FOUR WAYS TECHNOLOGY MAY BE AFFECTING YOU OR YOUR CHILD'S HEALTH

1. ANTERIOR HEAD SYNDROME AKA "TEXT NECK"

Today, the widespread use of smartphones, blackberries, and tablets has caused an epidemic of what is now referred to as "text-neck'. The term is used to describe abnormal stressors on the neck (also called the cervical spine) from looking down at the screens of mobile devices. The cervical spine supports the weight of the head, which generally speaking weighs between ten to fourteen pounds – about the same as a large bowling ball.



When the spine is in its proper position, the weight of the head is carried directly above the center of gravity, preventing it from pulling on the rest of the spinal column. When the neck is too far forward, the bones of the spine can get misaligned, which in turn places excess stress on the nerve exiting from the spine, and as a result, impacts the nerve impulses being transmitted up and down the spine – think brain-body connection.

In recent years with the increased use of technology and the constant head forward posture held by so many, more and more people are experiencing symptoms like headaches, neck and shoulder pain, jaw pain and even problems with sustained concentration. Long term effects of anterior head syndrome can lead to the flattening of the proper cervical lordosis, disc degeneration, recurrent muscle strains and numbness and tingling down the arms. To make things worse, anterior head syndrome is being seen in younger and younger generations due to the popularity of technologies in education and for entertainment. Why is this a concern? Youth are in the midst of development and abnormal stresses on their spine can have a negative influence on the mechanics of youth's skeletal structure as they age. Loss of proper spinal structure and function can also weaken important sensory input into the central nervous system which can, in turn, affect their overall development and well-being.

The solution? Assuring proper setup and posture when using our device is a good start as well as limiting the use of our technologies as much as possible. However, sometimes it is not enough as the curvature loss and the abnormal spinal biomechanics have already begun and one may need the help of a chiropractor to address the issue. Chiropractors detect and correct misalignments of the spine to reinstate its normal balance and function which allows the nervous system to send and receive information without interference. This allows the body to maximize its self-healing properties and correct its natural posture.

2. ELECTROMAGNETIC FIELD (EMF) EXPOSURE

Between TVs, laptops, cell phones and Wi-Fi; being exposed to electromagnetic fields is almost inevitable in this day and age. Although under much debate, emerging evidence is showing more and more that prolonged exposure to these EMFs can wreak havoc on both our physical and mental health.

Conditions such as persistent headaches, difficulty with concentration, anxiety, depression, and other radiation-related issues have a higher risk of occurrence with EMF exposure, and symptoms can develop more severely in younger children. Children have smaller heads, thinner skulls and more fluid in the brain, allowing them to absorb more radiation than adults. EMF exposure has been linked to hyperactivity, sleep disturbances—due to effects on the pineal gland, which produces melatonin— memory and attention deficits, and increased stress levels in children. Some research has even shown an increase in learning disorders and behavioral problems when kids are exposed to EMFs even in the womb.

Adults are subject to more extensive side effects when cellular or wearable devices are carried near certain body parts. For men who keep their cellphones in their pockets, some research has shown a correlation between radiation and low sperm count, leading to fertility issues. For women, research has shown potential risk of ovarian problems when phones or portable devices are constantly kept in the pockets, or even increased chance of breast cancer when these devices are kept near the chest.

Now in a world where complete isolation from EMF sources is nearly impossible, there are certain precautions one can take. Turning off Wifi signals at night, having a "no technology zone" in the bedroom, having an EMF blocker on mobile devices, and keeping technology off the body as much as possible are all great ways to minimize exposure.

3. BLUE LIGHT EXPOSURE

Until the advent of artificial lighting, the sun was the major source of lighting, and people spent their evenings in darkness; a very important factor in regulating sleep-wake cycles. Now, in much of the world, evenings are illuminated, but we may be paying a price for basking in all that light. At night, light (especially emitted from digital screens like TVs, computers, laptops, smartphones and tablets), electronic devices, and even fluorescent and LED lighting) throws the body's biological clock—the circadian rhythm—out of synch, causing our sleep and sleep quality to suffer. Even worse, research shows that this may contribute to the development of cancer, diabetes, heart disease, and obesity.

Now not all colors of light have the same effect. Blue wavelengths—which are beneficial during daylight hours because they boost attention, reaction times, and mood—seem to be the most disruptive at night. And the proliferation of electronics with screens, as well as energy-efficient lighting, is increasing our exposure to blue wavelengths, especially after sundown.

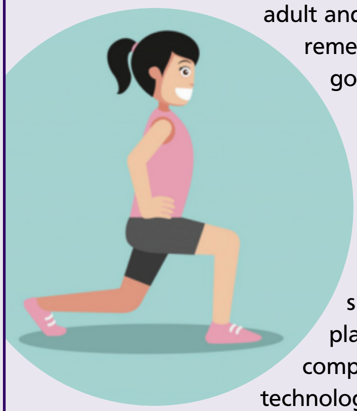
Moreover, prolonged exposure to these blue lights can greatly affect vision and even brain function. Digital eye strain is a new term used to describe the conditions resulting from the use of today's popular electronic gadgets and is considered a medical issue with serious symptoms that can affect learning and work productivity. Symptoms of digital eye strain, or computer vision syndrome, include blurry vision, difficulty focusing, dry and irritated eyes, headaches, and even trouble focusing.

Digital eye strain does not just affect adults. Children are also at risk for eye strain due to their growing use of digital devices. Children today have more digital tools at their disposal than ever before—tablets, smartphones, e-readers, videogames are just among a few, and many parents report increased use of these devices in the evenings.

Although it would be ideal to power down in the evenings and avoid looking at our devices altogether, this isn't always an option. Many tools are now available to help avoid the adverse effects of prolonged blue light exposure such as blue light blocking glasses, orange or red screen covers, and even apps and programs that allow your electronic devices to emit a warmer colored light.

4. LACK OF MOVEMENT

"Sitting is the new smoking" seems to be a catchphrase these days to describe the harmful effects of a chronic sedentary lifestyle. From long work hours seated at a desk to commuting to watching television, many adults aren't getting nearly as much exercise or daily movement they need to remain healthy. And worse, with the rise of technology, children are becoming more and more susceptible to this epidemic as well. The Centers for Disease Control (CDC) states that childhood obesity rates have tripled in 30 years and currently one out of every three kids are considered overweight. Moreover, lack of physical activity can interfere with both an adult and a child's ability to focus, learn, remember, process emotion and get good quality sleep.

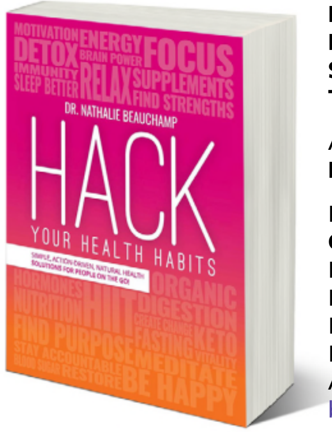


Although many parents blame technology for their child's lack of exercise, 74 percent of parents to spend family time with their kids sitting in front of the TV and 53 percent spend extra time with their kids playing video games or using the computer. It's hard to strictly blame technology as a cause of kids' inactivity when often parents are also not active because of that same technology. In our world full of technologies, parents have to make a conscious effort to set time for physical activity and exercise as part of the family's daily or weekly routine.

Technology has revolutionized the way we live, however, we must not forget that using technology can pose a risk to our health and the health of our children. We as parents have to lead by example and show our kids healthy lifestyle habits by following our own advice. Turn your off WiFi at night, set your phone's display to night mode in the evening, minimize time in front of the television and get outside with your children. All of these things will help set a good example for the whole family.•

ABOUT THE AUTHOR:

Dr. Nathalie Beauchamp, B.Sc., D.C., IFMCP is an Ottawa-based Chiropractor, the owner of Santé Chiropractic and Wellness Centre, a Functional Medicine Practitioner, an international lecturer, and Radio/ TV personality. She is the author of the book *Hack Your Health Habits: Simple, Action Driven, Natural Health Solutions for People On The Go!* and the creator of the online coaching program Hack Your Health Habits Mastery Program. She is also the host of The What The Hack?! Podcast where she interviews other natural health practitioners to help people take control of their health. Dr. Nathalie's mission is to educate, lead and empower people to live their best lives!

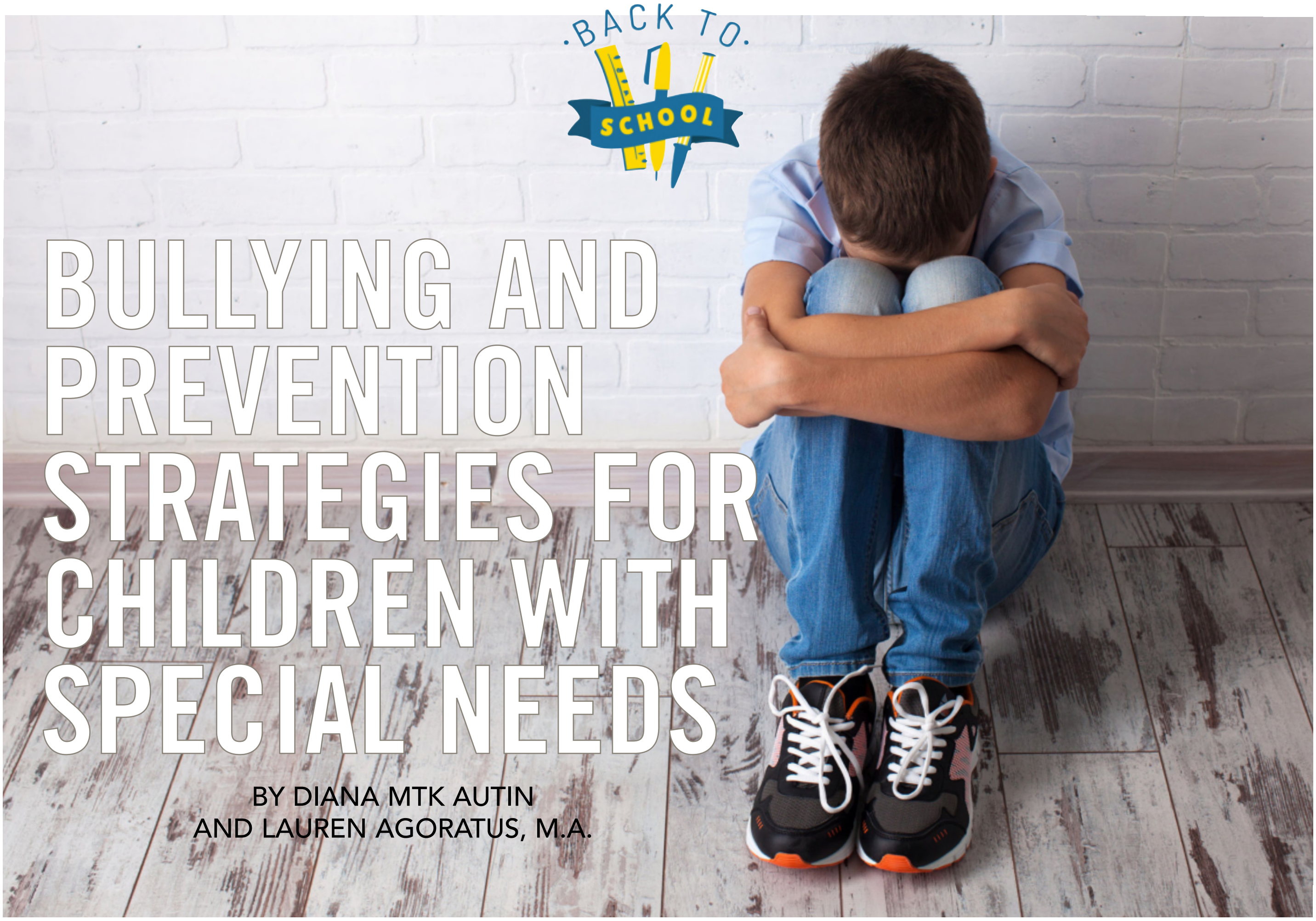


Title: **Hack Your Health Habits: Simple, Action-Driven, Natural Health Solutions For People On The Go!**

Author: **Dr, Nathalie Beauchamp**

Publisher: **Wellness On The Go Press**
Publication Date**: April 9 2019**
Paperback: **608 pages**
ISBN: **1775237230**
ISBN-13: **978-1775237235**
Available at amazon.com and barnesandnoble.com

BACK TO SCHOOL



BULLYING AND PREVENTION STRATEGIES FOR CHILDREN WITH SPECIAL NEEDS

BY DIANA MTK AUTIN
AND LAUREN AGORATUS, M.A.

One out of five children experiences bullying.[1] *Children with disabilities are more likely to be bullied than their peers. It was found that "35.3% of students with behavioral and emotional disorders, 33.9% of students with autism, 24.3% of students with intellectual disabilities, 20.8% of students with health impairments, and 19% of students with specific learning disabilities face high levels of bullying victimization."*[2]

Extreme bullying can even cause a child to develop special healthcare and mental health needs. Appropriate anti-bullying prevention and intervention strategies help both the victim and the bully. While evidence-based bullying prevention and intervention strategies help all children, there may need to be additional approaches when the "victim" and/or the bully have special needs.

TYPES OF BULLYING

Bullying comes in many forms. It can be physical, such as hitting or pushing, emotional, such as verbal insults, or social, such as exclusion. Cyberbullying adds the component of making the bullying widely "public" via social media. Bullying can also involve two or more of these forms. For example, a student with cognitive disabilities may be pushed aside in the hallway, being called the "R-Word" in the cafeteria, not allowed to play ball with other children at recess, and then made fun of online.

EFFECTS OF BULLYING

Bullying affects children in many ways. Some of these are:

- *Injury*
- *Loss of self-esteem*
- *Poorer academic performance*
- *School avoidance*
- *Increased anxiety or depression*
- *Increased drop-out rates*
- *Self-harm, including suicide*[3] *(especially due to cyberbullying due to its pervasiveness)*

PROTECTIONS FOR STUDENTS WITH DISABILITIES

Students with disabilities have additional protections against bullying and harassment under federal laws. Students with IEPs (individualized education programs) fall under the Individuals with Disabilities Education Act (IDEA). Students with 504 plans are covered by Section 504 of the Rehabilitation Act of 1973. The U.S. Department of Education Office of Civil Rights (OCR) issued guidance to school districts (see Resources). If families are having problems with bullying of their child with special needs, they can contact their Parent Center for free help. See Resources for OCR letter and Parent Center list.

BULLYING PREVENTION

It's important for schools to use evidence-based bullying prevention and intervention programs. Three effective programs include the Olweus Bullying Prevention Program (elementary through high school); Steps to Respect (grades 3-6); and KiVa (grades 4-6): **www.educationandbehavior.com/research-based-bullying-prevention-programs**

The Office of Justice Programs has an MPG-I Guide focused on bullying in schools at **www.ojjdp.gov/mpg-iguides/topics/bullying/index.html**

The U.S. Department of Education's information on evidence-based programs can be found at **www2.ed.gov/policy/speced/guid/idea/memosdcltrs/bullyingdcl-enclosure-8-20-13.pdf**

For effective strategies to prevent bullying in early childhood, go to **http://preventingbullying.promoteprevent.org/preventing-bullying-in-early-childhood.**•

School administrators/teachers, families, and students themselves need to recognize that bullying is not a "childhood rite of passage." Bullying causes lasting effects and is no longer tolerated. Parents and professionals, as well as students themselves, can partner to eliminate bullying of all students. •

ABOUT THE AUTHORS:

Diana Autin is the Executive Co-Director of the SPAN Parent Advocacy Network (SPAN), NJ's Parent Training and Information Center; Family-to-Family Health Information Resource Center; Family Voices, Federation of Families for Children's Mental Health, and Parent to Parent USA NJ affiliate; and Military Family 360 Support Project among other programs. Autin co-directs NE-PACT, the Parent Technical Assistance Center for Region A, providing technical assistance and capacity-building to the federally-funded Parent Centers, and co-directs Leadership in Family Professional Partnerships, providing assistance to the network of Family to Family Health Information Centers.
Lauren Agoratus, M.A. is the parent of a child with multiple disabilities who serves as the Coordinator for Family Voices-NJ and as the central/southern coordinator in her state's Family-to-Family Health Information Center, both housed at the SPAN Parent Advocacy Network (SPAN) at www.spanadvocacy.org

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3. https://www.cdc.gov/violenceprevention/youthviolence/bullyingresearch/fastfact.html?CDC_AA_refVal=https%3A%2F%2Fwww.cdc.gov%2Fviolenceprevention%2Fyouthviolence%2Fbullyingresearch%2Findex.html

BUDDIES NOT BULLIES : BULLYING PREVENTION RESOURCES

STOPBULLYING.GOV

StopBullying.Gov is run by the U.S. Department of Health and Human Services. Information is given to both schools and students themselves.

What Schools Can Do

www.stopbullying.gov/prevention/at-school/index.html

In Spanish: **https://espanol.stopbullying.gov/prevenci%C3%B3n/en-la-escuela-us4/%C3%ADndice.html**

What Kids Can Do

www.stopbullying.gov/kids/what-you-can-do/index.html

In Spanish: **https://espanol.stopbullying.gov/ni%C3%B1os/lo-que-puede-hacer-t4r/%C3%ADndice.html**

CENTERS FOR DISEASE CONTROL AND PREVENTION

The CDC has a section on bullying and violence prevention. There is information on bullying statistics, the effects of bullying, and a video for students, "Be Someone's Hero."

Preventing Bullying

www.cdc.gov/violenceprevention/youthviolence/bullyingresearch/fastfact.html

In Spanish: **ww.cdc.gov/violenceprevention/youthviolence/bullyingresearch/spanish/index.html**

Violence Prevention

www.cdc.gov/violenceprevention/youthviolence/index.html

In Spanish: **www.cdc.gov/violenceprevention/youthviolence/spanish/index.html**

PARENT CENTERS - HELP FOR FAMILIES AND STUDENTS

www.parentcenterhub.org/find-your-center

WRIGHTSLAW - BULLYING AND HARASSMENT

Wrightslaw has information specific to children with special needs. Data is provided on the prevalence of bullying of students with disabilities. There is also information on applicable laws such as IDEA and Section 504.

www.wrightslaw.com/info/harassment.index.htm

STOMP OUT BULLYING

Stomp Out Bullying addresses the responsibility of students to each other. There is also a hotline for students who need help.

www.stompoutbullying.org

POSITIVE BEHAVIORAL INTERVENTIONS & SUPPORTS

The National Center for Positive Behavioral Interventions and Supports is the cornerstone of addressing challenging behaviors, including bullying. The premise is being proactive instead of reactive after the fact. In addition, positive reinforcement, rather than negative punitive methods, are used to encourage students.

www.pbis.org/school/bully-prevention

U.S. DEPARTMENT OF EDUCATION,
OFFICE OF CIVIL RIGHTS - GUIDANCE TO SCHOOLS

www2.ed.gov/about/offices/list/ocr/letters/colleague-bullying-201410.pdf

WHEN PARENTS ARE BULLIED

MISINFORMATION REGARDING THE DEAF CHILD'S EDUCATIONAL SUCCESS

BY J. FREEMAN KING, ED.D.

Even though it is imperative that education addresses the numerous consequences that are promulgated when a child is a victim of bullying, the problem of parents being bullied by a well-intentioned education system regarding the deaf child's educational success is often ignored.

When research and good practices are intentionally or inadvertently ignored by professionals and parents, it is easy to provide misinformation that supports claims against the inclusion of natural sign language and encourage families of deaf children to focus exclusively on spoken language. An example of these unsupported claims can be found in an article that appears in Pediatrics (2017) by Geers and others entitled *Early Sign Language Exposure and Cochlear Implants.* Even though a vast amount of evidence exists that supports natural sign languages as being beneficial to the deaf child, these researchers claim there are harmful effects of sign language and that listening and spoken language are necessary for optimal development of deaf children. Is this misinformation that is being provided parents not an example of parental bullying?

Most hearing children are born into a world inundated with accessible language input, with language acquisition beginning at birth and mastery of their native language established by approximately age five. However, it is important to note that children who are deaf enter a world where language access is problematic. This results in adverse consequences in other developmental domains that depend on language (cognition, social-emotional skills, school readiness, and academic outcomes). Lacking fully accessible language is termed language deprivation.

There has been much progress over the last number of years to minimize the prevalence and severity of this delayed or incomplete mastery of language. Concurrently, deaf children are still significantly underperforming on standardized assessments of speech and spoken language.

Families continue to be advised and given misleading information by professionals who insist that they not use sign language with their deaf children despite the apparent underperformance of speech and spoken language. Claims that deaf children are better off without access to sign language and that they are at great risk if they do not have access to spoken language are examples of misinformation that are akin to parental bullying.

Deaf children would be better served if parents and professionals together aimed for what linguistic researchers call global language proficiency – that a deaf child's mastery of at least one language be prioritized over the child's mastery of any specific language. For many deaf children, this is likely best achieved by providing access to a natural sign language.

The most important educational outcome for a deaf child is that he/she develop age-appropriate mastery of at least one language, spoken or signed. For many children, this outcome is more likely to be achieved through a natural sign language because of the fact that the deaf child is by nature a visual learner. Does it not make educational sense to focus on the child's strength, vision, rather than their weakness, hearing, in the pursuit of this educational outcome? With or without cochlear implants or other hearing enhancements, the deaf child is primarily a visual learner.

If the children who do not successfully master a spoken language succeed in mastering sign language, then their subsequent cognitive, academic, and social-emotional development is at no more risk of suboptimal outcomes than hearing children with full access to spoken language, if their education is in a fully-accessible language environment. Deaf children learning sign language will not prevent them from learning spoken language skills.

The consistent effort by various professionals associated with the education of the deaf to advocate against exposure to sign language and focus on spoken language only can be damaging to many deaf children, because the critical period (0 to age 5) for language acquisition exists. Because of this critical period for language development, the highest priority must be to provide a deaf child with whatever type of linguistic input is most accessible and most likely to result in age-appropriate language mastery; for the deaf child

SOUND ADVICE: Parents should not be bullied into making decisions that are driven by theoretical arguments, practical concerns, misconceptions about sign language, and social biases.

this means taking advantage of his/her strength, vision, and not playing to their weakness, hearing.

Parents must make decisions on behalf of their child, and families of deaf children may prefer for their child to be raised in a manner that does not include a natural sign language. Therefore, it is incumbent on professionals who serve families to provide guidance to parents to help them make fully-informed decisions, and for the parents not to be given misleading information that is not fully research-based. The ignorance of the professional can inadvertently lead the parents into making ill-formed decisions that can put their child at risk of language deprivation. Parents should not be bullied into making decisions that are driven by theoretical arguments, practical concerns, misconceptions about sign language, and social biases (the misplaced prestige of spoken language relative to sign language).

There exist current research findings indicating that fully accessible language experiences during early childhood are the key to empowering deaf children's development potential. Certainly, language acquisition is a human right that transcends philosophical biases and misinformation. This misinformation that is shared with parents of deaf children by poorly informed and inadequately trained professionals becomes a form of bullying in which parents and their children become victims of a well-intentioned educational system. •

NOT JUST SPEECH, LANGUAGE : HOW TO AVOID BEING BULLIED

To assist parents in not being bullied or following misinformation that might be suggested by some professionals related to the use of sign language, the following suggestions are offered (borrowed from the excellent article, *Deaf Children Need Language, Not Just Speech*, written by M. Hall, W. Hall and N. Caselli that appeared in First Language, 2019):

1. Know that there is tremendous variability and unpredictability in outcomes of spoken language-only approaches.
2. Even with early access to high-quality interventions in a spoken language-only approach, there remains a significant risk that deaf children will not attain even minimal fluency in spoken language and experience language deprivation.
3. Given this risk, excluding sign language during the critical period of language acquisition puts children at risk of never mastering any language – spoken or signed.
4. Concordantly, approaches that actively exclude sign language carry a high risk of delays or disturbances in cognitive, academic, and socio-emotional development.
5. There is no evidence that sign language exposure harms spoken language acquisition; such claims (e.g., Geers et al., 2017, *Early Sign Language Exposure and Cochlear Implants*) are not justified by the available data.
6. The limited existing empirical evidence suggests that under optimal exposure conditions, sign language benefits spoken language acquisition.
7. Providing access to a natural sign language increases a deaf child's chances of attaining global language proficiency – which in turn promotes healthy outcomes in cognitive, academic, and socio-emotional development.

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BULLYING...

WHY DOES IT ALWAYS HAPPEN TO ME?

BY STEVE SIMPSON

People wonder why I'm so sensitive. People laugh because other people can take insults and jokes and I can't. I get angry, sad and depressed, which makes people make fun of me even more. What they don't know is that making fun of me or bullying me is nothing new. Long before I ever stepped foot in a school, I was a victim of bullying.

FOCUS ON BULLYING • EP SPECIAL SECTION •

It wasn't another student and it wasn't a neighbor. It was someone in my own family. Maybe it was because they were drunk, but whatever the reason, by the time I entered school I had already lived years of being put down, made to feel worthless, and had my self-esteem ripped apart. Let's not forget that the overwhelming damage of bullying is not so much done in schools or in the workplace, but at home. Because there is no worse bully than a child's own father or mother. I can tell you from experience that verbal abuse can at times be just as harmful or even deadly as physical abuse. I know, I've had both. The physical wounds healed, but the emotional wounds left scars, which can affect a person their whole life.

ILLUSTRATION PROVIDED BY RICK RADER, MD

How can it be deadly, you ask? Because many have been pushed to commit suicide as a result of bullying by one of their own parents or adults in the house; stepfather, stepmother, mother's boyfriend, father's girlfriend. Bullying at home may make someone more susceptible or vulnerable to bullying elsewhere. By the time these children go to school, almost all of their emotional protective layers have been ripped away by their own family, making them an open target for bullies that can sometimes sense this vulnerability. Now the bullying at school and other places just makes them think that everything their parents said were right, "Now even they're saying these things about me."

> "ONE OF THE MOST IMPORTANT THINGS TO LEARN AND WORK ON IS YOUR OWN SELF-WORTH AND SELF-ESTEEM. WHEN MY SELF-ESTEEM WAS LOW, I WOULD EASILY BELIEVE ANYTHING NEGATIVE SAID ABOUT ME. ONCE I HAD A HIGH SELF-ESTEEM, PEOPLE COULD NOT HURT ME AS EASILY BY JUST SAYING THINGS TO OR ABOUT ME."

For those being bullied, if you can honestly say that you've had verbal abuse in your own home then the answer is to work on the damage that that abuse has caused. Once you stop hurting over the things your own family members have said, and grow to realize that these things are not true, you will find it much easier to deflect the names thrown at you at school or work. They won't have the same effect on you or possibly even not hurt you at all. It's not a matter of you being weak. Nobody can grow up being verbally abused in their own home and then not have problems or be vulnerable outside your home.

One of the most important things to learn and work on is your own self-worth and self-esteem. When my self-esteem was low, I would easily believe anything negative said about me. Once I had a high self-esteem, people could not hurt me as easily by just saying things to or about me. I remember many fights I had even gotten into or over being called names. Once I had some self-worth, that didn't seem as important to me. When we feel good about ourselves, we are then able to see the source of where the bullying comes from. Is it because that person has an alcohol or drug addiction? Does that person simply want attention? Does that person have self-esteem issues too and the only way they can feel confident is by knocking someone else down? People can make themselves feel popular because they get others to laugh with them, but one whose popularity is based solely on getting people to laugh at others is false. You don't want to get in a habit of harshly judging others, but once you see through the person that is verbally attacking you, it takes away the sting of their words.

How do you get help to raise your self-esteem and self-worth? Certainly, if you are in school, there are school counselors, social workers and psychologists to help and you will find they understand you and your situation more than you thought. Community centers and churches many times also have counselors, 12-step programs and support groups. Please keep in mind that if you are a child of an alcoholic or have some abuse or dysfunction in your home that is more of a cause of your problems than the bully at school. When you get help you will realize that the effects from your home problems affected you a lot more than you thought, and made you vulnerable to begin with to the bullying. When you work on the problems from home and gain a self-esteem and self-worth once again, you will be strong and capable to not let the bullying affect you at all. Remember many are subject to bullying. You are not alone in this and you will see that when you get help by one of the places that I've recommended.

For those of you that think name calling and bullying are really no big deals and can't figure out what certain people's "problem" is, or why they act the way they do when you're simply "teasing them," I hope you will come to realize that it may not be so much what you're saying to them but what they are going through in their lives. By taunting and bullying these people you are actually becoming part of the abuse that they are going through at home. You are no better than the adults who are committing child abuse because you are helping their abuse have an even greater effect on their victims. Many abuse victims can hide their situations very well. Would you really want to even take a chance of picking on one of these individuals? Furthermore, you have to ask yourself why you have such a need to make fun of or put down others. Could you perhaps use some help for your self-esteem and self-worth?

Finally, if you are simply a bystander to someone's bullying or name calling, you can increase your own self-worth and self-esteem by either defending the person who is being bullied or at least letting everybody know that you don't agree with this at all, and that it's not cool. Maybe you can even try to say some kind words to the person being bullied and make sure they are okay.

Bullying or verbally attacking anyone from any family background is wrong and cowardly. However, doing it to someone who already has their fill of problems is worse than cruel. Something to think about. Instead of being a bully, how about being a hero? •

(From The Teenage and Young Adult Survival Handbook. Republished with author's permission.)

ABOUT THE AUTHOR:

Steve Simpson is a young adult author and youth advocate who is a former abused child of an alcoholic. He has spent the majority of his life writing and making media appearances, addressing these issues, as well as teen suicide, self-esteem and abuse. *The Teenage and Young Adult Survival Handbook* deals with most of the issues a young person living in a dysfunctional and abusive home might have to deal with. Steve is also the author of four young adult fiction novels (*Who Am I?, The World is Wrong, Runaway* and *Child's Island*). http://www.PowerPublishingCorp.com

There are thousands of genetic disorders and rare cancers in need of treatments, so the questions of price and affordability must be addressed. Additionally, research must continue on the current therapies to learn about their long-term efficacy. The early promise of gene therapy is being realized and hopefully these issues will be addressed for the benefit of everyone.

GENE THERAPY COMES OF AGE, BUT QUESTIONS REMAIN

BY ROBERT TOMAINO

For decades, gene therapy has been heralded as a potential game changer. A modern therapeutic technique that offers the hope of a cure rather than simply a treatment. Despite the great promise, gene therapy stumbled for decades, beset by setbacks and failures. However, in recent years, medical advances have led the Food and Drug Administration (FDA) to approve the first gene therapies in the United States. and have ushered in a new era of hope and excitement. However, questions still abound, including the price point of these therapies as well as the long-term, sustained effectiveness of the treatments.

INITIAL SUCCESS

In 1990, doctors treated a young girl with a rare disorder called severe combined immunodeficiency (SCID). The girl lacked an enzyme that was required for the proper function of her immune system. Consequently, she was highly susceptible to infection. In the past, SCID was also known as "bubble boy disease" after the release of a movie depicting a true story about a child born with SCID who lived in a hospital isolation contraption which prevented him from getting germs that could have otherwise killed him. The enzyme in question is produced by the *ADA* gene and doctors successfully inserted a healthy version of the gene into immune cells called T-cells. There was a dramatic improvement of the young girl's immune system. This provided a "proof of concept" for gene therapy.

Following this initial success, gene therapy was hailed as a coming revolution. However, the initial hope and promise quickly dissipated following two tragedies, one in the late 90s and one in the early 2000s. The first was the death of Jesse Gelsinger in 1999.

Jesse received an experimental gene therapy treatment for his rare genetic disorder called ornithine transcarbamylase deficiency (OTC). OTC causes ammonia to build up in the bloodstream, causing severe complications and potentially brain damage. Jesse had a milder form of OTC, but eagerly participated in the trial, in part, to help children in the future avoid what he went through. Researchers at the University of Pennsylvania administered the therapy and, within four days, Jesse had passed away from complications of the treatment, which caused many of Jesse's organs to shut down. The circumstances surrounding this trial, including questionable research practices, led the FDA to halt all gene therapy studies. In the United States, research into gene therapy slowed from a deluge to a trickle.

In 2003, doctors in France halted a gene therapy trial after some of the patients who had the same rare disorder as the young girl in the United states, severe combined immunodeficiency, developed leukemia following gene therapy. The therapy was initially going very well. Researchers suspected that the infusion of the gene that carried the needed enzyme probably landed in a place that did not need the enzyme and somehow activated a cancer-causing gene in the patients.

These two tragedies dimmed the outlook for gene therapy and quelled the early optimism. Researchers and government regulatory agencies urged a slower, more cautious approach to gene therapy. Although gene therapy fell out of the news cycle, researchers continued to work toward refining the process. In 2017, the FDA approved the first two gene therapies in the U.S. Both treated cancers of the blood. As of August 2019, there are now five gene therapies on the market in the U.S., and a few hundred more being studied. Gene therapy has skyrocketed back to the forefront of research circles and recaptured the early promise and optimism.

WHAT IS GENE THERAPY?

Gene therapy involves altering genes. Genes are units of DNA. They provide instructions for creating proteins that play critical roles in the body. Gene therapy can be separated into *in vivo* and *ex vivo* forms. When a gene is defective, the protein produced by that gene may be deficient, overproduced, faulty or ineffective. *In vivo* gene therapy involves either replacing defective genes with healthy copies or turning off the defective genes. Researchers create healthy copies of the defective gene in a lab and then deliver the healthy genes directly into the body. *Ex vivo* means that the genes that are altered are removed from the body (changed and then returned). An example is when scientists filtered out certain immune system cells and reprogrammed them to fight cancer before returning them to the body.

Ideally, physicians would produce healthy or reprogrammed gene copies in the lab and then inject them directly into a patient. However, directly injecting the healthy gene copies into a cell does not work, and physicians quickly learned that they must use a carrier. Eventually, they found the perfect delivery vehicle – viruses.

VIRAL SOLUTION: Ideally, physicians would produce healthy or reprogrammed gene copies in the lab and then inject them directly into a patient. However, directly injecting the healthy gene copies into a cell does not work, and physicians quickly learned that they must use a carrier. Eventually, they found the perfect delivery vehicle – viruses.

Researchers choose viruses because they have a unique ability to infect cells. Viruses attach to cells in the body and establish a parasitic relationship. A virus injects its own DNA into the cell and then infects nearby cells and then repeats the process. This is how someone becomes sick from a viral infection. In gene therapy, the viruses are modified so that they no longer cause disease or illness. Instead, the viruses function as a delivery service to deliver healthy copies of the altered gene to the body. These healthy copies then begin to produce the protein or target cancer cells.

The first two gene therapy approvals by the FDA are for *ex vivo* treatments. Both therapies involve altering immune system cells to destroy cancer cells. They are called CAR T-cell therapy or CART therapy, which stands for *chimeric antigen receptor T-cell* therapy. With this treatment, physicians filter T-cells, an immune system cell, from the patient's blood. The T-cells are reprogramed (genetically altered) to fight a specific cancer and returned to the body. Two CART therapies have been approved: Kymriah® for acute lymphoblastic leukemia and Yescarta® for non-Hodgkin lymphoma.

The official designation for Kymriah is for "patients up to 25 years old who have acute lymphoblastic leukemia (ALL) that has relapsed (went into remission, then came back) or is refractory (did not go into remission with other leukemia treatments)". The official designation for Yescarta is for "adults living with certain types of non-Hodgkin lymphoma who have failed at least 2 other kinds treatment." These therapies have led to remissions in children and adults who had failed to respond to other treatments.

In 2018, the third gene therapy approved by the FDA reflects the method of inserting healthy copies of an altered gene into the body. Some people in the medical community consider this the first "true" gene therapy to be approved in the United States because it is an in vivo treatment. Luxturna® is a gene therapy that treats a rare genetic eye condition called RPE65 mutation-associated retinal dystrophy. This disorder leads to the progressive breakdown of the retina, the light-sensing membrane in the back of the eye. *RPE65* is the name of the gene that is altered in this disorder; it produces a protein of the same name that is essential for the health of the retina. Many people with this altered gene are visually impaired at birth and the damage to the eye is progressive and can eventually lead to vision loss or blindness. Doctors create artificial, healthy copies of the *RPE65* gene and then insert these healthy copies into a patient's retinal tissue. The healthy copies will produce the RPE65 protein that is required for healthy vision.

The great appeal of gene therapy is that it offers a "cure." Whereas other treatments simply eliminate or ameliorate specific symptoms, or compensate for the effects of symptoms, gene therapy goes to the root of the problem. *In vivo* gene therapy fixes the underlying genetic defect causing a disease. By correcting the underlying defect, gene therapy is considered a cure and the hope is that it will be a one-time treatment.

Luxturna has been widely beneficial for many patients, stopping the disease's progression and greatly improving the vision of many of people.

QUESTIONS AND CHALLENGES REMAIN

Despite these success stories, there are issues with gene therapy. Drug pricing is a big issue throughout the world. While patients, ethicists, and others sound the alarm, more and more costly medications keep hitting the market unabated. The price of Luxturna is $850,000 (or $425,000 per eye). The most recent gene therapy approval by the FDA is Zolgensma®. Zolgensma is even more costly. The manufacturer, Novartis, has pegged the price at $2.215 million per patient. Zolgensma treats a rare neurological disorder called spinal muscular atrophy (SMA). There are many forms of SMA, and the two most severe can be fatal by the age of one or two. Other forms lead to progressive symptoms as a person grows older. Zolgensma has the potential to be a transformative medication.

The huge price tag made national news. Novartis defended the price, noting that the one time price for Zolgensma is better than the current alternative on the market, which is a drug called Spinraza® that costs $750,000 the first year and then $350,000 every year after. Within five to six years, Zolgensma becomes more cost effective. However, it becomes more cost effective than one of the most expensive drugs in the world. Is that really cost effective overall? A major insurance company, UnitedHealthcare, initially rejected covering the medication for some patients before changing its decision after appeals from affected families and the accompanying media coverage.

Sometimes the cost becomes prohibitive. The first gene therapy approved in the Western world was called Glybera®. The European Medicines Agency (EMA) approved Glybera in 2015. The manufacturer, UniQure, priced the therapy at $1,000,000, making it the most expensive treatment in the world at the time. The high costs, low number of patients, and questions about the therapy's long-term effectiveness led to the drug not being approved by insurers. In the end, only a few patients were treated with the drug and the company allowed the approval to lapse. The therapy is no longer listed on UniQure's website.

The Centers for Medicare & Medicaid Services (CMS) struggled to figure out how to pay for Yescarta and Kymriah, the two CART therapies approved by the FDA in 2018. In early August 2019, it was announced that Medicare would cover the medications although not the entire costs. Yescarta costs $373,000 and Kymriah costs $475,000. However, side effects can require hospitalization and, in some patients, costs are estimated to be closer to $1,000,000.

England initially denied covering Yescarta, citing the high cost. After striking a deal with the manufacturer, Gilead, the medication, will be covered for some adult patients. In Italy, the Agenzia Italian del Farmaco (Italian Medicines Agency) approved Kymriah after negotiations with Novartis. The Agency instituted a new reimbursement model called "pagamento al risultado" or payment to results, which may require the manufacturer to repay in full the treatment costs for patients who do not respond to the therapy.

The pushback on price has already started, and there are currently several hundred gene therapy clinical trials being conducted. How many, if successful, will carry a similar high price tag? How many can the market bear? How many until insurance companies cry "uncle"? At what point will the pricing decision on gene therapy open a debate on cost (and profit) versus the value of human life?

NEW CONTROVERSY

In early August of 2019, the FDA revealed that Novartis had manipulated data early in testing on animals with Zolgensma. The FDA released a statement and explained that "it was carefully assessing this situation and remains confident that Zolgensma should remain on the market."

The FDA stressed that the "the totality of the evidence demonstrating the product's effectiveness and its safety profile continues to provide compelling evidence supporting an overall favorable benefit-risk profile." So, the FDA has said that its safety and efficacy assessment hasn't changed, but this reminds us that gene therapy is a still a new success story with questions still to be answered.

Before the approval of Luxturna, the FDA asked scientists who were voting on its approval to consider whether the drug should be given more than once. According to the FDA, “it is unclear if the effect decays over time, as longer term follow up data is not available.” Some scientists wonder about repeated injections into the retinal tissue. The possibility that the positive effect of treatment can wane is true for all gene therapies because they are so new and there is no data about the long-term, sustained effectiveness. And there won’t be until time marches on.

It is very easy to get wrapped up in the accolades pouring forth for gene therapy. When people, including young children, receive a fatal cancer diagnosis and then become cancer free, it inspires everyone. When declining vision is restored, or children with a devastating neurological disease can walk and dance, it heralds the potential to completely change the medical landscape. The individuals and families who have benefited from these treatments must be eternally grateful. But there are thousands of genetic disorders and rare cancers in need of treatments, so the questions of price and affordability must be addressed. Additionally, research must continue on the current therapies to learn about their long-term efficacy. The early promise of gene therapy is being realized and hopefully these issues will be addressed for the benefit of everyone.•

ABOUT THE AUTHOR:

Robert Tomaino is a writer, editor and consultant. For more than 20 years, he has provided editorial support, guidance and strategic consultation to medical nonprofits, patient advocacy organizations, and pharmaceutical and biotechnology companies. Robert has extensive experience writing about rare disorders for both patients and physicians. Robert also understands the unique needs of patients in the rare disease community and works to foster better communication and understanding between these diverse groups and the industry representatives that work with them. He is a principal at Orphan Communications (http://www.orphancommunications.com/). He is also a member of the Fairfield Scribes (http://www.fairfieldscribes.com/).

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The path to accessibility starts with representation. People with disabilities are highly underrepresented both in front of and behind the camera.

RAISING EXPECTATIONS: The ReelAbilities Film Festival is trying to change both the perceptions of people with disabilities – through films that shine new light on this community, and as a festival, has entered the movement for further inclusion.

REELABILITIES:

ACCESSIBILITY IN MOVIES

BY ISAAC ZABLOCKI

When going to a summer blockbuster, one might catch the letters CC and AD listed next to the titles. This is not a new parental guide standard, nor a new form of digital experience. It is a listing of the accessibility aids provided for that film, making the films more accessible to all. This is the result of a new ruling which took effect last summer, which enforces all major cinemas to offer Audio Description and Closed Captions for all of their screenings. Despite this step in the right direction, the film industry still struggles with inclusion and accessibility for people with disabilities, and has a long way to go until it becomes truly accessible to all.

The path to accessibility starts with representation. People with disabilities are highly underrepresented both in front of and behind the camera. This fact is especially recognizable in the few films that do include a person with a disability, yet the part is clearly not written or directed by someone with direct access to the world of disability. Typically, those parts are also not casted authentically and ultimately bring to the public visions that have nothing to do with reality – causing a further gap between the perceptions of people with disabilities and the non-disabled community.

In addition to this, many films are first premiered at film festivals and are not shown with the required accessible aids. As the director of The ReelAbilities Film Festival, the largest disability film festival in the country, I go to many festivals and see films relating and not relating to the topic of disabilities. Despite the attempts of some festivals to be more accessible, most fall short of standard.

ReelAbilities Film Festival prides itself on being the most accessible festival in New York, travelling additionally around North America to share accessible films in more locations. Every year, ReelAbilities incorporates new ways to raise the bar on accessibility of film presentations. The ReelAbilities Film Festival is trying to change both the perceptions of people with disabilities – through films that shine new light on this community, and as a festival, has entered the movement for further inclusion. Over the years, the festival has learned ways to provide more accessible events but, more important, it has attempted to change generally accepted notions surrounding accessibility and inclusion for people with disabilities.

ABOUT REELABILITIES FILM FESTIVAL: NEW YORK:

ReelAbilities
FILM FESTIVAL
NEW YORK

Founded in 2007 by the Marlene Meyerson JCC Manhattan, ReelAbilities Film Festival: New York is the largest festival in the country dedicated to promoting awareness and appreciation of the lives, stories and artistic expressions of people with different abilities. The weeklong festival is renowned for its wide-ranging international film selection, riveting conversations, and performances, presented annually in dozens of venues across the New York metropolitan area. In 2010, ReelAbilities Film Festival: New York expanded into a national program, presenting its one of a kind programming in cities throughout the United States. More information is available at https://reelabilities.org

PHOTO COURTESY REELABILITIES

When we began the ReelAbilities Film Festival more than 12 years ago, in our attempts to be accessible, we presented all of our films with Open Captions (OC). This meant that the entire audience saw the captions on the screen. We felt that if viewers are open to viewing a movie with subtitles, why not have captions presented for all audiences? It was not until year two of ReelAbilities that we realized the needs of the vision loss or blind community and added Audio Description to select films and upon request.

However, we believe one should not have to request access, but rather that it should be a given. This is why we worked to make all of our films fully accessible. This is not an easy task. Many film festivals present films in fully accessible theaters, but if the films themselves do not have the accessibility aids provided, these features cannot be utilized. Most films do not create these accessibility aids when they are submitted to a festival – they only create these aids when required for a formal mainstream release. Therefore, for ReelAbilities, we need to create the captions and audio description for almost all the films, which is a very involved process of thoughtful script writing of all the visuals plugged in between dialogue in the least intrusive way, or in the case of a foreign film, adding the dialogue too for all spoken parts, and recording this and formatting correctly into the film – all with a very quick turnover time. This should be part of the artistic process of filmmaking, rather than an afterthought of the distribution process.

> We believe one should not have to request access, but rather that it should be a given. Many film festivals present films in fully accessible theaters, but if the films themselves do not have the accessibility aids provided, these features cannot be utilized.

Most festivals and arthouse screenings do not present films with accessibility aids. Even if they do, many often do not create materials that are accessible or have their conversations presented in the most accessible way. With aging boomers in this country who make up a large number of arthouse filmgoers, there is more need for access than ever before. Visual and hearing impairments are leading needs of this community. Theaters need to start thinking about how they can better accommodate beyond the standard.

The Americans with Disabilities Act (ADA) was passed nearly 30 years ago providing equal access to all, and we've come a long way since then. But beyond the given right, there needs to be a cultural shift to facilitate lasting change. If we do not see more people with disabilities on our screens, in our environment, and represented in our cultural space, the efforts for accessibility will fall short. People with disabilities were not a part of the film experience for so long that we need to start building this culture from scratch. It starts with films that have responsible portrayals of people with disabilities. We need to see more actors with disabilities, more extras with disabilities, more correct depictions of disability life experiences. If you look at Hollywood films, you would think disabilities rarely exist, as opposed to the twenty percent of society that it makes up. People with disabilities should be able to see themselves on the screen and be a part of the story (and not just a dramatic twist). Often, people with disabilities are depicted as a source of pity, for an easy emotional effect, or dramatized as superhumans or villain characters. Very rarely do we get to see the complex and normal human existence of people with disabilities. The disabled community should be depicted as part of the fabric of our society, with normal human experiences.

> America's fear of titles in movies needs to change. We should not be afraid of reading. Ask any European, it becomes second nature to the point that you will miss it when they are gone.

We should simultaneously be more aware of how to serve the disabled community. This is often forgotten as we attempt to create a more diverse and inclusive society. How can we be more welcoming at events? From soup to nuts, how can we be more accommodating? Do we hire people with disabilities on our staff? Are there any obstacles for people with all different kinds of disabilities in attending events? We need to take a proactive approach.

Simple elements are often overlooked. Take for example post-screening conversations. Q&A screenings should all happen with a microphone that runs through the same sound system as the film as to reach T-Coil hearing aids where provided. And of course, questions from the audience should be asked through the microphones as well. I rarely see this being done. Of course, if the films are finally captioned, should we not also provide live captions of the conversations? We need to ensure that everyone can feel a part of the full experience.

Technology is changing cinema and making accessibility easier. The digital world allows multiple layers of data to be displayed on the screen with relative ease. Still, the new screening formats should allow captions to be put up on the screen and not only sent to the little personal screens or the mirrored option that most theaters use. Who thought that having captions on a separate little screen was a good way to view a film? Some countries use special glasses for captions. But why not screen films with open captions? I personally love watching the captions on my Netflix screen. America's fear of titles in movies needs to change. We should not be afraid of reading. Ask any European, it becomes unnoticed and second nature to the point that you will miss it when they are gone.

Most important, we need to create a welcoming environment. Once everyone feels welcome at every screening, we will see more people actually using these aids and joining the culture of filmgoers. It will not happen overnight, but once we see the change in the movies, the cultural change can happen off the screen as well.•

ABOUT THE AUTHOR:

Born in New York, Isaac Zablocki grew up in Israel and served in the IDF's leading film unit as an educational film producer. He attended film school at Columbia University and went on to work at Miramax films. At the Marlene Meyerson JCC Manhattan, he runs weekly screenings, and programs multiple film festivals annually including the acclaimed Other Israel Film Festival and Reelabilites: NY Disabilities Film Festival. Isaac has developed the largest online database of Israeli films as well as Israel Film Center Stream, the leading site for streaming Israeli films. Isaac lectures around the world in major institutions and writes for a variety of publications including the Huffington Post.

INTRODUCING THE ALL-NEW WWW.EP-MAGAZINE.COM

EP's Innovative New Digital Strategy

Exceptional Parent Magazine is proud to announce the launch of www.ep-magazine.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.

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

We, along with many other healthcare advocates and organizations, believe a nationwide systemic change is needed to ensure all health care professionals have mandatory training about people with IDD.

Promoting Better Health Care Appointments

LET'S MAKE THE UNFAMILIAR FAMILIAR!

BY ELIZABETH PERKINS PHD RNLD FAAIDD FGSA AND SETH VANZANT MD, MPH

This article highlights a range of free health resources available from the Florida Center for Inclusive Communities (FCIC), a University Center for Excellence in Developmental Disabilities, at the University of South Florida. They were designed to improve health care encounters for people with intellectual/developmental disabilities, their family members, and their health care providers.

People with intellectual/developmental disabilities (IDD) are a unique population – they are more likely to have multiple health conditions, they are often disadvantaged in being able to access good quality care, and even more frustrating, is the fact that the vast majority of health care professionals receive very little training on how to best support and communicate with people with IDD. Inadequate training can amplify feelings of apprehension and awkwardness from health care professionals, through no fault of their own. Poorly prepared professionals can leave people with disabilities feeling dissatisfied with their health care encounters.

GETTING TO KNOW YOU: FCIC's approach has been to produce health advocacy resources that can empower the person with IDD, their families, and their health care provider to know more about each other, and bridge the communication and knowledge gaps that can exist on a 1:1 basis.

We, along with many other healthcare advocates and organizations, believe a nationwide systemic change is needed to ensure all health care professionals have mandatory training about people with IDD. Such initiatives are already underway, though they will take some time to implement, as skills and competencies need to be developed, agreed, and endorsed. Furthermore, implementation into already dense training curricula in medical, nursing, physical therapy, and other allied health professions, will ultimately mean that "something's gotta give" i.e. coverage of some other topic will need to be reduced or removed to make space. Buy-in from licensing and accreditation bodies will also need negotiating. It's certainly a long road ahead.

FCIC provides training to medical, nursing, and students in other allied health professions, and continuing education to those already in the field.

So what can we do in the meantime? How can we make the unfamiliar familiar? FCIC provides training to medical, nursing, and students in other allied health professions, and continuing education to those already in the field. Beyond that, our approach has been to produce health advocacy resources that can empower the person with IDD, their families, and their health care provider to know more about each other, and bridge the communication and knowledge gaps that can exist on a 1:1 basis. Indeed, the introduction of these resources by a person and family member has resulted in not just one health care provider using them, but their subsequent adoption in numerous clinics, hospitals, even state-wide systems!

RESOURCES TO PROMOTE BETTER COMMUNICATION

MY HEALTH PASSPORT

One of our most popular resources is My Health Passport (flfcic.fmhi.usf.edu/docs/FCIC_Health_Passport_Form_Typeable_English.pdf) – a four-page document that was designed for when people with IDD are needing in-patient hospital care (e.g. for surgery, diagnostic screening etc.), and may need to spend a few days in hospital with staff who are very unfamiliar with them. It is designed to be shared with many types of healthcare providers, in clinic and hospital settings, especially for those who are not very familiar in providing care to individuals with IDD. It describes the unique supports and preferences of an individual. My Health Passport is completed by the patient/caregiver and then shared with their health provider.

My Health Passport has been endorsed by the American Academy of Developmental Medicine and Dentistry (AADMD), and the Developmental Disabilities Nurses Association (DDNA). "Successful patient care can often be hampered by having inadequate personal and health information between the individual with developmental disabilities, their family and caregivers, DSP's and other agency staff, and the healthcare provider. My Health Passport is a wonderful document that contains basic and essential health information as well as personal characterizations of the individual. I highly recommend it." Seth Keller, MD - former President of AADMD.

My Health Passport

If you are a *health care professional* who will be helping me,
PLEASE READ THIS
before you try to help me with my care or treatment.

My full name is: ______
I like to be called: ______
Date of birth: ___/___/___
My primary care physician: ______
Physician's phone number: ______

Attach your picture here!

This passport has important information so you can better support me when I visit/stay in your hospital or clinic.

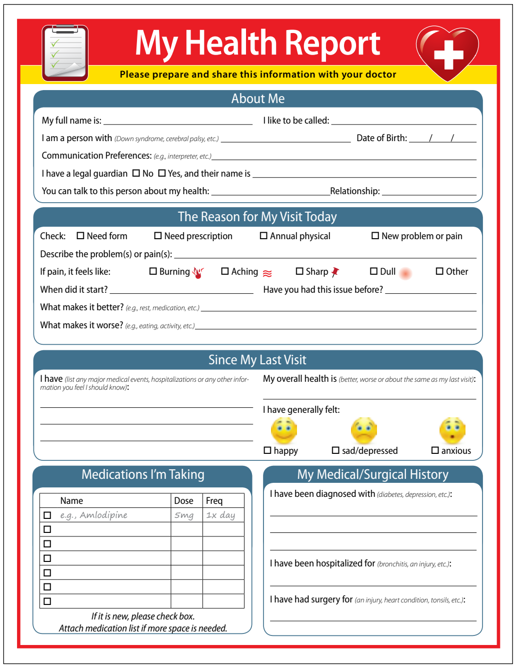
Please keep this with my other notes, and where it may be easily referenced.

My signature: ______ Date completed: ___/___/___
You can talk to this person about my health: ______
Phone number: ______ Relationship: ______

I communicate using: (e.g. speech, preferred language, sign language, communication devices or aids, non-verbal sounds, also state if extra time/ support is needed)

MY HEALTH REPORT

My Health Report (flfcic.fmhi.usf.edu/docs/FCIC_My_Health_Report_Fillable.pdf) is two-page document to be used for primary care appointments with a person's family doctor. It was designed for adults with IDD, with feedback from family physicians to help individuals and family caregivers give relevant health information as efficiently as possible. It is designed to contain information to help to quickly establish the reason for the visit, prompt the patient/family remember information about their symptoms, leaving more time to be available for discussion and treatment options. The form also reminds the physician to enquire about overall health status too.



My Health Report

Please prepare and share this information with your doctor

About Me

My full name is: ______ I like to be called: ______
I am a person with *(Down syndrome, cerebral palsy, etc.)* ______ Date of Birth: ___/___/___
Communication Preferences: *(e.g., interpreter, etc.)* ______
I have a legal guardian ☐ No ☐ Yes, and their name is ______
You can talk to this person about my health: ______ Relationship: ______

The Reason for My Visit Today

Check: ☐ Need form ☐ Need prescription ☐ Annual physical ☐ New problem or pain
Describe the problem(s) or pain(s): ______
If pain, it feels like: ☐ Burning ☐ Aching ≋ ☐ Sharp ☐ Dull ☐ Other
When did it start? ______ Have you had this issue before? ______
What makes it better? *(e.g., rest, medication, etc.)* ______
What makes it worse? *(e.g., eating, activity, etc.)* ______

Since My Last Visit

I have *(list any major medical events, hospitalizations or any other information you feel I should know)*:

My overall health is *(better, worse or about the same as my last visit)*:

I have generally felt:
☐ happy ☐ sad/depressed ☐ anxious

Medications I'm Taking

	Name	Dose	Freq
☐	*e.g., Amlodipine*	*5mg*	*1x day*
☐			
☐			
☐			
☐			
☐			
☐			

If it is new, please check box.
Attach medication list if more space is needed.

My Medical/Surgical History

I have been diagnosed with *(diabetes, depression, etc.)*:

I have been hospitalized for *(bronchitis, an injury, etc.)*:

I have had surgery for *(an injury, heart condition, tonsils, etc.)*:

Developing these types of resources is a careful balancing act between keeping it user-friendly to people with disabilities and their family caregivers, while at the same time providing pertinent information to the healthcare professional. As such, it is vital that resources are developed in conjunction with and feedback from people with IDD, family members of people with IDD, and medical professionals with high caseloads of people with IDD to ensure such utility. Overall, our health advocacy resources serve three different objectives - i) to improve communication and knowledge between specific patients with IDD and their healthcare professionals, ii) to empower individuals to learn more about health, and iii) to improve provider knowledge about disability.

We hope you use and share these resources with your healthcare providers, and health advocacy activities with others. Help us to make the unfamiliar familiar! •

Learn more at FCIC's Health Resources page: **flfcic.fmhi.usf.edu/program-areas/health.html?tab=2**

ABOUT THE AUTHORS:

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Seth VanZant MD, MPH is a resident physician in the neurodevelopmental disabilities program at the UPMC Children's Hospital of Pittsburgh. His research interests include the provision of care and health advocacy for patients with intellectual and developmental disabilities. He is an active member of the American Academy of Pediatrics Section on Children with Disabilities and the American Public Health Association Disability Section. While pursuing his MD at the Morsani College of Medicine, at the University of South Florida, Dr. VanZant was mentored by Dr. Perkins in their FCIC UCEDD Trainee/Mentorship program.

RESOURCES TO EDUCATE PEOPLE ABOUT HEALTH

EDUCATION FOR LIFELONG HEALTH AND LIFELONG MENTAL HEALTH FACTSHEETS

These factsheets were designed as educational resources for people with mild intellectual disability. Usual treatments and prevention tips are also highlighted. Current topics available are:

Anxiety

flfcic.fmhi.usf.edu/docs/ELMH_Anxiety.pdf

Cancer

flfcic.fmhi.usf.edu/docs/FCIC_EFLH-4-Cancer%20Fact%20sheet.pdf

Cancer Treatment

flfcic.fmhi.usf.edu/docs/FCIC_EFLH-5-Cancer%20Treatment%20Fact%20sheet.pdf

Depression

flfcic.fmhi.usf.edu/docs/ELMH_Depression.pdf

Diabetes

flfcic.fmhi.usf.edu/docs/FCIC_EFLH-2-Diabetes%20Fact%20sheet.pdf

Good Health and Hygiene

flfcic.fmhi.usf.edu/docs/FCIC_EFLH-1-Hygiene%20Fact%20sheet.pdf

Osteoporosis

flfcic.fmhi.usf.edu/docs/FCIC_EFLH-3-Osteoporosis%20Fact%20sheet.pdf

Seizures & Epilepsy

flfcic.fmhi.usf.edu/docs/FCIC_EFLH_7_Epilepsy.pdf

How Do I Talk to My Doctor?

flfcic.fmhi.usf.edu/docs/FCIC_EFLH-6-TalkingToMyDoctor_Fact%20sheet.pdf

RESOURCES TO IMPROVE PROVIDER KNOWLEDGE


Physician's FACT SHEET

Improving Communication with Patients who have Intellectual and Developmental Disabilities

We also believe in being proactive and helpful to healthcare providers and staff who will come into contact with people with IDD. Many may have received little-to-no actual training about disability in general, and especially concerning adults and older adults with IDD. The most fundamental aspect we emphasize is how communication can be improved, along with useful but brief guidance to facilitate better awareness. Our factsheet Improving Communication with Patients who have Intellectual and Developmental Disabilities (**flfcic.fmhi.usf.edu/docs/FCIC_PhysicianFactSheet_1_Improving_Communication.pdf**) provides an overview of why healthcare providers need to pay much more attention to this population, ways to improve communication and build rapport, guidance on how to conduct appropriate physical examinations as well as referencing scholarly articles for those interested in further research into this topic.

Excelling in care for patients with DD through communication, environment, and logistics, i.e. XCEL (**www.xcel.flcic.org**) is an entertaining 8-minute video resource that is designed for all types of health and support staff who may encounter people with DD in healthcare settings. There are handy hints on how to communicate appropriately, how to be mindful of how the environment can be modified to be more welcoming and inclusive of people with disabilities, and how we can help make appointments more convenient for people with IDD. There is also an accompanying factsheet – to help reinforce and remind people of the major points highlighted in the video, as well as more in-depth resources for those seeking further information.

PEOPLE WITH INTELLECTUAL AND/OR PHYSICAL DISABILITIES CAN HAVE GREAT POTENTIAL.

TRY TO PROVIDE MANY OPPORTUNITIES FOR THEM TO SHOW YOU THEIR ABILITIES.

DISPROVING MYTHS ABOUT PEOPLE WITH ID:

AN OT'S PERSPECTIVE

BY LAURA LAWSON, OTS

I had the pleasure of attending Orange Grove Center (OGC) for my clinical experience during my first year of school. Orange Grove Center is a community program that supports children and adults with intellectual and physical disabilities from Tennessee and Georgia.

While there, I spent my time in a classroom with low-functioning adults, meaning they are unable to work or volunteer in the community due to limitations from their disabilities. I had the unique experience of interacting with these adults from an OT perspective. I had very little previous experience working with people with intellectual disabilities, so while at OGC I discovered three "myths" about them that I want to disprove. After each myth, I provide a take-home message for tips everyone should keep in mind when working with people who share these qualities. My goal is for these tips to shed light on ways people working with and/or caring for individuals with intellectual disabilities can better relate to them.

Even though some of this information may seem obvious, I hope my take-home messages are helpful for those with little experience who are working with and/or caring for people with intellectual disabilities. As for students and clinicians, I think it

MYTH VERSUS REALITY: WORKING WITH PEOPLE WITH ID

MYTH #1

PEOPLE WITH INTELLECTUAL DISABILITIES WHO ARE NONVERBAL OR NEAR NONVERBAL DO NOT UNDERSTAND WHAT IS GOING ON AROUND THEM.

I was in a classroom with a handful of adults who either did not speak, had speech that was difficult to understand, or repeated short statements. These adults showed me that they can understand much more than they are able to express through their words. For example, one woman was able to correctly identify colors even though she did not have the verbal skills required to say the name of each color. When different colored objects were placed in front of her, she was able to point to each one as I listed their colors.

TAKE-HOME MESSAGE

Try to communicate with people who cannot speak or who have trouble speaking as if they are able to speak clearly and form full sentences. To help them make their own decisions and direct their own care, it is beneficial to give them objects or images to look at so they can point to what they want.

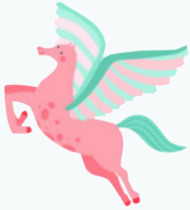
MYTH #2

PEOPLE WITH INTELLECTUAL DISABILITIES WHO ARE NONVERBAL AND PHYSICALLY AGGRESSIVE ARE TOO DIFFICULT TO WORK WITH IN THERAPY.

On my first day, I was with a young woman who expressed her anger and frustration by pulling my hair when she did not get what she wanted. I later learned that she had experienced a rough morning that day, which is why she was acting out. Pulling hair was the only way she knew how to share with me how she was feeling. To understand her better, I tried putting myself in her shoes. I imagined being unable to say what I wanted to and having someone new tell me what to do. On top of that, I imagined being in an already bad mood from having a rough morning. If I were in her situation, I would have probably acted similarly to the way she did.

TAKE-HOME MESSAGE

I think it is beneficial to teach clients who are aggressive and/or nonverbal ways they can express and manage their feelings. An emotion chart can be used to help them communicate their feelings and teaching them how to use deep breathing when they are angry can help them manage their emotions in a more appropriate way instead of acting out aggressively. Also, try to keep in mind that some people are naturally better at relating to people with intellectual disabilities who share these qualities and it is okay if it does not come naturally to you. All you can do is try your best.



MYTH #3

PEOPLE WITH INTELLECTUAL AND PHYSICAL DISABILITIES WHO ARE CONSIDERED LOW-FUNCTIONING CANNOT DO ANYTHING FOR THEMSELVES.

I learned to not assume individuals' skill levels based on their physical appearances. One young man at OGC displayed impressive musical talent, even though he does not have the skills necessary to perform a traditional job in the community. Another young man, who uses a power wheelchair, can walk with the help of a walking device. A young woman who also uses a power wheelchair can swim with help.

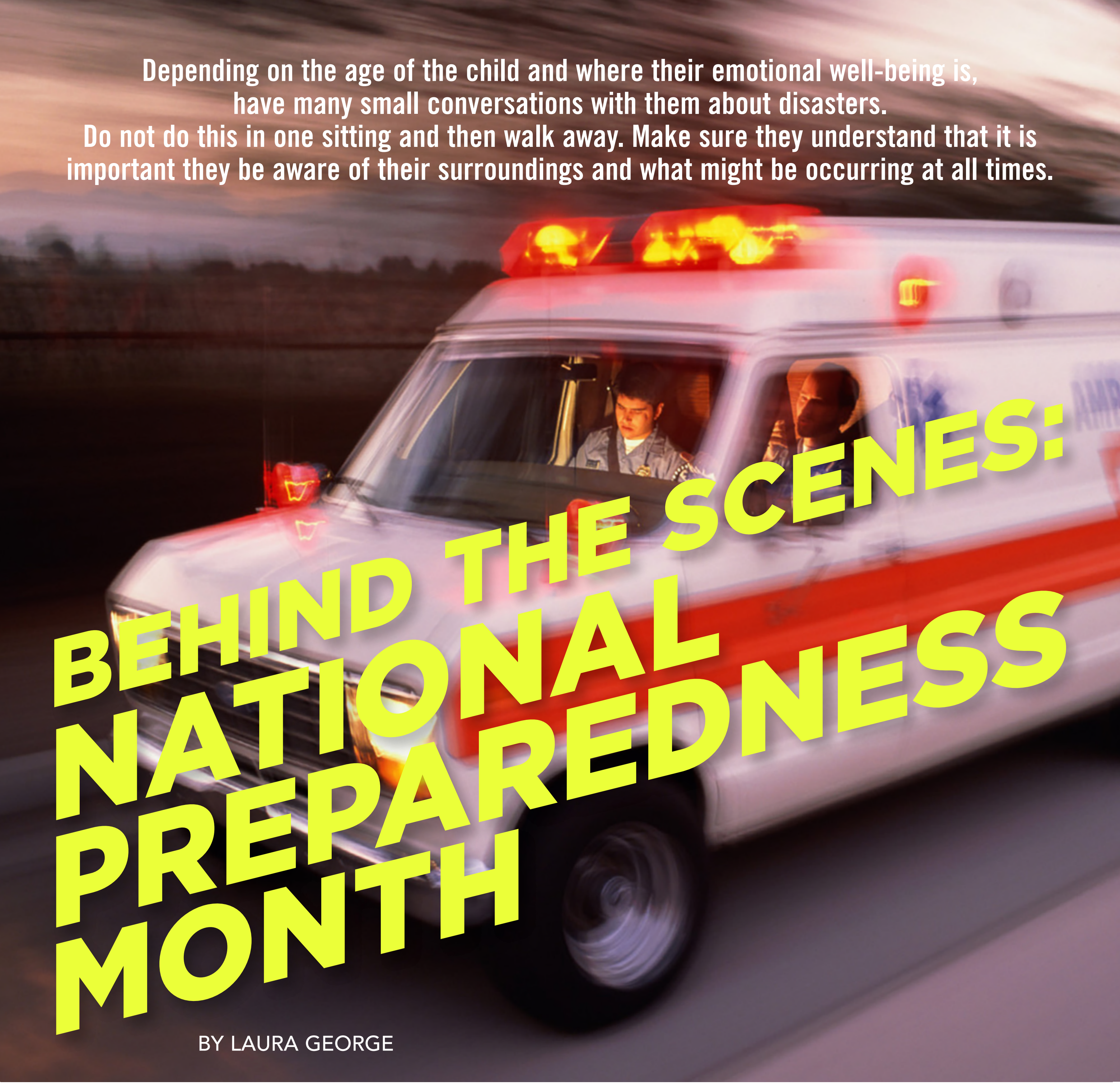
TAKE-HOME MESSAGE

People with intellectual and/or physical disabilities can have great potential. Try to provide many opportunities for them to show you their abilities. You can try taking them to a basketball court to shoot hoops, giving them a puzzle to complete, or giving them paper to shred to learn job-related skills, among many other things. Try not to limit their abilities without letting them first show you all they are capable of.

is beneficial for us to not assume we know everything because of our textbook knowledge, clinical experience, and degree. I think we should practice putting aside our pride and asking for help when needed. Caregivers and teachers are great resources we can rely on for information and perspective to provide the best care for our clients with intellectual disabilities. •

ABOUT THE AUTHOR:

Laura Lawson is an occupational therapy (OT) doctoral student at the University of Tennessee Chattanooga. Occupational therapists help people with disabilities be as independent as possible through rebuilding lost abilities or learning new skills in areas such as personal hygiene, child rearing, working, forming and maintaining relationships, and much more. Laura has always been interested in working in the medical field and fell in love with OT when she learned she can use her creativity and love of science to help people achieve their goals.



Depending on the age of the child and where their emotional well-being is, have many small conversations with them about disasters. Do not do this in one sitting and then walk away. Make sure they understand that it is important they be aware of their surroundings and what might be occurring at all times.

BEHIND THE SCENES: NATIONAL PREPAREDNESS MONTH

BY LAURA GEORGE

If you have ever read some of the other articles I have written for this awesome magazine, Exceptional Parent, *then you know I don't take a traditional approach to the topic. National Preparedness Month occurs every September. As it is the season to reevaluate our preparedness plans, our first thoughts go to the traditional list of supplies that are needed to have for the first 72 hours after a disaster. This can easily be found at* **www.ready.gov/build-a-kit**. *As parents of children with disabilities, we know there are always additional things beyond what is noted in the list that our child will also need to be prepared for in a disaster. One way to prepare them is to get them involved through games* (**www.ready.gov/kids/games**). *I have even played a few of them myself!*

ACTION PLAN: Take time to connect with your local community resources such as the fire, police and health departments. Many times, they will have emergency preparedness fairs where there will be items handed out that can be placed into your family's emergency preparedness kits.

Have you given thought to creating a plan for your child's transportation program, or the school they attend? An extremely thorough resource that I discovered recently, called "Ability Hacker" (www.abilityhacker.com) posted an article on August 6, 2019, called, *School Planning for Kids With Disabilities.* The article presents many scenarios to consider including some sample emergency plans that can be edited and shared with the child's school. Please take a tour through the site as there are many other additional well-written topics on the subject.

Consider also your community gathering places such as a house of worship, community center or library. Learn and understand what plans are in place to protect or evacuate your child should an event happen. Inquire as to the staff's training and procedural knowledge. Church Planting Tactics (www.churchplantingtactics.com/church-emergency-response-plan/) highlights several key points and also offers a sample plan. If one doesn't exist, do not be afraid to get involved and help them create a plan. Remember that you are all learning while protecting your families together.

Sit down with your child and make sure they know some disaster planning basics. Some basic knowledge they should know might be: name, address, phone number and a back-up number as well. If it is an older child than they should know where the parents work, what their routine is, exterior family members and some of the communities that their parents connect with. Depending on the age and the strength of their well-being, they should also have some basic knowledge of finances, companies and passwords that parents work with.

"SIT DOWN WITH YOUR CHILD AND MAKE SURE THEY KNOW SOME DISASTER PLANNING BASICS."

Parents, grandparents, guardians, family and friends can easily create a binder that holds all the personal, medical and financial information it takes to run the house. It should include such things as details about the child's health, paperwork relating to the service animal, where they should go if something happens to you, the birth certificates, mortgage (also handy if your neighborhood is destroyed and you need authorization to get back to your home), passwords, companies who regular bills are paid to, and model/serial numbers for any equipment that is medically inserted or relied upon to be able to conduct their lives independently. Consider including organizations or people that are relied upon to communicate or pass information through such as an interpreter or out-of-state relative. Bonus points are earned if, after creating this book, it is realized that it "recreates" your child and your family completely on paper if everything were lost. Additional points are given if the entire book has been twice scanned or photographed, put on USB key fobs and sent to one in-state and one out-of-state family member or friend.

Depending on the age of the child and where their emotional well-being is, have many small conversations with them about disasters. Do not do this in one sitting and then walk away. Let them know you care. Make sure they understand that it is important they be aware of their surroundings and what might be occurring at all times. In schools, sadly we now have to talk with them about active shooters. By now the school should have communicated its activation plans and if not, approach them directly. Make sure the child knows what to do during a fire, tornado or other drill situation. Learn and know where the school's reunification site will be and create a plan with your child as to how you will find each other. When you go to the airport with your children take the time to pre-discuss safety precautions rather than surprising with the instructions once there. My child and I always wear matching outfits at the airport to make it easy to identify the other in a panic situation.

Take time to connect with your local community resources such as the fire, police and health departments. Many times, they will have emergency preparedness fairs where there will be items handed out that can be placed into your family's emergency preparedness kits. Even better, stop and talk with them. Find out how they can help you help your child. This may include formal introduction of the family to them and/or a "wellness visit" from them, to see the house and specialized equipment that is important to the child's well-being. Take advantage of any fingerprint or DNA programs that are being offered and put those into the binder that you created earlier as well. Reach out to the nearest Center for Independent Living found through the National Council for Independent Living (**www.ncil.org**) or through the Association of Programs for Rural Independent Living (**www.april-rural.org**) or both administered for and by people with disabilities and ask them about their involvement in your community's emergency preparedness plans. They will be happy to help to create a plan and assist with obtaining additional resources for implementation. If it seems weak, offer to get involved and help them connect with the community. (That is what I did and am still doing 13 years later!)

If the child is in a group home, find out what their evacuation policies and procedures are as well as how you will be reunited with them. If reunification is not possible, then make sure the plan is well documented on paper as to where they will receive continued care and how soon the information will be relayed to you. Of additional importance is if knowing if they are living in a young adult community to find out how their ability to live independently is designed and maintained to continue through a disaster, instead of being sent to a medical facility.

After a disaster everyone deserves and has the right to return to life as they know it. While the location may change, the right to keep the family together and continue to live independently is sacred. To borrow the phrase, *Disability Rights, Obligations and Responsibilities Before, During, and After Disasters,* is something every parent, and every community lay person should know when it comes to addressing children in disasters. That quoted phrase comes directly from a line underneath the title of an After-Action Report called, *Getting It Wrong: An Indictment with a Blueprint for Getting it Right*. It was authored by Marcie Roth; June Isaacson Kailes; Melissa Marshall, J.D. and published by the Partnership for Inclusive Disaster Strategies with financial support from Portlight and other financial allies in the disability community of May 2018. It is a 166-page document pointing out weakness in the current status of national emergency design in accommodating people with disabilities in disasters that also offers suggestions, laws and congressional testimonies in addressing the topic (**http://disasterstrategies.org/application/files/3615/2718/6466/5-23-18_After_Action_Report_-_May__2018.compressed.pdf**).

Please read further on current additional legislation headed by Senator Bob Casey's office in Pennsylvania on the Real Emergency Access for Aging and Disability Inclusion for Disasters Act (REAADI) and the Disaster Relief Medicaid Act (DRMA) at (**https://reaadi.com**) which are both going through the House and Senate as we speak.

> ***"EVERYONE HAS THE RIGHT TO RETURN TO LIFE AS THEY KNOW IT. WHILE THE LOCATION MAY CHANGE, THE RIGHT TO KEEP THE FAMILY TOGETHER IS SACRED."***

The REAADI Act was created to address and secure that the disability and elderly communities have equal accessibility to pre, during, and post emergency design activities along with planning for their communities. DRMA addresses the ability to have access to Medicaid insurance when temporarily relocated to another state as a result of the disaster.

With new thoughts on legislation making improvements on the topic, consider also, new tools in the emergency preparedness kit that you create for your child. A brand new favorite tool of mine, which I recently tested at training with the No Town Left Behind organization (**www.notownleftbehind.org**) is the Adapts Portable Transfer Sling (**www.adapts.org**) created to address the concerns of an elderly couple and a triple amputee who were concerned with the ease of evacuation off of a plane. It is extremely portable and easy to use. The creator has provided a discount of 15% (code LGEO15) when purchasing the product. Another great product that is good for keeping medications cool for more than a day where is no power is the "Frio® Insulin Cooling Case (**www.frioinsulincoolingcase.com**) which is reusable, and water activated. Portable oxygen tanks and CPAP batteries may also be some new technology to consider along with a stylish medical alert bracelet that can hide a USB key fob. One more tool is the workbook I created, called, *Emergency Preparedness Planning* (**www.leaninlink/epp-workbook.com**) to collect, keep and educate on all the medical data kept for your child.

In conclusion, no one likes to talk about disasters, let alone those that might include our children, and especially when they are exceptionally wonderful. But it is important to take five minutes each week during National Preparedness Month and follow through on a thought of what should be done to prepare your child and you to be safe from a disaster. Do not concern yourself with how traditional preparedness is designed, instead create a preparedness kit that you are confident in and can easily follow through with. A great emergency preparedness plan is unique and successful. No matter how little is in the kit, it will help benefit and give your child access to a safe future.

Be prepared! Be Alert! Be safe!

ABOUT THE AUTHOR:

Laura George is an Emergency Management Disability Liaison and has been recognized for being a subject matter expert and educator on the topic of emergency design and disabilities. She is also the Inclusive Community Director for No Town Left Behind, is a member of the National Council for Independent Living (Emergency Preparedness committee), works with Miracle Relief Collaboration League (Disaster Assistance), works with Georgia Storm Trooper Network, and is now administrating the FB: InclusiveDisasterNews [https://www.facebook.com/groups/InclusiveDisasterNews/] page launched as a result of Hurricane Dorian. She is also an author, presenter and caregiver.

DISASTERS DON'T
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Paving a Path to Success

BY DANIEL CASTAÑEDA

Kirk Wint is an exemplary athlete who is motivated by his love of sports and an active lifestyle. When people describe Kirk, the first words that pop up in their heads are determined and active. Kirk's active lifestyle creates a perspective that lets him view the world as his playground. Growing up, Kirk wanted to be a pilot; he still holds this dream today.

His aspirations may not seem so distant after his success at the 2019 Special Olympics World Games. Abject poverty stood between him and his desire for inclusion, but it did not break him; his strong will prevailed. Growing up, Kirk had limited function of his legs, but his parents could not afford to buy him a brace that would help him walk. Without the brace, Kirk's condition could not be rectified, and as such, he is not able to walk on his legs. Instead of giving up, Kirk learned how to walk and run using his arms and knees. He successfully ran in his own way at the Special Olympics World Games Abu Dhabi 2019. The 2019 World Games was not his first time representing Jamaica; he has previously competed with Special Olympics

PHOTO PROVIDED BY STEPHANIE CORKETT / SPECIAL OLYMPICS

before. Kirk, a 17-year-old Special Olympics Jamaican athlete, was born with both intellectual and physical disabilities, yet he does not allow them to define who he is.

When he arrived in Dubai for the first time, where his competitions were taking place, he couldn't keep himself from looking up at the sky in awe. He was astonished by the buildings and the lights there, the image of a city that he could have never imagined, right in front of his very eyes.

Kirk has spent years training as a Special Olympics athlete and when he earned a chance to represent Jamaica on the world stage, he didn't take it for granted. Working hard and not giving up, Kirk ran and crossed the finish line of his 50m dash race. He kneeled down, resting his hands on the ground in front of his body. He then slowly dragged his feet towards his arms. He started running, gnashing his teeth and using his arms to support himself. He felt as if his knees were being pierced by sharp arrows. He closed his eyes, he told himself that he could do it and kept moving forward. He opened his eyes and suddenly people were clapping and cheering for him. When he finished, a silver medal was resting on his chest and he wore it proudly. At age 17, he made it.

BLAZING HIS OWN PATH: *(Opposite page)* Kirk runs at the Special Olympics World Games Abu Dhabi 2019; *(Above, left to right)* Kirk trains for a softball competition; Kirk with the Hon. Prime Minister and the Hon. Minister of Sports; and Kirk with Lorna Bell *(left)* and Timothy Shriver *(middle)*.

> *"Kirk winning a silver medal in the 50m dash and a bronze medal in the softball throw were not the only achievements he went home with that day. He had received a shout- out from his idol, Usain Bolt, a fellow Jamaican."*

Kirk winning a silver medal in the 50m dash and a bronze medal in the softball throw were not the only achievements he went home with that day. He had received a shout- out from his idol, Usain Bolt, a fellow Jamaican. Bolt congratulated Kirk on his success; he wrote on Facebook "Kirk Wint Jamaican Special Olympic Athlete won Silver medal in 50m dash at the Special Olympic World Games in Dubai. Respect goes out to all Special Olympians #AnythingIsPossible #DontThinkLimit." Kirk admires Bolt. "Kirk was so excited that he could not at the time and still cannot stop talking about Usain Bolt congratulating him." his mother stated, "That's all he talks about."

Kirk shares a very special bond with his mother, in fact, they are so close that after he ran 50 meters in 15.06 seconds his first words were "I love you, mommy." Kirk's coach, Andre Johnstone, told the International Sports Press Association that his mom is the person he leans on when he is tired, who holds his hand when he is laughing. Not only is Kirk a devoted loving son, but he is also a twin! Kirk and his twin sister share a bond that cannot compare to others and, as twins, they are supportive of each other.

When Kirk is not racing and being paid tribute by his idol, he attends school at the Lyssons Centre of Excellence. At school, Kirk is a bright student who strives to do his best. His teacher describes him as "amiable, easy to teach, fits in very well," and that "there's nothing that he thinks he cannot do."

Kirk's achievements have now opened doors for a wave of new runners to participate in sports they never thought they could be part of. Few people believed in Kirk's ability to achieve this due to his disability, but Kirk, the hard-working person he is, showed the world that there is no definitive way to do something you love. Set the goals you want and have a drive for success, and you can achieve anything your heart desires. Kirk is an inspiration to athletes all around the world showing that determination and being passionate are keys to success. Fans will continue to root for Kirk Wint and look forward to hearing more of his success in the future. •

ABOUT THE AUTHOR:

Daniel Castañeda is a Special Olympics intern and rising sophomore at The George Washington University in Washington, DC.

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MILITARY SECTION

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A NEW SCHOOL FOR YOUR CHILD

HERE'S WHAT YOU SHOULD KNOW

For your kids, moving to a new duty station means changing schools. Here's what you and your children need to know about making the transition a smooth one.

AN INTERSTATE AGREEMENT TO MAKE THE TRANSITION EASIER

The Interstate Compact on Educational Opportunity for Military Children (www.mic3.net) is designed to make the school switch easier for military families moving between states. The Compact is applicable in all 50 states and helps in areas of enrollment, placement and attendance, eligibility and graduation.

ENROLLMENT: The compact makes it much simpler to get started at a new school.

- ***School records:*** *You can obtain a copy of your child's school records from their old school to bring to the new one. Use these until the official records arrive.*
- ***Immunizations:*** *You have 30 days from the time of enrollment to give your child any new required immunizations.*
- ***Kindergarten and first grade:*** *Children can continue in their current class year, even if the new school has a different age requirement.*

PLACEMENT: Your child's progress in their previous school will be recognized.

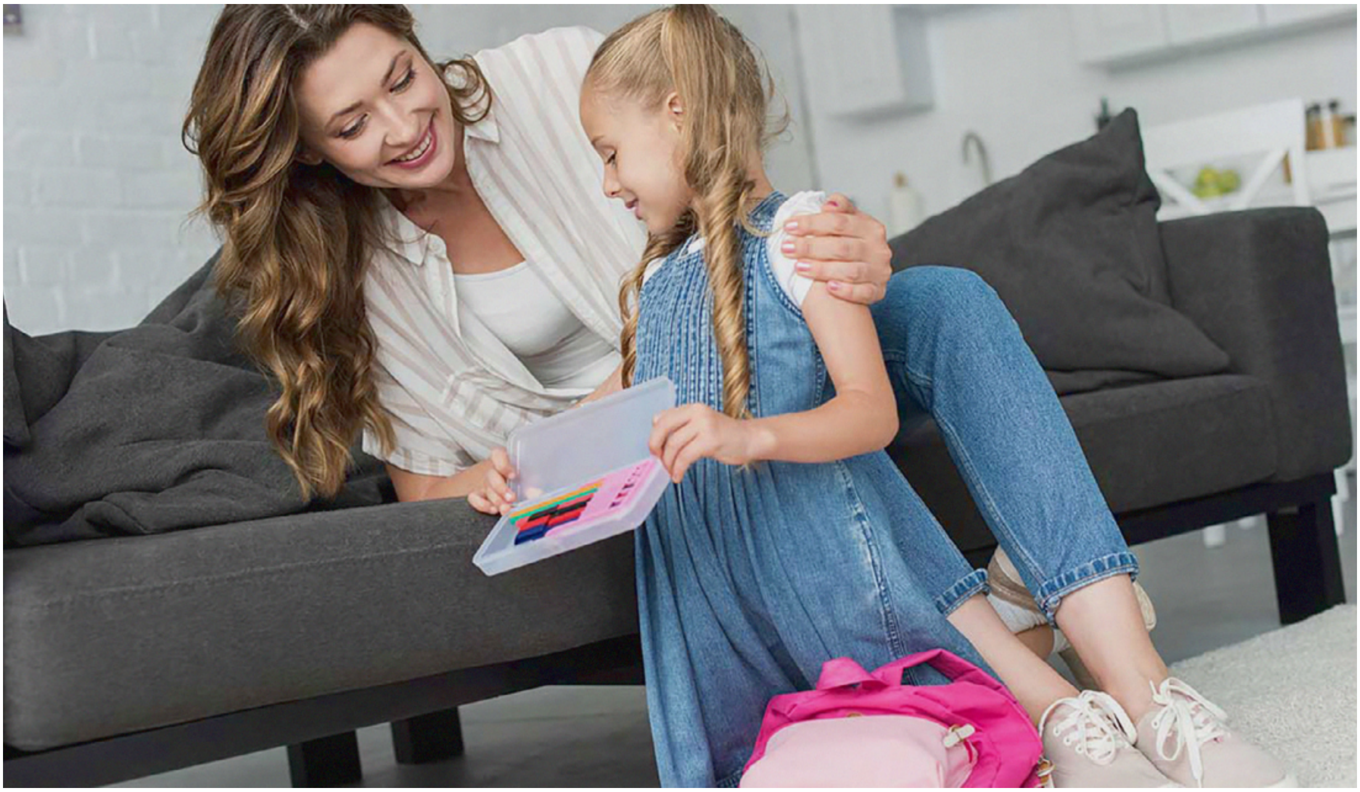
- ***Course and program placement:*** *If your child is already in a program, such as advanced placement, the new school must honor that if they have an equivalent.*
- ***Placement flexibility:*** *Your child won't have to repeat basic coursework if they've taken something similar already.*
- ***Attendance:*** *The Compact enables a student to miss school for military-related reasons.*
- ***Absence related to deployment:*** *Students may request excused absences before, during and after the related deployment period.*

ELIGIBILITY FOR ACTIVITIES: Your child's eligibility for attending school and extracurricular activities won't be affected.

- ***Enrollment:*** *Your child can continue to attend their same school if they're living with a relative, friend, or non-custodial parent during the deployment. The guardian will, however, need a power of attorney to enroll or give permission to participate in school activities.*
- ***Extracurricular activities:*** *Even if tryouts or application deadlines have passed, the school will help make it possible for the child to participate.*

GRADUATION: With the Compact, graduation for kids in high school won't be affected.

- ***Course waivers:*** *If your child has already completed similar*



CHANGE FOR THE BETTER: Switching schools doesn't have to be stressful. No matter what age your children are, the transition can be a positive change for the whole family.

coursework, they can waive courses required for graduation at a new school.

- ***Exit exams:*** *The new school district may accept your child's exit exams and achievement tests required to graduate from their previous school.*
- ***Senior-year transfers:*** *If your student changes school during their senior year, the two school districts will work together to get a diploma from the former school to ensure on-time graduation.*

CHILDREN WITH SPECIAL NEEDS ARE ALSO PART OF THE COMPACT

- ***Special education:*** *If the Individuals with Disabilities Education Act covers your child, they have the right to comparable services provided by their most current Individualized Education Program, or IEP.*
- ***Timeline:*** *Alert your new school and your medical provider at least 30 days ahead of your move. Request a copy of their complete educational and medical records and submit it to the new school as soon as possible.*
- ***Reevaluation:*** *The new school system may reevaluate your child's eligibility for special education services to determine a new IEP.*
- ***The Education Directory for Children With Special Needs:*** (apps.militaryonesource.mil/MOS/f?p=EFMP_DIRECTORY:HOME:0) *The directory provides the information you need to make informed decisions about education and early intervention services.*
- ***Exceptional Family Member Program:*** *Your local installation EFMP Family Support staff can help you identify and access programs and services related to education, outreach, local school and early intervention services.*
- ***Special Needs Consultants:*** *Special needs consultants can be accessed through Military OneSource Exceptional Family Member Program Resources, Options and Consultations, or EFMP ROC* (www.militaryonesource.mil/confidential-help/specialty-consultations/efmp-roc). *Consultants are available by phone or video to help you navigate the medical and educational needs of your family and connect you with military and community-based support. Schedule an appointment by visiting Military OneSource or by calling 800-342-9647. Military families can make an appointment 24/7 by live chat or phone. Special needs consultations are available via phone or video session.*

Switching schools doesn't have to be stressful. No matter what age your children are, the transition can be a positive change for the whole family.

If you have questions or need help, Military OneSource has military-trained consultants in education (www.militaryonesource.mil/confidential-help/specialty-consultations/education) and special needs (www.militaryonesource.mil/confidential-help/specialty-consultations/special-needs). Call 800-342-9647 at any time to schedule an appointment. OCONUS/International? Visit www.militaryonesource.mil/international-calling-options for calling options.

– Military One Source

EASE BACK-TO-SCHOOL TRANSITIONS WITH A MILITARY ONESOURCE EDUCATION CONSULTANT

Whether you are considering going back to school, your 5-year-old is starting kindergarten, or your 20-year-old is heading back to college, an education consultant at Military OneSource can ease back-to-school transitions. These free and confidential one-on-one sessions with a professional knowledgeable about education resources can give both your child and you a shot of confidence.

HOW CAN EDUCATION CONSULTANTS HELP YOU?

Consultants look into education options for you, refer you to education services that best meet your needs and connect you to a wide variety of resources. They can answer your questions and provide information about services and benefits. You can arrange a consultation for help with:

- *Referrals to in-home tutors and tutoring centers in your area*
- *Public and private school information if your family is moving*
- *Choosing a college based on your desired degree or specific request*
- *Sources for financial aid and scholarships*
- *Profiles on specific colleges and their credentials*
- *Finding military-friendly schools and institutions that allow you to transfer previous college credits*
- *Help getting your credentials converted and diplomas translated to meet specific state or country requirements*
- *Contact information to help eligible military spouses find tuition assistance for certification through the MyCAA Scholarship (*https://mycaa.militaryonesource.mil/mycaa*)*
- *Information on the SAT and ACT test preparation programs.*

WHO IS ELIGIBLE FOR SERVICES?

An education consultant can help eligible service members and family members *(*www.militaryonesource.mil/confidential-help/non-medical-counseling/military-onesource/eligibility-for-confidential-non-medical-support-services*)*. For example, they can help you with information about colleges and financial aid for yourself – and they can help find a tutor in the area for your child.

Connect with a Military OneSource education consultant *(*www.militaryonesource.mil/confidential-help/specialty-consultations/education*)* to access the information and resources you need to meet your education goals. Set up your consultation by calling Military OneSource at 800-342-9647. OCONUS/International? Visit www.militaryonesource.mil/international-calling-options for calling options.

– Military One Source

ONE THING I'D LIKE TO SAY TO ALL OF YOU IS YOU'RE NOT CRAZY.

I had a complete meltdown with PTSD (posttraumatic stress disorder). I thought I was losing my mind. I'd never been out of control before, and it was hard to admit I needed help, but I wanted my old self back. I've gotten that and more. I'm strong. I'm healthy. I have tools, I have knowledge, and I have strength and courage to deal with it. I'm doing just fine.

RON WHITCOMB SGT US ARMY 1968 - 1969 SQUAD LEADER, VIETNAM

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PUZZLES & CAMO SHELLY HUHTANEN

Comfort in a World of Change

Regression through transition involving our kids with autism is real and parents and their siblings brace themselves on how it is going to manifest itself. It can be in ways that we've seen before or in ways that are entirely new.

It's been almost two months since we have moved and I'm amazed at how well Broden has transitioned to where we live now. I give credit to Broden being able to start therapy in a new ABA clinic. Watching how Broden has acclimated to his new surroundings reminds me how crucial it is for access to care for our kids. Each time we move, we gamble with our children's progress and frankly, it can be scary.

Each week that goes by, Mark and I sigh in relief. We look at each other and say, "We're out of the woods, right?" Regression through transition involving our kids with autism is real and parents and their siblings brace themselves on how it is going to manifest itself. It can be in ways that we've seen before or in ways that are entirely new. Our family knows this quite well.

The week before Broden was supposed to start therapy, I walked by his room to see that he had smeared poop on his wall and his sheets. I hadn't seen this behavior in about eight years. What I also noticed that was new was that he figured out pretty quickly that he wasn't going to sit around while he watched me clean the mess he created.

DON'T LEAVE US HANGING: Watching Broden reminds me how crucial it is for access to care for our kids. Each time we move, we gamble with our children's progress and frankly, it can be scary.

After he helped me clean up the mess, he pulled the sheets off the bed and I had him carry the sheets to the washer. After receiving a lesson in laundry, Mark and I told him, "You do this again, you'll clean it up again." Broden gave us a look like a typical teenager does when he knows he's been outsmarted. He turned around and marched back upstairs. Mark and I quietly gave each other high fives and nodding to each other that autism wasn't going to win that day.

The next week when clinic started, I could see a shift in Broden. He was experiencing the structure that he has had most of his life. Discreet trial is how he learns. It is what he knows. It is comfort to him. The other day, his tutor told me he had already figured out the afternoon routine for going home at the end of therapy. He knows that initials of children are called on the tutor's walkie talkies to notify them that their parent has arrived. Broden's initials had not been heard yet, but he turned to his tutor and said, "My mom is here." About two minutes later, his initials were called and he started to pack up. For him, comfort is in routine and knowing what is going to happen next. For military life, it's the little things we can count on. For him, knowing that I was going to be there waiting for him makes a difference.

Two weekends ago, we started decorating his bedroom walls. He had white letters that spell his name. These letters have been hung on his wall since he was a baby. In Texas, he used to stand on his bed, take them off the wall and chuck them across the room. We have a template that we tape to the wall to guide us on where to hammer the nails. Once the template was up, Broden looked up and smiled. He knew what was next. After Mark and I hammered the nails, we did something we haven't done before. We told Broden to grab the letters, stand on the bed and hang them on the wall himself. He grabbed an "N", then an "O" and continued on until his name was complete. He sat back down on his bed and looked at his name on the wall, smiling.

In the end, Broden is more like us than different. We all strive for comfort and are a little bit more at ease if we have an idea of what is going to happen next. I smile a little more when I open a box in our home and pull out things that surrounded me at the last place we lived. In the military, our life is filled with so much change, it's nice when we can experience comfort through routine. For our son, maybe it's knowing that his name will be on his wall. •

PUZZLES & CAMO

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

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