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EXCEPTIONAL PARENT
MAGAZINE
OCTOBER 2018
\$7.95

BETTER OUTCOMES:

**RAISING EXPECTATIONS *for*
YOUTH *with* DISABILITIES**

INSIDE:

**TRANSITIONING *from*
HIGH SCHOOL *to* EMPLOYMENT**

THE ANNUAL ISSUE:

EMPLOYMENT & TRANSITION

AND: AADMD

**GOOGLE IS
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PLUS: NEW MODELS

**THE RETAIL DIVE
and TRANSITIONING
to EMPLOYMENT**





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ON OUR COVER

A successful transition for individuals with disabilities from school to school, college, or work requires collaboration. Students play an important role in planning their transition, and should be included throughout the process. EP's Annual Employment and Transition Issue features several informative articles about ensuring better outcomes in transition planning. Coverage begins on page 18.

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FROM OUR FAMILIES... TO YOUR FAMILIES

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AS TOOLS FOR
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FOR THE SPECIAL
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Information and Support for the Special Needs Community
VOLUME 48 ISSUE 10 ■ ESTABLISHED 1971

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

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 www.subscribe.ep-magazine.com

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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 ©2018 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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Note from the Editor-in-chief: EP World, Inc. advocates for the dignity of all citizens with disabilities including the use of "people first language" where possible. We do not normally edit articles and submissions that do not reflect this language, therefore, at times, readers might see alternative nomenclature.

— Rick Rader, MD

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



Tom Cheetham, MD

One of Tom’s passions was “knowledge spread.” He was instrumental in creating and disseminating the first clinical “guidelines” for primary care physicians. This was a comprehensive collection of clinical insights, protocols, procedures, milestones, “red flags” and benchmarks in the approach to patients with a variety of syndromes – Down syndrome, Fragile X, Prader-Willi, Smith-Magenis syndrome, and others.

In 1994 I was a newcomer to the field of intellectual and developmental disabilities. I had responded to a seductive ad in the *Journal of the American Medical Association* and became the Director of the Habilitation Center at Orange Grove in Chattanooga Tennessee. I was responsible for creating innovative programs in healthcare for patients with special needs. I was enthusiastic but quickly realized I knew nothing about this marginalized population and less about how to address healthcare disparities.

It quickly became apparent that I needed to immerse myself in the mainstream, learn the lingo and formulate a foundation to do some good.

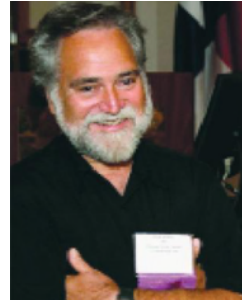
The first conference I attended was the annual meeting of the American Association of Mental Retardation (now the American Association on Intellectual and Developmental Disabilities). It was overwhelming. There were multiple tracks, workshops, committees, seminars and special interest groups. I found a break out session with a focus on nursing, healthcare and disparities... and bingo! After the lecture, there was a robust period of questions and answers. There was one individual who seemed to be asking the most interesting, provocative and challenging questions. He wanted to know “what I wanted to know,” and that was, “why continue to do things that don’t work?”

I knew I had to hitch my wagon to this guy. I knew I had to shadow him, befriend him and handcuff myself to him. He was going to be the solution to my problem of

not knowing what I didn’t know. This was Dr. Tom Cheetham, a Canadian family practice physician working in a large institution somewhere in the boonies of Ontario. Tom knew his stuff. He was a visionary, a clinician, and an advocate. We became friends, colleagues and disrupters for the next 24 years until his passing in 2018.

I loved his story, his path and his journey. It was the stuff of movies.

Tom started out where everyone in the field should start out—as a house manager



dedicated to improving the lives of people with intellectual disabilities. He had aspiration beyond managing a group home. At that time, a new, innovative medical school was created. McMaster University threw out the traditional model of both medical

education and the criteria of selecting medical students. While the candidates had to demonstrate that they had the intellectual “staying power” to make the grade (even though they didn’t give grades) they didn’t have to have the traditional “premed” background. Whatever it was they saw in Tom, they made the right decision and admitted him to the inaugural class. Tom Cheetham, House Manager, became Tom Cheetham, Medical Doctor. Tom’s clinical acumen was coupled with the lessons he learned as a house manager and he emerged with the skills, insights, intuition and understanding that no other physician could be so equipped.

Over the next few years Tom and I collaborated on several projects involved in providing comprehensive community based medical care, medical education, biomarkers and advocacy.

One of Tom’s passions was “knowledge spread.” He was

instrumental in creating and disseminating the first clinical “guidelines” for primary care physicians. This was a comprehensive collection of clinical insights, protocols, procedures, milestones, “red flags,” and benchmarks in the approach to patients



A VISIONARY, A CLINICIAN, AND AN ADVOCATE: “We became friends, colleagues and disrupters for the next 24 years until his passing in 2018. I loved his story, his path and his journey. It was the stuff of movies.”

to a bunch of guys with “mental retardation” (the accepted language at the time). He served his apprenticeship with no degree, no formal training and no guidelines. Tom was a high school drop-out.

Over the next few years Tom became

with a variety of syndromes – Down syndrome, Fragile X, Prader-Willi, Smith-Magenis syndrome and others. The “Guidelines” formed the foundation of a clinical toolkit that would enable clinicians to provide comprehensive care, including disease prevention and wellness, to patients that had previously been rejected by community-based physicians.

Years later, I recruited Tom to become the Medical Director of our clinic at the Orange Grove Center in Chattanooga. While Tom was a respected leader in the field, as a Canadian-trained physician, he was subject to sitting for and passing a barrage of exams required of all foreign-trained doctors. Rather than having Tom spend six months reviewing basic medical courses that he had taken 40 years ago, we were able to get him a rare exemption based on being able to identify him as having unique and rare skills and

“Tom spent several years raising the bar of medical care to our challenging patient population and created deep personal relationships with both the patients and the staff at Orange Grove. His Volvo with the Ontario license plates was often a lone figure in the parking lot after midnight.”

knowledge that would be of benefit to the United States. Obtaining one of these special visas was the equivalent of winning the lottery, but his credentials, reputation, skills and experience paved the way. He was granted an exemption by the United States Department of Homeland Security.

Tom spent several years raising the bar of medical care to our challenging patient population and created deep personal relationships with both the patients and the staff at Orange Grove. His Volvo with the Ontario license plates was often a lone figure in the parking lot after midnight.

Tom was recruited back to Toronto to assist with the province’s program of closing down the institutions. He was assigned to be the liaison between the primary care physicians and the Canadian medical authorities.

Following this challenge, he entered into the final phase of his career and assumed the position as the Assistant Commission for Health for the Tennessee Department of Intellectual and Developmental Disabilities. Over the several years he held this position, he became a champion for elevating the primary care for people with intellectual and developmental disabilities. He was appointed to the Vanderbilt University faculty where he contributed to the creation of the respected Vanderbilt University Toolkit for Primary Care Physicians. He continued in his commitment to train, inspire and

encourage medical students to learn both the joys and challenges of caring for patients with complex healthcare needs.

For his efforts, accomplishments and tireless commitment, he was awarded the inaugural Spirit of the Surgeon General’s Award by his friends and colleagues at the American Academy of Developmental Medicine and

Dentistry.

Tom’s loss is felt by everyone he touched over the years. His teaching, advocacy and initiatives will benefit the disability community for decades to come. For me, personally, he will always be that voice from the back of the lecture hall that announced to me that “here’s this guy who would challenge the status quo, and could possibly get me going down that same road.” Thanks, Tom. •

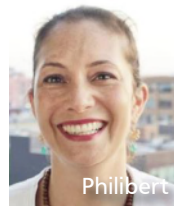
ANCORA IMPARO

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

Council for Exceptional Children Announces General Session Speakers

The Council for Exceptional Children (CEC) recently announced that Carla Tantillo Philibert and Dan Habib will be the CEC 2019 Convention & Expo General Session Speakers.

Carla Tantillo Philibert is a recognized expert on social-emotional learning (SEL), mindfulness, and yoga practices in schools. Philibert will focus on SEL and building strong teacher-student relationships. Dan Habib is an award-winning filmmaker and presidential appointee. Habib will highlight current trends in education that point to a future in which people of all abilities are included.



Philibert



Habib

CEC’s Convention & Expo is a professional development event for all educators. “When selecting general session speakers, we look for speakers who are engaging and motivational. We want to bring our convention attendees exciting content that makes them reflect on their profession,” shared Convention Co-Chair David Bateman.

Convention Co-Chair Cindy Perras added that she is excited that Dan Habib accepted CEC’s invitation to speak. “Dan Habib is inspirational and his work strongly aligns with CEC’s mission and core value of inclusiveness.”

The convention will be held in the Indiana Convention Center in Indianapolis, from January 30 to February 2, 2019. CEC attracts more than 4,000 educators from around the world to its annual meeting. The 2019 conference will feature almost 700 sessions covering public policy, arts in special education, instructional strategies for students at risk or with learning disabilities, technology, cultural and/or linguistic diversity, and much more.

The CEC is the professional association of educators dedicated to advancing the educational success of children and youth with exceptionalities that accomplishes its mission through advocacy, standards, and professional development. Learn more about CEC at www.cec.sped.org •

WHAT'S HAPPENING

ECLC of New Jersey's Special Education School Receives Grant from Investors Bank

ECLC of New Jersey's Chatham school for students with special needs received a \$1,500 grant from the Investors Foundation for a new Sensory Room to provide therapy for the growing number of students with autism.

"It was a great pleasure to personally see the great work and love given to the students of ECLC," said Investors Assistant Vice President and Chatham Branch Manager Gregory Schmidt. "I was honored to be able to provide the Grant on behalf of Investors Bank and Investors Foundation."

ECLC is celebrating its 30th year in a former Chatham public school building. During that time, the student population has dramatically changed, requiring new tools and techniques to support them. Three decades ago, ECLC students primarily were classified with learning disorders, such as dyslexia. Today, about one-third are diagnosed with autism or another disability with a behavioral component.

For students with autism and certain other disabilities, the everyday world at times can become overwhelming. Walking into a classroom might seem like walking into a crowded nightclub, with flashing lights and booming music. At any point in the day, students may start to feel overloaded and "dysregulated." In contrast, there is another group of students who are "under-reactive."

These students need to increase their alertness and activity level to succeed at school.

The Sensory Room creates a new, permanent space to help students smooth out their emotional states. It creates an atmosphere of soothing calm and quiet. The room is a "Snoezelen Room" and delivers stimuli to various senses, using dim, lighting effects, color, gentle pressure, sounds, music, scents and vibration.

A therapist, teacher, or aide always accompanies students when they use the room. Students come to relax or take a break from class, when they are over-stimulated or during times of stress. They can also earn time in the room as part of their behavior plan. Each student has a customized list of activities and uses for the Sensory Room.



SENSING A NEED: Elected officials showed their support for the ECLC Chatham school.

ABOUT ECLC



ECLC stands for offering "Education, Careers & Lifelong Community" to children and adults with special needs, including autism, Down syndrome and other developmental disabilities. ECLC was launched in 1970 as the "Early Childhood Learning Center" by a group of parents and others to provide early-intervention services to a handful of pre-school children. Today, ECLC serves more adult clients than students and that number increases with each graduating class. ECLC is an accredited, nonprofit, educating students ages 5-21 with severe learning and/or language disabilities, autism spectrum disorder, Down syndrome or multiple disabilities at two schools. Visit: <http://www.eclcofnj.org/>

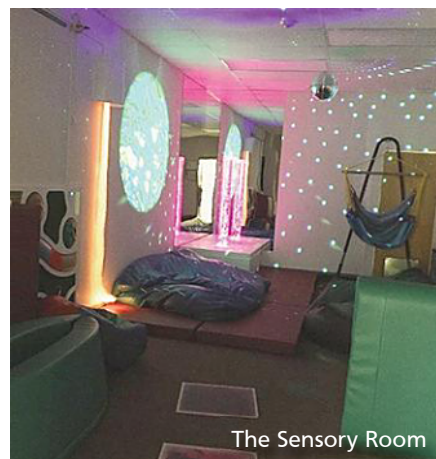
BREAKING FOR SUCCESS : THE BENEFITS OF A SENSORY ROOM

The room is dimly lit when in use and quiet, calming music is played. A bubble tube light, with flowing bubbles and soft changing lights provides a multi-sensory calming environment. The equipment is highly specialized. It includes a gentle "squeeze machine" that provides deep pressure, controlled by the student. A contour "relax" chair allows students to sit in a semi-reclined position on a soft surface. There is a hammock swing to offer slow, rhythmic swinging and a gentle squeeze. Students can climb into inflatable canoe-shaped seats, which provide a steady hugging pressure. Weighted blankets are gently placed on stu-

dents to provide additional pressure.

"As the student population has changed, our school has proactively addressed their needs," said Principal Jason Killian. "We are always looking for new ways to support our students and help them thrive. We have found tremendous success with providing sensory breaks and sensory input to help students regulate and succeed in school."

Parents of children with special needs and any member of the public can arrange for a visit and tour ECLC's school at 21 Lum Ave., by contacting Principal Killian at jkillian@eclcofnj.org or (973-601-5410).



The Sensory Room

WHAT'S HAPPENING

CDC Releases Guideline to Improve Care of Children with Mild Traumatic Brain Injury

The Centers for Disease Control and Prevention released new clinical recommendations for healthcare providers treating children with mild traumatic brain injury (mTBI), often referred to as concussion.

The CDC Guideline on the Diagnosis and Management of Mild Traumatic Brain Injury Among Children, published today in *JAMA Pediatrics*, is based on the most comprehensive review of the science on pediatric mTBI to date—covering 25 years of research.

“More than 800,000 children seek care for TBI in U.S. emergency departments each year, and until today, there was no evidence-based guideline in the United States on pediatric mTBI—inclusive of all causes,” said Deb Houry, MD, MPH, director of CDC’s National Center for Injury Prevention and Control. “Healthcare providers will now be equipped with the knowledge and tools they need to ensure the best outcomes for their young patients who sustain an mTBI.”

Offering 19 sets of clinical recommendations that cover diagnosis, prognosis, and management and treatment, the CDC Pediatric mTBI Guideline is applicable to healthcare providers in all practice settings.

“We have heard from healthcare providers that they want and need consistent, current, and evidence-based guidance for diagnosing and managing mTBI. And this guideline can help,” said



FORWARD PROGRESS: The hope is that this Guideline will lead to future studies and guidelines that further advance the care of patients of all ages with mTBI and other serious brain injuries.

Houry. “However, we also designed the guideline so it can help inform efforts aimed at supporting families, sports coaches, and schools—who are all integral to keeping children safe and healthy.”

In developing the guideline, CDC followed a rigorous process. An extensive review of scientific literature, as well as feedback from clinical experts, the public, and partner organizations informed the development of the recommendations. The hope is that this Guideline will lead to future studies and guidelines that further advance the care of patients of all ages with mTBI and other serious brain injuries.”

To help healthcare providers implement the recommendations, CDC developed supporting tools and materials. Ranging from screening forms to assess young patients to discharge instructions and recovery tips for parents, these resources will help healthcare providers take action to improve the care of young Americans with mTBI. These tools and materials are available at www.cdc.gov/HEADSUP.

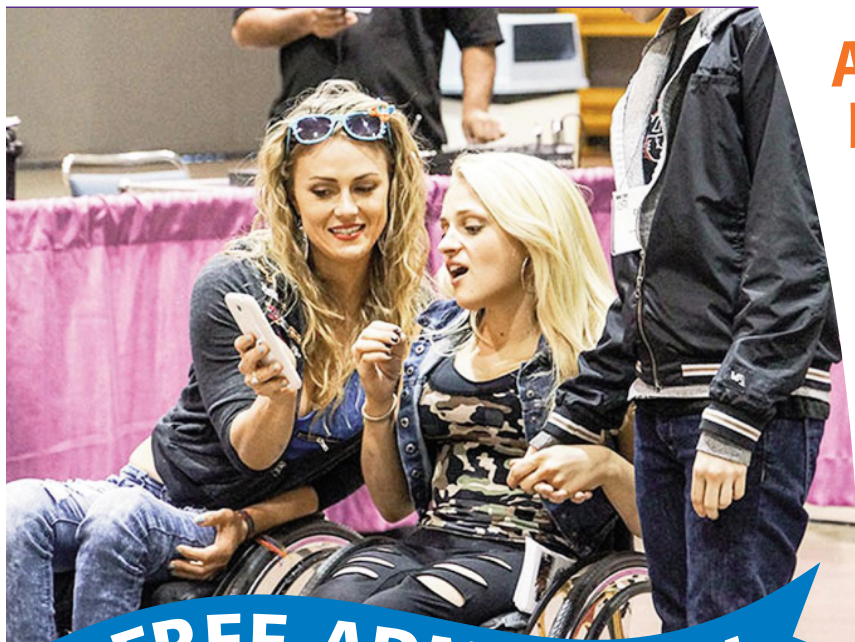
As the nation’s leading public health agency, CDC is committed to helping those at increased risk for mTBI and other serious brain injuries. There is not a one-size-fits-all approach to protecting young Americans from these injuries. However, this guideline is helping fill a critical gap aimed at improving the care of this vulnerable population.

CDC works 24/7 protecting America’s health, safety and security. Whether disease start at home or abroad, are curable or preventable, chronic or acute, or from human activity or deliberate attack, CDC responds to America’s most pressing health threats. CDC is headquartered in Atlanta and has experts located throughout the United States and the world.●

HEADS UP: NEW CLINICAL mTBI RECOMMENDATIONS

The CDC Pediatric mTBI Guideline outlines specific actions healthcare providers can take to help young patients and their parents/caregivers, including five key practice-changing recommendations:

1. Do not routinely image pediatric patients to diagnose mTBI.
2. Use validated, age-appropriate symptom scales to diagnose mTBI.
3. Assess for risk factors for prolonged recovery, including history of mTBI or other brain injury, severe symptom presentation immediately after the injury, and personal characteristics and family history (such as learning difficulties and family and social stressors).
4. Provide patients and their parents/caregivers with instructions on returning to activity customized to their symptoms.
5. Counsel patients and their parents/caregivers to return gradually to non-sports activities after no more than a 2-3 days of rest.



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THE RIGHT TOUCH



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allow progression through grades 1 and 2 Braille. Mode 1: Letters and Dots, Mode 2: Letters only, Mode 3: Letters and Words. Play one sound tag at a time, place a tag on the target area and press down to activate. For privacy, headphones can also be used. Custom Braille or other tactile symbol sound tags can be created with blank tags.

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LOLLACUP

Lollacup is a sippy cup with a weighted straw that allows children as young as a nine-month-old to easily and effectively drink from the straw. The flexible straw is narrow, which helps control the flow of liquid, and is valve-free. The weighted end keeps the straw anchored in the liquid, even when the cup is tipped. The cup's two handles are designed to be easily gripped by children's hands, and can be removed to make it cup holder-compatible. The Lollacup was designed without valves as an alternative to spill-proof cups that have valves, which make them both difficult for young children to drink from and for parents to clean. This construction allows for the promotion of correct mouth postures, aiding those with speech delays and oral malformation. Latex-Free, BPA Free, Phthalate-Free.

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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>.

NEW PRODUCTS



AVAZ LITE

The Avaz Lite is an Augmentative and Alternative Communication (AAC) mobile app designed to help children with autism who are non-verbal develop their language and communication skills. This app allows children to communicate through either picture-based, or text-based messages. When in picture mode, children can access an extensive list of symbols representing core words and tap the symbols they want to enter into the message box. When they are in text mode, they can type out their message, word by word, using the on-screen QWERTY keyboard. When they are done, they can tap on the message box to have their message spoken aloud. Avaz Lite also offers quick access to frequently used sentences, a vocabulary

search bar, picture-assisted and text-assisted word prediction, as well as many other customizable features. Parents and caregivers can add multiple words into Avaz Lite, set vocabulary words with photographs or voice recordings, and track the child's communication development through graphs and charts. Avaz Lite has more than 15,000 symbols in its Symbolstix vocabulary and four Ivona voices to choose from. It is compatible with iPad and requires iOS 9.0 or later.

AVAZ INC.

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BITE BANDS

Bite Bands are super absorbent necklaces designed for children ages four and up with autism, sensory processing disorder, and attention deficit-hyperactivity disorder who need to chew or bite for calm and focus. Unlike plastic chew necklaces, these terry cloth bite bands soak up drool, keeping shirts dry even after extended periods of chewing. Bite Bands also exercise oral motor and facial muscles to prepare kids for good eating habits. Includes a set six bands, one of each color: red, yellow, blue, green, purple, and orange. Made from a polyester/cotton blend. Pack of six. Measures 12 inches in length. Use with adult supervision. Machine wash and air dry.



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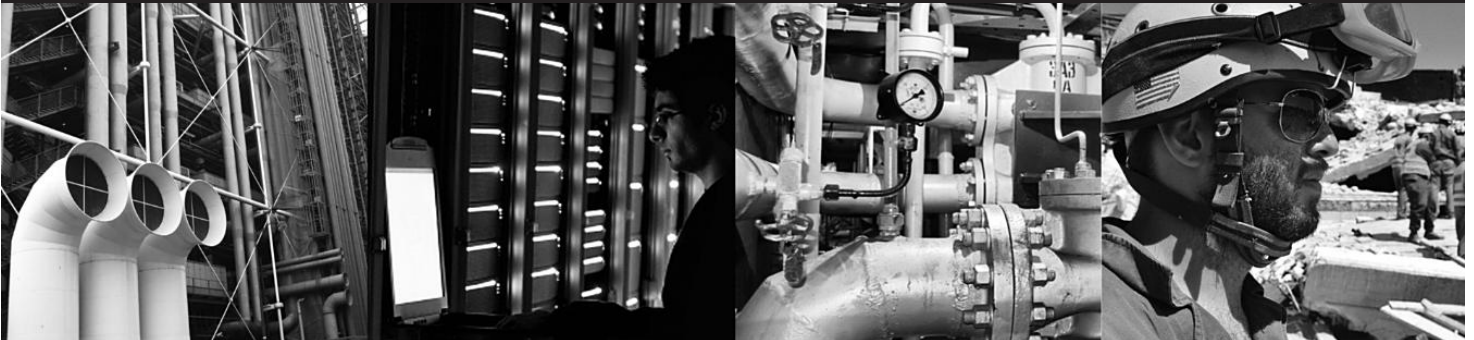
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Have a Healthier Halloween!

One statistic estimates that the average Jack-O-Lantern bucket holds about 250 pieces of candy! That could add up to 3 pounds – and a whopping 9000 calories!

It is that time of year again, a holiday children equate with eating candy. And holidays no longer are restricted to a single day, for they tend to spill over into weeks before and after. So, you need an action plan to get through October—as well as the last months of the year for the other holidays—without packing on additional pounds. It is also important to remember that you are helping to shape habits in your children. Make them healthy habits.

Let's start with how to increase the amount of activity you can incorporate into the holiday. Consider visiting a pumpkin patch or cornstalk maze where the family can walk together. Maybe you can come up with a haunted hike, or take a walk or bike ride through the neighborhood to see all of the fun decorations that people put up. Make it into an "I Spy" game to keep the kids engaged and extend the activity time.

When it comes to handing out candy, wait until the last minute to buy anything so the temptation is not sitting around you. Also, buy a candy that you do not particularly like so that if you have any leftovers, you are not tempted when you know it is sitting in a bowl in the kitchen. Store any treats out of sight, and even better, in an inconvenient location that allows you to think for a couple of extra seconds if you really want to snack on sweets or if you can talk yourself into a piece of fruit.

While you may not be the most popular house on the block, consider handing out healthier snacks. If you have the means to make a homemade treat, this can be a fun activity to do with your children as well as a way to limit how much candy other children are getting. You could make a trail mix that has

chocolate chips, or a Chex mix, or animal crackers, or even homemade baked goods.

Perhaps you can even stray from the expected edible treats all together and hand out inexpensive toys! Bouncy balls, jump ropes, or hacky sacks are inexpensive, small, and encourage physical activity. Chalk or crayons are also small and inexpensive, and encourage creativity. Glow sticks are just fun! The kids will still like getting these goodies, especially when they have a bag full of sugary treats. One statistic estimates that the average Jack-O-Lantern bucket holds about 250 pieces of candy! That could add up to 3 pounds – and a whopping 9000 calories!



limit the amount of candy that can be consumed. Taking in protein and fiber is always a way to make you feel more satisfied, and less likely to make you eat mindlessly. This could be tricky (pun intended!) with the timing of trick-or-treating, but it will prevent being hungry when being handed pounds of candy.

Be picky with which candy you snack on, and teach your children to do the same. Choose the fun size over the full size, so that if you are not fully satisfied, you can have another. There are denser candy bars that



have more calories, and there are options that have nuts or fruit that take up space from basic sugar.

After the late-October holiday is over, think about how much candy you want sitting around the house. Consider giving it away – there are several charities that take donat-

ed candy for deployed troops or children's hospitals. Let your kids decide what they would like to do so they can also feel good about giving it away.

Consider devising a game for your kids to get rid of excess candy without eating it. You could make a trade-in game that allows them to trade candies for non-food treats. Maybe they would want to go to a movie, or stay up for half an hour later, or get 10 more minutes of screen time. Whatever else could be considered a treat in your home. More candies traded in can mean bigger prizes, and this would incentivize them to not eat all the tempting sugary sweets!

Lastly, enjoy the holiday! Halloween only happens once a year. Have fun! Enjoy some treats! Teach your children that candy is just that – a treat, not a norm, so they can see the fun in celebrating. Then get back on track with good nutrition. •

THE FITNESS PRIORITY

Kristin McNealus, PT, DPT, ATP received her Masters in Physical Therapy from Boston University then went on to earn her Doctorate in Physical Therapy from MGH Institute of Health Professions. She has been a staff physical therapist on inpatient rehabilitation for people with spinal cord injuries at a number of hospitals in Southern California, as well as Director of a community adaptive gym for people with neurological injuries. She is a member of the International Network Spinal Cord Injury Physiotherapists, and has contributed to the APTA Guidelines for Exercising with a SCI. She has completed three marathons, and 25 triathlons, including the Ironman! SCI Total Fitness is designed to promote health and wellness for people with physical disabilities.

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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.

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We've introduced a range of new content to the website, including *In This Issue* that highlights selected content from our latest issue, and

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

Google is not God!

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

Recently one of us (HBW) was confronted by a dental student who claimed that we mistakenly marked her response wrong on a test question. She had checked her answer with Google and reported she was right. We consulted the law school graduate faculty member who wrote the question and told us that, “Google was wrong” and explained the reasoning. We then spent time fruitlessly trying to explain to the student about the rationale for the proper answer and that “the computer was not God.”

Unfortunately, the reality is that in today’s world, we raise our children from the time they can hold an animated tablet and can press action buttons (while sitting in their carriage) until that two year old becomes an adult. The “baby” computer is more than a babysitter, companion and teacher. **It becomes the child’s “world” with seemingly all the answers and leaves one with a diminished need for direct companionship, a drive to explore other sources of information and discover the world beyond the immediacy of their own environment.** In addition, texting is not an opportunity to hear voice tones, innuendos and the real feelings of others. Also, it may well be a mistaken response as the computer “corrects” words that are misspelled.

WHAT DOES THIS HAVE TO DO WITH YOUNGSTERS WITH SPECIAL NEEDS?

The impact of computer usage on the youngster with disabilities, as they grow into their teen years and beyond, is the same as for all children; **only more so.** The over challenged parent with a child with special needs may rely to a greater extent on “the computer as a child-sitter” in an effort to satisfy the needs and demands of other members of the household. Impact on the child with disabilities may well be limitations of inter personal experiences, exag-

eration of “the computer fictionalized world,” lack of inter-personal communication and just about any of the multitude of stimuli which transform a youngster into an adult.

“Analyses indicated that participants with disabilities, mainly the ones with motor disability showed an increased use and dependence on technology. Although this suggests the importance for young people with disabilities of the Internet use, it also indicates that disability, especially motor disability may be a vulnerability factor for an abusive use.”¹

“Children with autism spectrum disorders (ASD) are uniquely vulnerable to various brain-related... Why? Because a brain with autism has inherent characteristics that screen time exacerbates. In truth, these impacts occur in all of us, but children with autism will be both more prone to experiencing negative effects *and* less able to recover from them; their brains are more sensitive and less resilient.”²

“Any child can become “addicted” to computer games, but kids with ADHD seem to be at particular risk. Many of them have poor social or athletic skills, and this doesn’t matter in the world of computer games. Such games level the playing field for children with ADHD. And kids bothered by distractibility in the real world are capable of intense focus (hyperfocus) while playing. The computer game “trance” is often so deep that the only way to get the player’s attention is to shake her or “get in her face.”³

“The ease of access to endless information, without the limitations let young people with physical limitations experience changes in their life that otherwise may be difficult or even impossible for them... However, while the Internet has become a channel that promotes access to information and communication, as any other technological tools, its misuse and overuse can cause various



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.

personal and social problems...(The) internet (can) reduce the social circle and affect the psychological well-being, decreasing social activity and replacing the strong links by other weaker than traditional (arrangements).”¹

A study in *The American Journal of Drug and Alcohol Abuse* found that as many as 8.2 percent of Americans may suffer from Internet addiction (IAD). Other studies estimate that the disorder may affect more than 18 percent of college-aged Internet users, according to the *Internet Addiction: A Handbook and Guide to Evaluation and Treatment*. While anyone can develop IAD, the majority of people who do so are males in their teens, twenties, and thirties. Some reports suggest that Internet addiction is a particularly acute problem in Asian countries.

South Korea may have as many as 680,000 young people ages 10 to 19 who are addicted to the Internet, according to a 2013 report from Reuters.⁴

THEN THERE ARE COMPUTER GAMES

Computer game addiction generally refers to an excessive, unhealthy amount of time playing computer games. Rather than engaging in the real world, an addicted user devotes the majority of his or her time to gaming. The addicted gamer often isolates him/herself from others, ignores more important responsibilities, and is often obsessed with obtaining higher status / rankings / achievements in his/her favorite computer game.⁵

There are some signs and behaviors that are almost always included in definitions of computer addiction, such as:

- “Significant interference with school, work, or relationships
- Often avoiding other commitments in order to keep playing

CONNECTION FAILURE: The internet can reduce the social circle and affect the psychological well-being, decreasing social activity and replacing the strong links by other weaker than traditional arrangements.

- Frequently turning down social invitations in favor of gaming
- Using most or all of one’s free time for gaming
- Regularly playing late into the night, which results in poor sleep habits
- Loss of interest in previously enjoyed activities
- Regular gaming “binges” of 8 hours or more nonstop.”⁵

AND THERE ARE CONSEQUENCES

Social: As a computer game addict spends more time gaming, he / she tends to spend less time interacting with others in person. As such, he / she may lack face-to-face human contact, experience isolation & loneliness, and the loss of friends or relationships.

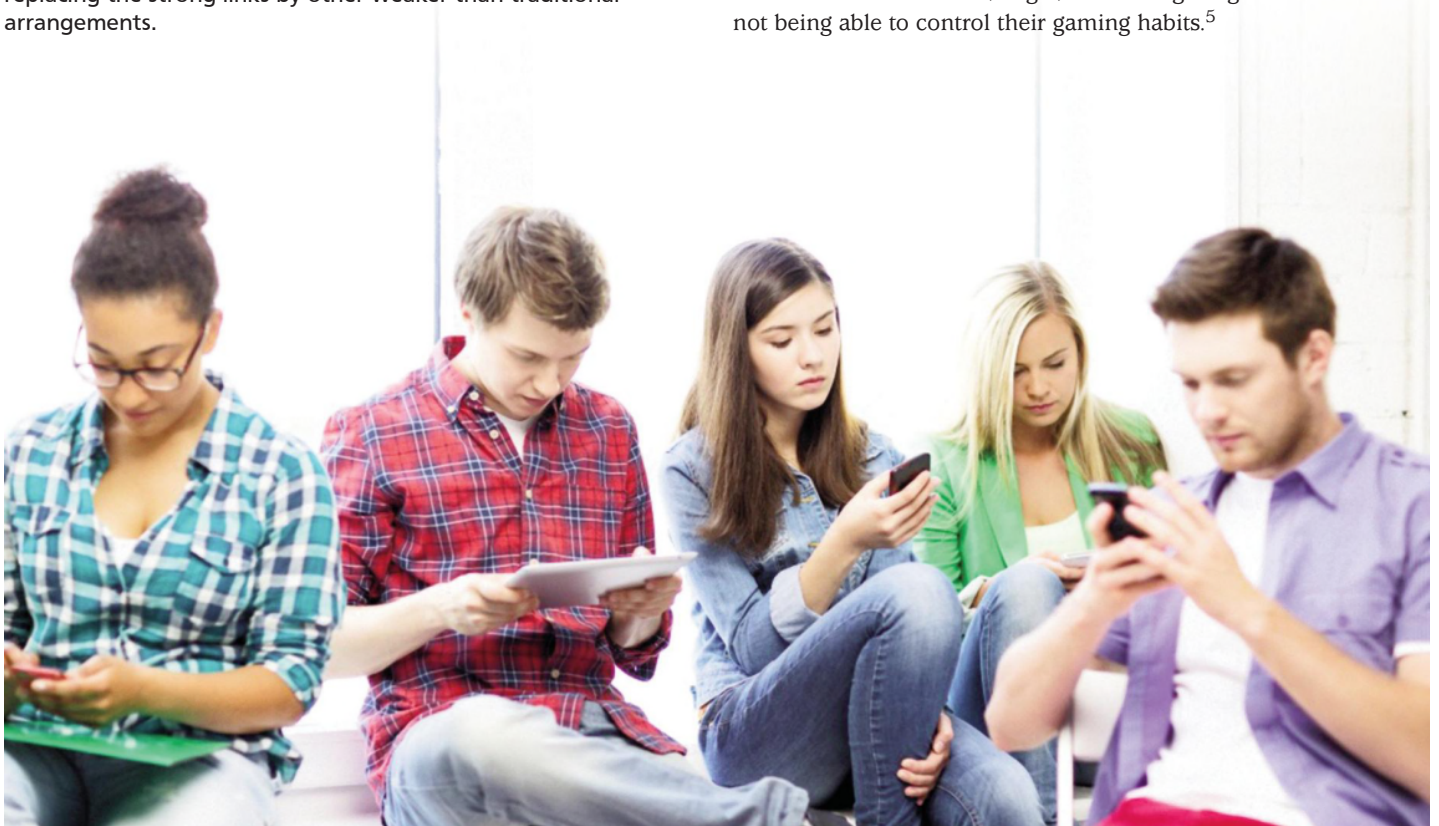
Academic / Career: Children and teens who are addicted to computer games very often experience falling grades and decreased academic performance and dedication. Completing homework, studying for tests, and efforts during school become very low priorities. Adults who are addicted to computer games may experience a similar deterioration in work performance, job dedication, and career aspirations.

Financial: Adults and teens may spend large amounts of unaffordable money on new games, expansion packs, micro-transactions, service fees, and computer upgrades.

Family: Computer game addiction often leads to deterioration in family relationships. Tension and conflict between family members escalates as requests to cut back or stop are ignored. Parents of addicted children may disagree on how to address the problem, which may lead to frequent arguments and conflicts.

Health: Computer game addicts may neglect personal hygiene, have poor sleep habits, give up healthy physical activities, and may make meal decisions based on quick and easy preparation (so that gaming is not interrupted) rather than dietary needs.

Emotional / Psychological: Those addicted to computer games may experience depression mood, low self-esteem, social anxiety, low frustration tolerance, anger, and feelings of guilt and shame for not being able to control their gaming habits.⁵



HOW IS COMPUTER GAME ADDICTION TREATED?

Because computer game addiction is a new disorder in the world of mental health, treatments are not as well established as those for depression, anxiety, anger, etc. “Most interventions take a behavioral approach which involves changing how the addict thinks about the addiction (for example, recognizing that the game distortions are designed to convince the gamer that it is not a problem).”⁵

Capio Nightingale Hospital, in central London, has launched the first addiction service which allows young people to go “cold turkey” from their technology compulsion.

“The service, which will be offered for children as young as 12, comes amid growing concerns about children’s behaviour with technology which puts their health at risk and has led to police being called to sort out family disputes.

Children will be forced to go ‘cold turkey’ from their technology use as well as being encouraged to cut out any problem use, such as computer games, and restrict the time spent using their phone or computer.

They would also be taught face-to-face social skills at a residential unit.

It also encourages them to think about their relationship with their phone, computer games or social networking websites like Facebook and teaches them skills to help them to switch off.”⁶

HOW CAN COMPUTERS HELP CHILDREN WITH DISABILITIES?

More and more schools are moving away from segregated special education to partial or full inclusion. As a result, more students with disabilities are coming into the general education classroom. Many of these students need support for physical, cognitive, and other disabilities. In many ways, computers can be great help.

“When playing at the computer with young children with special needs, one of the best approaches is to use software that is errorless. That means that no matter what the children do, there are no right or wrong answers. Exploration and trial and error are the learning styles that are rewarded, with fun noises, humorous animations, great graphics, lots of music and natural sounding speech. All kinds of learning goes on and there just are no things to do wrong.”⁷



WINNING STRATEGIES: More students with special needs are coming into the general education classroom, and computers can be great support for physical, cognitive, and other disabilities.

“Most children like to play computer games, and some are highly educational or otherwise beneficial. Your child’s teacher may use math, phonics, and other computer games in his or her classroom. He or she may have a subscription to a site like Lumosity.com, where children can work on word-forming, math, recall, and other skills. For example, a child who struggles with dyslexia may benefit from Word Bubbles, a game that challenges players to think of as many words as possible that begin with a three-letter combination.

For older children, you can use certain social media games at home with supervision. For instance, Pearl’s Peril and other hidden object games featured on Facebook can help children with visual disabilities or poor muscle tone, as they require visual acuity and a certain level of speed.

Children with disabilities such as dysgraphia (inability to write coherently) or forms of cerebral palsy that affect handwriting can benefit from programs or games that teach typing. Mavis Beacon Teaches Typing is a popular program in many schools, and many teachers have mini-games as options in their classrooms or in computer labs.”⁸

SO WHAT IS A GOOGLE?

“A googol is 10 to the 100th power (which is 1 followed by 100 zeros). A googol is larger than the number of elementary particles in the universe

The term was invented by Milton Sirota, the nine-year-old nephew of mathematician Edward Kasner, who had asked his

nephew what he thought such a large number should be called. Such a number, Milton apparently replied after a short thought, could only be called something as silly as a ‘googol.’”⁹ •

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WHY DEAD MALLS AND THE RETAIL DIVE OF 2017-2018 COULD SPARK A BRAND-NEW HIGH SCHOOL TRANSITION MODEL FOR YOUNG ADULTS WITH DISABILITIES

BY STEPHEN HINKLE AND LINDA SHANDRICK LENGYEL

Transition planning for secondary students is critical for successful post-school outcomes. First mandated by the Individual with Disabilities Act (I.D.E.A) of 1990, and further strengthened in reauthorizations, transition services became a focus for parents and professionals alike. Quickly we came to understand that school systems should be preparing students for adult life before they exit out of special education services. The areas of preparation generally fall into the categories of employment, postsecondary education, community participation, and

independent living. Transition services should be individualized and localized to best meet the student's needs. Several practices have emerged to promote successful transition that include the supporting and instructing students in high school programs with Community-based vocational exploration and learning (CBL). The Division on Career Development and Transition of the Council for Exceptional Children define CBL "as students engage in work learning opportunities to learn about careers and support their ability to make more effective decisions."

MANY SCHOOL DISTRICT-BASED TRANSITION PROGRAMS IN SCHOOLS TODAY STILL FOLLOW THE OLD MODEL OF ASSUMPTIONS, PREPARING ADULTS FOR ENTRY-LEVEL POSITIONS. THE TIME TO CHANGE THIS MODEL ON A NATIONAL LEVEL IS NOW FOR MANY REASONS.

Because the teaching and learning of transition-aged youth is often occurring in the community, the places selected are critical to the future success. The real-life experiences provided must take into consideration future planning, with careful thought to where the post-school graduate will be spending time living, working, and recreating. Most students are currently likely to be spending some time in retail stores, however, the future of retail brick and mortar settings is questionable as the retail sector is declining today as an industry. It can be tempting to rely on retail settings for CBL; however, this trend is seen as a threat to people in transition programs and people with disabilities looking for jobs. This necessitates the rethinking of traditional transition programs with community-based exploration and learning experiences that have relied heavily on the retail industry, calling for a model that expands beyond traditional training into a more diverse range of career paths and that takes advantage of the person's interests and talents.

Historically many of the life-after-high school transition programs operated by most school districts in the USA are for young adults aged 18 to 22, although the ages vary across the states. The purpose of the non-diploma track special education transition programs has been to train people with disabilities to work in the workforce in an entry-level position. The programs often involve working towards a job in the retail sector, the fast food sector, and the janitorial sector, among others. Common positions include grocery baggers, greeters, inventory people who stock shelves, cashiers, food service and janitorial workers. The hope is that young adults graduating out of special education services will have jobs in the communities they want to live in, providing them a level of independence and the pride of contributing back to their community.

While this arrangement seemed beneficial when it was created, this model is no longer built for today's time and job markets. We are discovering that many people with disabilities have unique talents to share and are becoming more accepted into mainstream society through inclusion. The retail sector is declining today as an industry. Social security and Medicaid asset caps are way below the

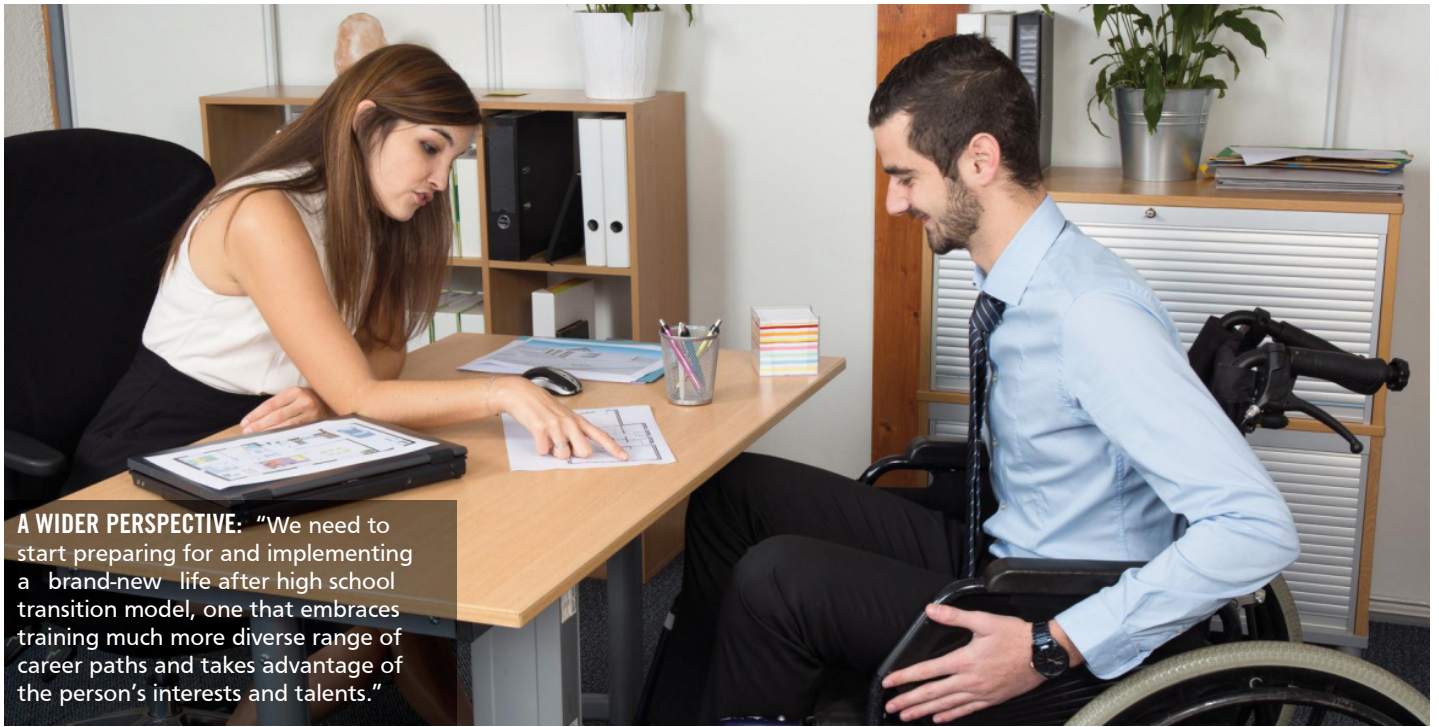
cost of living in many cities around the country, and apartment and home rental prices keep treading upwards across the nation. More and more people with disabilities are choosing to go on to college after high school. Yet, many school district-based transition programs in schools today still follow the old model of assumptions, preparing adults for entry-level positions. The time to change this model on a national level is now for many reasons.

The first main reason is the recent retail dive. Throughout 2017 to 2018, there have been numerous retail store closures. In 2017 alone, over 6700 stores have closed in the USA, and more closings are predicted in the coming years. Many of these closures have included big names like Sears, Kmart, Macy's, Toys R Us, JCPenney, GameStop, Payless Shoe Source, Staples, and many others. Some of these chains have declared bankruptcy and many more are expected to do so in the near future.

Store closures have led to entire shopping malls falling on hard times. Malls all across the USA are going vacant and dying. The term "dead mall" is used to describe a shopping mall that is on its last leg. Either this is a mall that has a very high vacancy rate and has very few shops remaining, or the entire mall has closed and became abandoned.

When malls close up, communities are left with empty buildings and fewer jobs, especially entry-level jobs. Some of these malls eventually face the wrecking ball and get torn down and redeveloped into condos and apartments, or re-purposed for use by non-retail tenants such as schools, college campuses, data centers, web hosting companies, warehouses, mega churches, offices, medical centers, and even government services, among a variety of other things. When non-retail tenants take over a mall building, the education requirements to qualify for a job in the building and the type of jobs offered in the area changes significantly.

But there is an even bigger threat looming to retail jobs in the 21st century, the rise of online shopping. More and more people are doing their shopping online through websites like Amazon, eBay, Revolve, Zappos, and others. This means less people are going to be shopping in brick and mortar stores. As the result, according to the firm Credit Suisse, over 25% of the malls in the USA could die with-



A WIDER PERSPECTIVE: “We need to start preparing for and implementing a brand-new life after high school transition model, one that embraces training much more diverse range of career paths and takes advantage of the person’s interests and talents.”

in a few years. The current trend in retail is less big box stores, and that stores of the future will be smaller than today.

With what some have coined “the retail apocalypse,” there can be a significant impact to people with disabilities trying to

find entry-level jobs. Many stores have embraced the self-checkout model, adding to the reduction of jobs. There are going to be fewer and fewer retail jobs if these trends of online shopping and automation continue. Additionally, many millennials are pre-

ferring healthier and a more diverse range of food options and less traditional fast food leading to more changes in the industry.

As the result, we need to start preparing for and implementing a brand-new life after high school transition model, one that embraces training much more diverse range of career paths and takes advantage of the person’s interests and talents. Such a model will require many changes, including encouraging more people with disabilities to take standard diploma tracks in high school, supporting students on college campus, and more self-determination, all requiring creativity and flexibility.

EXCEEDING EXPECTATIONS : STEPHEN HINKLE

Co-author Stephen Hinkle has his own experiences to share that demonstrate the power of inclusive schooling and high expectations.

“While I was in school, many of my teachers had low expectations for me as a student. I had one English teacher that didn’t want me in her class and tried to get me to drop out to go into the Special Education English class. There were other people that put low expectations on me and thought I should get an alternative diploma. But I took AP classes in Physics, Computer Science, and in Calculus, all as a Special Education student. I did struggle with English and History as inferring messages was harder, and I had modifications. I graduated with a real high school diploma and went on to San Diego State University as a computer science major. Later I attended Northern Arizona University for a Special Education degree with emphasis in Disability Policy Studies. Currently I am a Ph.D. student at Chapman University!”



WHAT MIGHT SUCH A TRANSITION MODEL LOOK LIKE?

Currently, many high schools have functional skill-based tracks that often begin in ninth grade and lead to an alternative diploma options such as certificates of completion, IEP / Special Education diplomas, and vocational certificates. The alternative diploma route provides a less rigorous academic option that can create barriers to future employment and college experience options.

Instead, more students with disabilities can be in inclusive high schools that continue to foster academic skills, as well as higher order thinking such as problem solving, goal setting, and autonomous decision making. Academic and career tech classes can be encouraged that focus on subjects

and areas of expertise or even fascinations. Many students can have difficulties in academic areas such as reading, and at the same time be quite gifted in another area such as technology or science. By taking a more personalized approach that goes beyond typical entry-level jobs students can expand on talents and strengths that may define their career path in the 21st century.

Currently, some students are in school-based programs until they reach age 21 or 22, or older depending on the state. Although these programs do offer community experiences, their “home base” is still the high school building. Movement to settings such as colleges or universities, vocational training centers or college campuses would provide more age appropriate experiences and the opportunity to build relationships with same aged peers.

There are some great programs for young adults with intellectual disabilities on college campuses. The book *Think College* by Meg Grigal and Debra Hart is a great resource. Some of these college-based programs overlap with school-based programs by using special education monies for funding, others require the applicant to have exited out of Special Education services.

While these programs are meeting the needs of many young adults, there are still young adults who may not be ready for those programs, or are seeking a different type of college experience. Therefore, other options are also arising. The second author, Linda, is working in partnership with a few 18 to 22-year-old transition programs to pilot a college experience. In an undergraduate Social Justice Service Course several students in a school-based program will be auditing the course, taking it alongside undergraduates. The outcome of the course is the development and implementation of a service project designed collectively by the class. While it is a limited one-course experience, it provides an inclusive college experience for students who otherwise may not have that option. It’s a pilot ... a start.

Times are changing, more and more students are interested in going to college like their siblings, and are rejecting the notion of going straight into the entry-level workforce. Likewise, transition programs may be losing their job-sites in the retail industry, creating an opportunity for more creative and flexible options. The best way to determine which career path one should explore is to really examine one’s strengths, talents, and interests and then explore all of the

places in the community and workforce that could use those talents. Doing so will require expanding into other industries instead of solely focusing on low wage, entry-level positions. •

ABOUT THE AUTHORS:



Stephen Hinkle, a well-respected international speaker and self-advocate, has been presenting and speaking for over 16 years. He has inspired audiences, successfully advocated for inclusive education and better outcomes for people with special needs, and assisted others on how to help people with disabilities. Stephen has spoken at many conferences and events in 24 US States, plus Australia.

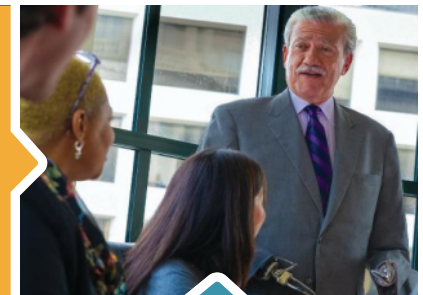


Linda Shandrick Lengyel is an Associate Professor at Lesley University, and the director of the Severe Disabilities Teacher Licensure and Transition Specialist Programs. Before entering Higher Education, Linda supported persons with complex profiles and their families in school, work, and home settings. Dr. Lengyel also has an extensive history of advocacy, advocating for inclusive opportunities across all environments.

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AN INVITATION FROM ONE SPECIAL EDUCATOR
TO FAMILIES, FRIENDS AND COLLEAGUES:

LET'S ADJUST OUR SAILS AND CONTINUE THE VOYAGE TOGETHER

BY ANGELA SHAW

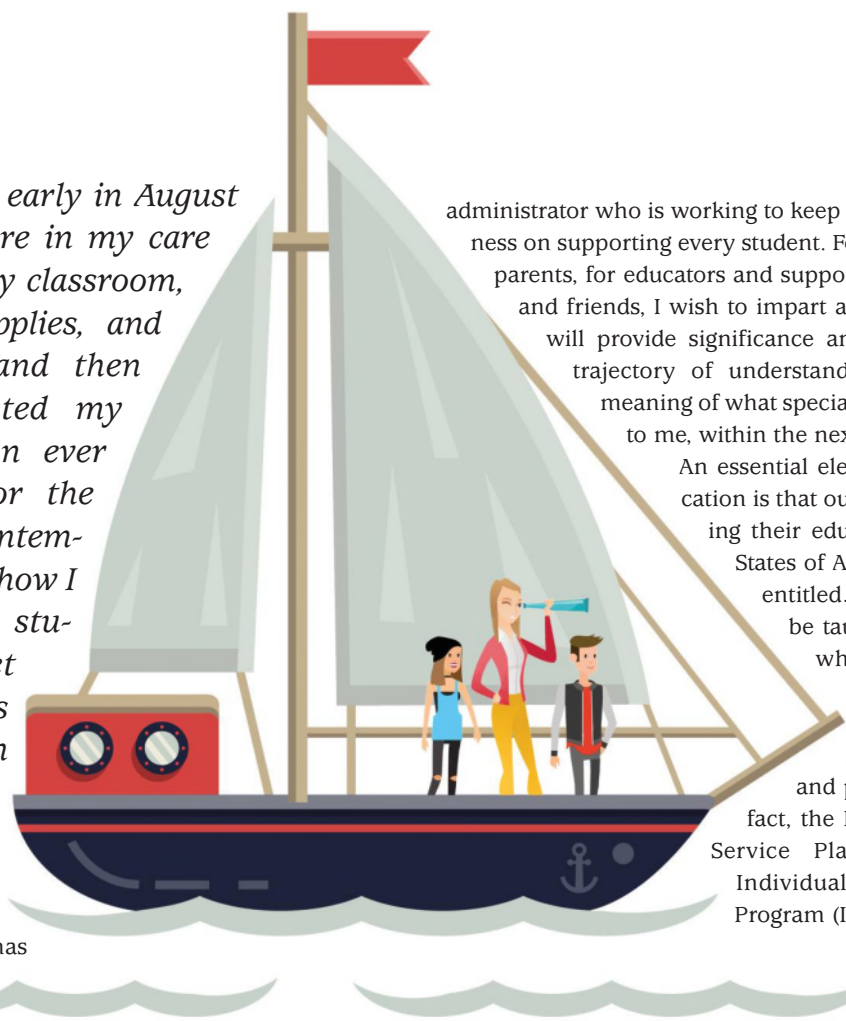
The school bell rang early in August for the students who are in my care and for me. I cleaned my classroom, readied my school supplies, and wrote and rewrote, and then adjusted and readjusted my schedule to include an ever increasing caseload for the 18th year of my life. I contemplated, yet again, about how I could best support the students I serve to get through their 12 years of school and beyond in order to attain the goals they envision for themselves.

Being a special educator has been a blessing and burden in my life. I sometimes feel that I am alone in this journey, but then I have the opportunity to meet so many great parents, wonderful grandparents, and supportive aunts. I get to sit at an IEP table and hear the authentic and beautiful words of a general education teacher; listen to the response of my students as they connect with the patient and competent paraprofessional I am graced to work with; see the eager expression of an

administrator who is working to keep the focus of our business on supporting every student. For parents and grandparents, for educators and support staff, for neighbors and friends, I wish to impart a message that I hope will provide significance and create an upward trajectory of understanding about the core meaning of what special education is, at least to me, within the next few paragraphs.

An essential element of special education is that our students are receiving their education in the United States of America and, thus, are entitled... yes, ENTITLED... to be taught by professionals who are equipped to support them toward accessing learning in a positive and pro-active manner. In fact, the Individualized Family Service Plan (IFSP) and the Individualized Education Program (IEP) are born out of a national legal statute, commonly called

IDEA (Individuals with Disabilities Education Act). This law, initially created in 1975, was put in place specifically to ensure that our children, from infancy to 22 years of age, are provided access to an education that provides specially-designed instruction, at no cost to parents, to meet the unique needs of a child with a disability – including a continuum of services options and a range of settings.



The array of professionals that children who are provided educational services under the umbrella of IDEA, may range from a certificated teacher with a general education credential and/or a certificated teacher with an education specialist credential. The professional may be a related service provider, such as an occupational therapist, a speech/language pathologist, a vision specialist, a deaf hard of hearing specialist, a counselor, a school nurse or a physical therapist. The professional may be an administrator, a school secretary, a custodian, a paraprofessional, a bus driver, a school psychologist and so on. The key here is that the adults who work on and around our school campuses are professionals and have something to teach every one of our students, yes, including those children with special needs. Notice I did NOT say, especially children with special needs. This is because children with special needs are people first and a part of our families, our school community and our larger society.

Preparation for real-world living is precisely where the emphasis has always been within the realm of special education. Children with special needs are people who will grow up to become whatever they choose to become. They may choose to be the neighborhood

OFTENTIMES, ADULTS WHO LEARN THAT I AM A SPECIAL EDUCATOR WHISPER TO ME, "I WAS IN SPECIAL EDUCATION... AND I TURNED OUT OKAY."

mechanic you depend upon to keep your car running so you can get to your job, your doctor's appointment, or the grocery store. They may grow up to become the dental hygienist who cares for your teeth and ensures their longevity so you can eat and thrive. They may be the yoga instructor who helps keep your body and mind healthy. They may be the retina specialist who saves your vision. They may be your own child's teacher.

They may be military or law enforcement personnel that protects and serves your community and your nation. They may even grow up and become your best friend.

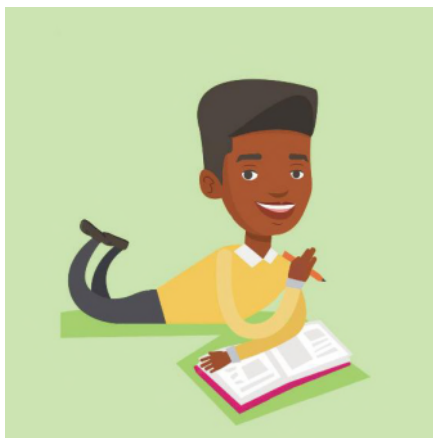
Children with special needs are vital, and grow to be productive and successful members within the fabric of our small towns, our

ENDLESS POSSIBILITIES FOR EVERY CHILD

Philosophers across time and space have searched for the meaning of life and the purpose of education. Within our nation, many of us have experienced paradigm shifts in education across our own lifespan, as students, parents, and/or educators. Today, the Common Core State Standards are said to provide for preparing America's students for college and career (www.corestandards.org). This purpose is not a new concept to IDEA. Legislative intent of preparing students for life after leaving school is hardwired into IDEA through ever-expanding transition planning within the Act and through the IEP process. IDEA 2004 endures to increase this intent to include transition planning and purpose:

To ensure that all children with disabilities have available to them a free appropriate public education that emphasizes special education and related services designed to meet their unique needs and prepare them for further education, employment, and independent living (IDEA 2004, D. Purpose [1] [A]).

The intent and purposes of both Common Core and IDEA merge well with every parent's desire to see their child grow to follow their bliss, to become independent, happy, resilient, successful adults within society. Within IDEA '04, a results-orientation approach provides focus upon improving the academic and functional achievement of a child with a disability. IDEA's expectation that local education agencies, community and state agencies, and families work together to design and implement educational programs that prepare students with disabilities for life after leaving public school, is presented within the Act under transition services through a coordinated set of activities implemented at a specific age.



All children, including students identified with a disability under the guidelines of IDEA, have potential within them that reaches far beyond what they are often educated for within the confines of Kindergarten through twelfth grade (and even college and university). The formal school setting serves as a foundation for learning to learn—but parents and educators need to keep the door ajar to unlocking learning, for opportunities and interests that

stretch beyond our own imagination and the current state of reality. The imagination of Leonardo da Vinci, Marie Curie, or Albert Einstein, were not fueled by today's STEM Education (Curriculum based upon the idea of educating students in four specific disciplines—science, technology, engineering and mathematics). Additionally, most of us cannot even fathom the ideas of Bill Gates, Stephen Hawking, or the musical genius of Paul McCartney. Whether your child is identified and taught within the Gifted and Talented Education (GATE) program, a special education program, or involved in a fully-funded STEM program,

by being mindful of the endless possibilities that our children and youth's unique neurology and experiences can create, we contribute to helping them grow and become great in whatever field they choose.

In the meantime, let us meet our children where they are now, through the scaffolds and differentiation they need today. Let us support them on their path of happiness, independence and success so they can experience their unique possibilities.

big cities, and the many places and spaces of our nation. When their special education tag falls away and their Individualized Education Plan (IEP) dissolves into a pile of shred, those that bore the title “child with a special need” become just another one of the folks in the neighborhood.

TURNED OUT OKAY

Oftentimes, adults who learn that I am a special educator whisper to me, “I was in special education... and I turned out okay.” Sometimes, a parent of child who is identified as being adversely affected by one of the thirteen qualifying conditions under IDEA will whisper to me, “I was in special education...and I turned out okay.” The conversations are often shaded with worry, doubt and/or shame. When we compound that shame, and that worry, and that doubt with thoughtless acts of isolation; increase barriers by ignoring or denying the crucial scaffolds of support that are needed for this moment in time; ignore opportunities to celebrate the seemingly small victories of our hardworking children, we are perpetuating the shame, adding to the worry, and causing doubt to insinuate itself into every crevice of our children’s being.

In order to turn this around there is still much work to be done on the home-front and the school-front. It begins with opening our eyes to the wonders of each child’s individual “spice,” opening our ears to one another, and opening our hearts to the fact that we

may need to try something different to reach and teach this child or that child, including the child with an identified special need.

It truly does take a village, and the stakeholders in our children’s lives start with family; however, the circle merges ever outward.

Like ripples from a pebble breaking the surface of the sleek blue water across a tranquil pond, the rings of the ripples embrace educators, friends, neighbors, our community and our nation at large.

Moving onward, upward, through the rough waters, and weighty gusts of learning differences, families, educators, community members, and local government are all invited to village-up. Let us roll up our sleeves, adjust our sails and TEACH our kids together. It is called collaboration (co, as in together) (labor, as in work).

Work together, teach together, learn together, laugh together and, most important of all, thrive together. •

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ABOUT THE AUTHOR:

Angela Shaw is a special educator in Southern California. She synthesizes her diverse education and experience to provide students learning that will grow for a lifetime and support educators and families in their endeavor guide their students in a proactive and productive manner. Her focus is upon special education topics to include articles such as: “Seven Things Every Child with Dyslexia Wishes you Knew” (March 2017, *Exceptional Parent Magazine*). Shaw earned her Masters’ Degrees in Special Education and School Counseling from Azusa Pacific University.



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When trying to determine the best path for your son or daughter to take on their road to independence, the attainment of a college degree, in and of itself, should not be the ultimate goal. Rather, the ultimate goal should be employment and independent living.



WHICH WAY DO WE GO?

TRANSITIONING from HIGH SCHOOL to EMPLOYMENT

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

One of the most daunting decisions faced by parents with a child who has a disability, is what to do next when their son or daughter reaches the age of 18. Parents of non-disabled youth are in a different position. Often, they take their direction from their daughters and sons who decide either to follow a trade, or continue his or her education at a community college or a four-year institution of higher education. Depending upon the nature of the disability, parents of disabled youth may need to take the lead in the decision-making process.

The decision about what to do next is a high-stakes one and can feel overwhelming, especially when one considers the facts about unemployment and disability. According to the U.S. Department of Labor (2018), the current unemployment rate is 3.9%. Economists view the country as being at full employment when the unemployment rate is 5%. Consequently, the current labor market is considered good for individuals looking for a job. However, when one looks more closely at the unemployment figures for individuals with disabilities, the numbers are not nearly as encouraging as those for people without disabilities.

The U.S. Department of Labor collects data on employment of individuals with disabilities only in the aggregate. The agency does not compile disability specific data. The type of disability and level of impairment can profoundly affect employers' willingness to hire a person with a disability. The federal government provides a rather broad definition of a person with a disability which appears to emphasize physical disabilities:



NEXT STEPS: Parents with a child who has a disability face daunting decisions about what to do when their son or daughter reaches the age of 18. The key to successful employment and independent living is finding the right post-secondary educational experience. There are more options now than ever.

A person with a disability has at least one of the following conditions: is deaf or has serious difficulty hearing; is blind or has serious difficulty seeing even when wearing glasses; has serious difficulty concentrating, remembering, or making decisions because of a physical, mental, or emotional condition; has serious difficulty walking or climbing stairs; has difficulty dressing or bathing; or has difficulty doing errands alone such as visiting a doctor's office or shopping because of a physical, mental, or emotional condition. (U.S. Department of Labor, 2018b).

The manner in which the agency collects data grossly underestimates the scope of the unemployment problem for individuals with disabilities. Excluded from their estimates are individuals who are institutionalized, non-civilian individuals, those potentially working in agriculture, and most

important, those individuals who have given up looking for work. This latter group is sizeable among the disabled population. "A large proportion of persons with a disability--about 8 in 10--were not in the labor force in 2017, compared with about 3 in 10 of those with no disability" (U.S. Department of Labor, 2018c).

Even the manner in which the data are reported is not as clear cut as the national unemployment rate for people without disabilities:

In 2017, 18.7 percent of persons with a disability were employed, the U.S. Bureau of Labor Statistics reported today. In contrast, the employment-population ratio for those without a disability was 65.7 percent. The employment-population ratios for both persons with and without a disability increased from 2016 to 2017. The unemployment rates for both persons with and without a disability declined from the previous year to 9.2 percent and 4.2 percent, respectively (U.S. Department of Labor, 2018c).

That being said, the unemployment rate for people with disabilities is over 2 times greater than the non-disabled population at 9.2%. Even when employed, individuals with disabilities are more likely to be employed part-time than those with no disability (32% versus 17%) (U.S. Department of Labor, 2018c). Not only are they almost twice as likely to be working part-time time than their non-disabled peers, but they more likely to be self-employed (10.6% versus 6% with no disability) (U.S. Department of Labor, 2018c).

WHERE ARE INDIVIDUALS WITH DISABILITIES MOST LIKELY TO BE EMPLOYED?

In 2017 workers with disabilities are more likely to be concentrated in the service industries according to the Department of Labor. One out of five individuals with a disability work in the service sector of the economy compared to 17.3% of the non-disabled population (U.S. Department of Labor, 2018c). The next largest segment of the economy where people with disabilities are employed is in the production, transportation and materials moving occupations where 14.1% of individuals with disabilities work as compared to 11.6% of their non-disabled counter-parts (U.S. Department of Labor, 2018c). People with disabilities are less likely to work in management, professional and related occupa-

tions by almost 6%. They also are most likely to be employed by government and less likely to receive private salary wages.

HOW DOES ONE INCREASE THE LIKELIHOOD THAT THEIR SON OR DAUGHTER WITH A DISABILITY WILL BE EMPLOYED? IN WHICH DIRECTION SHOULD SHE OR HE HEAD?

The answer is in the direction of more education, post-high school. When people read more education post-high school, they assume this means getting a college degree. Getting an associate degree or even a bachelor degree not only increases the likelihood that someone will be employed, but it also decreases the likelihood they will be laid off in an economic downturn, and shortens the length of time one is unemployed and searching for work. In fact, if a person with a disability can earn a bachelor degree, their employment rate is virtually identical to their non-disabled peers, with no statistical difference in the rates they are hired.

However, not everyone is "otherwise qualified" to enter college and earn a degree. A student entering the college environment must be able to complete the requirements of each and every course. The phrase, "otherwise qualified" comes from the Americans with Disabilities Act (ADA) of 1990. Prior to entering college, children with disabilities are protected by the Individuals with Disabilities Education Act (IDEA) under which education is a right. The child with a disability is entitled to a Free and Appropriate Public Education (FAPE) in the Least Restricted Environment (LRE). Each student has an Individualized Education Program (IEP) which outlines modifications the school must make to the student's assignments and learning environment. Goals are established, responsibilities are assigned, and the student's progress is monitored on an annual basis at the very least. Often parents are the driving force behind the IEP process and the necessary modifications, which are done to maximize the possibility of student success.

WHAT HAPPENS WHEN A STUDENT WITH A DISABILITY REACHES THE AGE OF 21?

When a student with a disability reaches the age of 21, or has received their diploma from high school and had their exit IEP

interview, the school district's responsibilities end, as do the protections under IDEA. Now an individual with a disability falls under the protection of the Americans with Disabilities Act (ADA). There are two major conceptual shifts that occur during this transition. First, education is no longer an entitlement or right, it is a privilege. The student must be "otherwise qualified" to benefit from the college education. The college or university may not discriminate against an individual with disability and prevent them from receiving the benefits of the university. The college or university must provide "reasonable accommodations" under the ADA. The notion is to level the playing field and remove barriers to receiving the benefits of a university education, not maximize the student's chances of success. Reasonable accommodations vary from institution to institution, based upon their size, budget, and interpretation of the law. Typically, these accommodations are extended time on testing, quiet and separate testing locations, notetakers etc. Other types of accommodations may be related to physical disabilities and can include sign language interpreters, braille or audio versions of textbooks, the recording of lectures etc.

Generally, what is not done, is modifying the course requirements. The student with the disability must do the same work as any other student. The second major conceptual shift is in who is the driving force when advocating for reasonable accommodations. When a student reaches 18, they are entitled to privacy under the Family Education Rights Privacy Act (FERPA) and this law precludes colleges and universities from sharing information with "3rd party entities". Parents become "3rd party entities" when their sons and daughters reach age 18. Now, students with disabilities must self-advocate and self-identify. They must contact the Office of Disability Services, not their parents. These offices go by a variety of different names. It is incumbent upon the student with the disability to locate the office, provide documentation regarding the nature of their disability, and discuss their accommodation needs. Students may not ask professors for the accommodations. They must work with the Office of Disability Services in order to receive those supports and must do them in advance.

Using the Office of Disability Services at a college can be an effective means of obtaining a degree and transitioning to the world

of work and independent living. The students who benefit the most from this path tend to have "milder" forms of learning disabilities or physical disabilities. Students with dyslexia, dysgraphia, and less severe cases of attention deficit disorder who avail themselves to these supports earn degrees and get jobs.

When trying to determine the best path for your son or daughter to take on their road to independence, the attainment of a college degree, in and of itself, should not be the ultimate goal. Rather, the ultimate

goal should be employment and independent living. The students who benefit the most from this path tend to have "milder" forms of learning disabilities or physical disabilities. Students with dyslexia, dysgraphia, and less severe cases of attention deficit disorder who avail themselves to these supports earn degrees and get jobs.

ing worked outside the home for pay since leaving high school. Further, young people with ASDs had lowest rate of employment among all disability groups. Young adults with an ASD also earned an average of \$8.10 per hour, significantly lower than average wages for young adults in the comparison groups, and held jobs that clustered within fewer occupational types than other disabled peers. These data seemed to confirm the data from the National Transition Longitudinal Study-2 (Standifer, 2012). Standifer's team



AT YOUR SERVICE: One out of five individuals with a disability work in the service sector of the economy compared to 17.3% of the non-disabled population.

goal should be employment and independent living. Four-year liberal arts degrees tend to be broader and more general in their orientation. Courses are not necessarily directly linked to a specific job and most courses do not address aspects of independent living. Associate degree programs, in general, are more directly linked to a specific job or career.

However, students who need explicit instruction, or have more significant learning challenges, will not benefit from earning a college degree. Young adults with Autism Spectrum Disorder (ASD) face a particularly difficult time obtaining and retaining employment regardless of educational level. Shattuck (2012) found 34.7% of young adults with ASDs attended college and 55.1% had paid employment with 6 years after high school. His team also found that over 50% did not participate in employment 2 years after high school. Roux (2013) had a similar finding with 53.4% of young adults with ASDs ever hav-

found that the proportion of young adults with ASDs were employed at comparable levels to young adults with deaf-blindness or multiple disabilities.

However, young adults on the spectrum earned 86% of the income as compared to young people with all other disabilities. In fact, half the young people with ASDs worked less than 20 hours a week, which is at a rate that is 4 times lower than all other disabilities. Even their average number of hours of work per week were 36% less than their disabled peers (23.3 hours vs. 35.8). Sadly, the proportion young adults with ASDs working full time is 1/3 of all other disabilities (26% vs. 71%) (Standifer, 2012).

Education and training still matter and can make a significant difference in the young person's life, whether they have an ASD, an intellectual disability or some other disability. Preliminary research indicates that vocational training, and post-secondary programs can have a significant impact upon the employment of a young person

with a disability. Miligore et al. (2012) found that the odds were greater for employment if job placement services were received from state offices Vocational Rehabilitation. Unfortunately, only 48% ASD youth received such services.

Post-secondary college services is the best predictor of better earning. Only 10% of the Vocational Rehabilitative Services dataset analyzed by Miligore went to a post-secondary college-based program.

DO THESE POST-SECONDARY PROGRAMS THAT ARE COLLEGE-BASED REALLY WORK FOR STUDENTS WITH AUTISM OR AN INTELLECTUAL DISABILITY?

The preliminary research seems to suggest the answer is, "Yes!". Wehman et al. (2013) conducted an experiment where he randomly assigned students with ASD to a vocational training program versus a control group which was referred to as business as usual, meaning the student worked with her or his high school and the local office of vocational rehabilitative services. The results showed that 87.5% of the vocational group were employed 6 months after the training as compared to only 6.25% of the control group were employed. Moore & Schelling (2015) found that 9 out of 10 students with an Intellectual Disability (ID) who graduated from a post-secondary program were employed within 2 years of the study. According to the NTL-2 only 1/2 high school graduates with ID were employed. Diamant (2015) in her study found neither I.Q. or academic ability were better predictors of employment and independent living, than the ability to successfully and consistently complete activities of daily living.

Post-secondary college-based transition programs can help students with a variety of disabilities learn important job skills through internships and even earn industry-recognized certificates. They can also help a student learn important independent living skills, including activities of daily living. With the passage of the Higher Education Opportunity Act in 2008, some colleges have created transition programs referred to Comprehensive Transition and Post-secondary (CTP) programs. These are approved by the U.S. Department of Education to administer some forms of Federal Student Aid, namely Pell Grants, Federal Supplemental Education Opportunity Grants (FSEOG) and Federal work study monies. Currently, these programs are not allowed to offer Federal Student Loans.

There are approximately 70 CTP programs in over 25 States. To locate these programs please visit the FAFSA.gov website. The direct link to the list is: <https://studentaid.ed.gov/sa/eligibility/intellectual-disabilities>.

For other transition program listings including the CTPs, Boston University's Think College! is a useful site at <https://thinkcollege.net>. George Washington University hosts the Heath Center National Youth Transition Center <https://www.heath.gwu.edu/> which can also help families plan for the future and provides listings of college programs designed to help students with disabilities. Lesley University Threshold Program has published a comprehensive guide to 75 programs nationally. To download an e-booklet with tips for selecting the right transition program for you, visit: [Lesley.edu/exceptional-parent](http://lesley.edu/exceptional-parent).

A FINAL PATH TO EXPLORE ON THE ROAD TO EMPLOYMENT AND INDEPENDENCE FOR YOUNG ADULTS WITH DISABILITIES IS RELATIVELY NEW

The Workforce Innovation Opportunity Act (H.R. 803) now requires state offices of Vocational Rehabilitative Services to allocate 15% of their budgets to serving transition aged youth. These services now include pre-employment services and have a goal of transitioning youth into integrated competitive employment settings. State Offices of Vocational Rehabilitative (VR) Services can subcontract this work to One-Stop Service Delivery Centers which can include colleges and universities. In order to find out where these centers exist in your State, please contact your local office of Vocational Rehabilitative Services. Just note that each state has a different name for VR Services. For example, in Massachusetts, it is referred to as the Massachusetts Rehabilitation Commission, or MRC. In New York it is known as ACCES-VR. In New Jersey, the name is referred to as the Department of Vocational Rehabilitative Services (DVRS). Connecticut simply refers to it as BRS, for the Bureau of Rehabilitative Services.

There are many pathways to employment and a life of independence. The path for a transition aged youth with a disability depends upon their interests, aptitudes, cognitive abilities, and level and type of disability. There are a growing number of post-secondary options for this population who do not want to pursue a college degree. The key to successful employment and independent living is finding the right post-secondary educational experience. There are more options now, than ever.

ABOUT THE AUTHOR:

Ernst VanBergeijk, Ph.D., M.S.W. is a professor at Lesley University in Cambridge, MA and is the Director of the Threshold Program which is a post-secondary transition program for students with a variety of disabilities. www.lesley.edu/threshold

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EP MAGAZINE: THE JOURNAL FOR SPECIAL NEEDS FAMILIES AND PROFESSIONALS

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RAISE-ing Expectations and Outcomes for Young Adults with Disabilities

BY LAUREN AGORATUS, M.A.

Even though the disability community makes up the largest minority group in the world, it also ranks as the minority group with the highest unemployment and under-employment rates. According to the U.S. Bureau of Labor Statistics, in 2017, 18.7% of people with disabilities were employed in comparison to the 65.7% of their nondisabled counterparts. Without a job and income, people with disabilities require additional funds and services. Further, without an income, they are limited in their ability to contribute to society through taxes, buying power, or simply using their skills and knowledge through employment. Although the nature of some disabilities may be a barrier to gaining employment, the larger issues often are a lack of information about rights, services, supports, and opportunities.

Responding to this need, the Rehabilitative Services Administration (RSA) of the US Department of Education Office of Special Education and Rehabilitative Services funded seven RSA Parent Training and Information Centers (PTIs) and a national center to provide technical assistance to those RSA PTIs.

About Raise

RAISE coordinates and supports the work of the RSA PTIs. These RSA-funded PTIs “develop and disseminate information and resources that increase their capacity to serve youth and young adults with disabilities and their families.” These seven RSA PTIs work with Parent Centers, individuals with disabilities and their families. RAISE has a website (www.raisecenter.org), facilitates periodic webinars, and disseminates a monthly newsletter available (*see Resources*). RAISE helps RSA PTIs and other parent centers to:

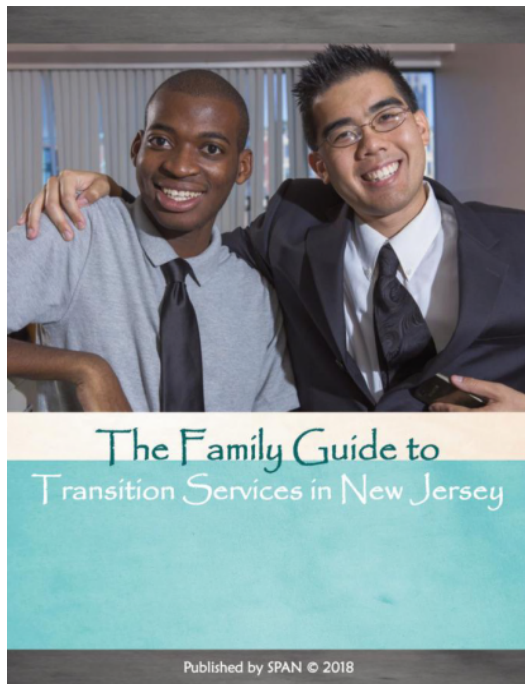
- Assist individuals with disabilities and their families to better understand and more easily access vocational rehabilitation (VR), independent living programs and services, supported employment, and other resources;
- Provide follow-up support for transition and employment programs;
- Assist in communicating more effectively with transition and rehabilitation personnel and other relevant professionals;
- Provide support in the development of the individualized plan for employment.

The RSA PTIs support these entities in the following states: Arizona, Colorado, Connecticut, Indiana, Kentucky, Maine, Massachusetts, Missouri, New Hampshire, New Jersey, New York, Ohio, Pennsylvania, Vermont, and Washington.

REACH for Transition

The REACH (Resources for Employment, Access, Community Living, and Hope) for Transition project is an example of an RSA funded PTI. Housed at the SPAN Parent Advocacy Network, REACH involves parent center organizations and their partners in the states of Connecticut, Maine, Massachusetts, New Hampshire, New York State, New York City, Rhode Island, Pennsylvania and Vermont. REACH serves families, self-advocates, professionals, Vocational Rehabilitation agencies, Centers for Independent Living, “and other adult system partners who are represented on the project’s 22-member Governing Board. REACH and its partners assist families and self-advocates to:

- *access innovative, supportive information on the Rehabilitation Act;*
- *receive support in navigating multiple programs and systems;*
- *learn tools and strategies to actively participate in the development of useful, relevant, and meaningful plans for independence; and*
- *become collaborative leaders with transition professionals to help youth impacted by disability achieve their goals.”*



A WAY FORWARD: Transition can be a complicated time. *The Family Guide to Transition Services in New Jersey* can answer your questions and can make transition a successful period for families and young adults with disabilities.

www.spanadvocacy.org/NJFamilyTransitionGuide

REACH’s innovative and responsive services are designed with and involve diverse youth/young adults with disabilities and their families. Through a regional Community of Practice, REACH enhances participating parent centers’ capacity, reach, and partnerships around transition and adult service systems.”

Other resources from REACH include transition tip sheets in English/Spanish, and webinar series on Becoming a Healthy Adult, healthcare across the lifespan, and youth leadership.

REACH for Transition parent centers have provided information (203,921), and web based resources (236,676), training (42,028) and support (40,108) to tens of thousands of youth/young adults, parents, and professionals.

In the past 4 years, the RSA PTIs have provided information (4,394,910), training (32,696) and support (36,670) to hundreds of thousands of families, youth/young adults, and the professionals who serve them.

RSA-funded PTIs and RAISE Transition TA Center engage all the key stakeholders, including families and self-advocates, with a goal of achieving the best outcomes in transition in all areas of adult life. Parents and youth/young adults can also reach out to their Parent Training and Information Center and/or Center for Independent Living for free assistance with transition issues. •

ABOUT THE AUTHOR:

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 SPAN, found at www.spanadvocacy.org

THE FUTURE IS NOW : RESOURCES FOR TRANSITION SERVICES



NATIONAL RAISE TECHNICAL ASSISTANCE CENTER RESOURCES ON TRANSITION

www.raisecenter.org

To find an RSA (Rehabilitation Services Administration) funded Parent Training & Information Center

www.raisecenter.org/rsa-parent-centers



REACH FOR TRANSITION

www.spanadvocacy.org/content/reach-transition-resources-employment-access-community-living-and-hope

Archived Webinars on Transition Topics

www.spanadvocacy.org/content/reach-transition-webinars-0

Further transition resources for families and self-advocates:



CENTER FOR PARENT INFORMATION & RESOURCES (NATIONAL) AND STATE AND LOCAL PARENT

www.parentcenterhub.org/find-your-center



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TAKING CARE: Caring for our children requires lots of love and lots of patience. If you have a child with special needs, that care can also be challenging. Respite care providers can help you.

CAREGIVERS NEED CARE TOO

“Primary caregivers often don’t realize just how stretched and stressed they are until they get a real break and can look back.”

The Child Neurology Foundation (CNF) wants parents to consider respite care services as a trusted option that could benefit their child and the rest of the family. Developed with families, the popular Respite Care Notebook includes fully-customizable forms that bring together all information about a child and his / her needs into one place.

Respite caregivers can use that information to provide the best care for the child.

We are sure you'd agree that caring for our children requires lots of love and lots of patience. If you have a child with special needs, that care can also be challenging, at times. Respite care providers can help you.

Families who have used respite care tell us that respite helps

them “create a better balance” in their lives. Respite care helps parents take time for themselves, to be with their partner or spouse, or with their other children. Some parents pursue their own interests, with support from respite care. In a small survey of 17 families, one parent reported returning to work, and another parent said she went back to school –thanks to respite care.

Respite care can also be good for your child. “Respite caregivers have helped my son participate in fun activities,” said one family. Respite care allowed another child to attend a weekend camp. Respite care can encourage friendships, build trust, and expand social skills. Respite care “is just as useful to our son as it is to us,” reports a parent. “We get a chance to have a break and our son has a chance to meet new people and form other relationships outside

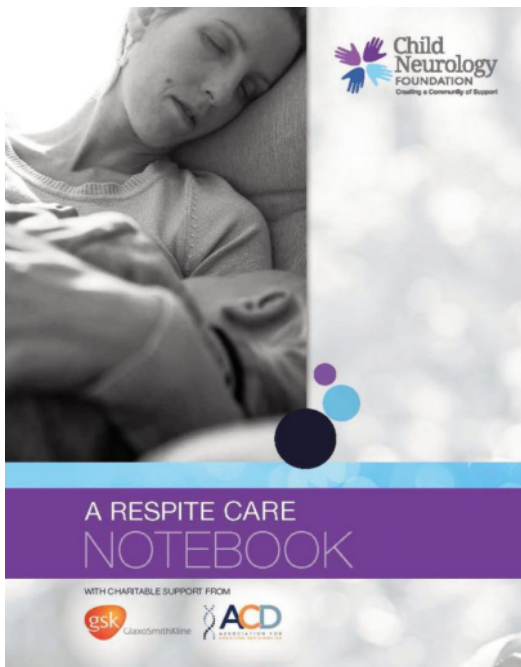
his own family. Even though he is non-verbal and has severe and profound intellectual impairment, it is very obvious to us that he enjoys his time in respite care.”

“Respite care expanded our circle of caring adults capable of providing high quality care for our son,” says one mother. In case of an emergency, it can be critical to have someone to call whom you trust to care for your child. If you can’t be available, respite care can step in.

The Child Neurology Foundation created the Respite Care Notebook for families who now use respite care services, and families who are thinking about respite care services. It is a tool to help guide the respite care provider in caring for your child. Some things to keep in mind:

1. *Respite care can be used for a few hours, several days, or even longer.*
2. *You decide how to use respite, based on your family’s needs, services available, and coverage/costs.*
3. *You fill out the forms in the Notebook that apply to your child. Skip the forms that don’t.*

This notebook is designed with a two- to three-day respite in mind. You may find that some of the information we ask for isn’t needed for shorter visits. For a longer visit, you may need to include more information, like how to restock the supplies, or how your child will be taken to school or therapy. Additional forms are provided with items to think about as you prepare for longer respite care visits.



TAKING NOTE: The Respite Care Notebook includes fully-customizable forms that bring together all information about a child and his/her needs into one place.

just how stretch[ed] and stressed they are until they get a real break and can look back.”

We hope this notebook will help you create a complete plan for your respite care provider so that your mind can be at ease while you are away from your child.

Visit the The Child Neurology Foundation at www.childneurologyfoundation.org

You might find that the notebook also helps remind other family caregivers of changes in medication or routine. As you update forms, you might keep the old ones, and build a record of your child’s care, growth, and use of respite services. We want this notebook to be useful for you, your child, and other families with special needs. As you become familiar with using respite services, we hope you will share your experiences with other families. If you need more information, or have questions or comments, email us at info@childneurologyfoundation.org.

Download the free, fully-customizable Respite Care Notebook

www.childneurologyfoundation.org/respite-care

Above all, we know you may feel nervous letting someone else come into your home and care for your child. But please remember that caretakers need care too! As one family member told us, “Primary caregivers often don’t realize

HERE TO LISTEN AND HELP : THE FAMILY SUPPORT AND EMPOWERMENT PROGRAM

CNF was a finalist for a 2018 EyeForPharma National Award in the Most Valuable Pharma Collaboration category – for collaborative work in developing a patient education initiative on respite care, which included our Respite Care Notebook.

If you need someone to talk to, CNF’s free Family Support and Empowerment Program (FSEP) offers families a direct connection with an experienced, compassionate Peer Support Specialist to help navigate the journey of disease diagnosis,

treatment, and management for a child living with a neurologic condition. Connect today with a Peer Support Specialist today: www.childneurologyfoundation.org/FSEP

CNF thanks GlaxoSmithKline for supporting the development and production of the Respite Care Notebook. CNF also thanks our advocacy partner, the Association for Creative Disorders, for additional support of the Notebook production.



As people have moved out of the developmental centers and into our homes,
into our neighborhood schools and into our communities,
these moves toward inclusion must include inclusive health and health care.

HEALTH DISPARITIES FOR ADULTS WITH IDD MAKE INCLUSIVE HEALTH A WORTHY GOAL

BY JANET SHOUSE



Did you know that people with intellectual and developmental disabilities die an average of 16 years earlier than typical Americans? And unlike other Americans, women with IDD die earlier than men with IDD.

This is not information any of us really want to hear.

So why is this happening?

We know that people with intellectual and developmental disabilities have a higher rate of co-occurring physical disorders, such as epilepsy, chronic constipation, obesity, vision impairment, hearing loss, diabetes and Parkinson's disease. They also have higher rates of mental health conditions, such as anxiety, schizophrenia and depression.

We know that people with IDD often are prescribed medications that can lead to medical conditions, such as metabolic syndrome, diabetes, osteoporosis, tardive dyskinesia and chronic constipation.

Individuals with IDD may not be able to report easily when or if they are in pain or feeling sick, leading to difficulties in diagnoses or even missed diagnoses. Often folks with IDD have experienced trauma in the past, including trauma related to health care professionals and medical procedures, and they may be reluctant to seek medical care or resistant to exams and treatments.

Some other issues include:

- *Physicians, nurses and other health care professionals may have had little or training in caring for people with IDD, especially adults. And they may have little or no experience with people with disabilities in their lives, so they may not feel equipped to interact appropriately.*
- *Clinicians may feel inadequate or anxious.*
- *Medical facilities and equipment may not be physically accessible, such as scales to weigh someone who uses a wheelchair or an examination table that allows for easy transfers.*
- *Access to health care providers may be limited by a lack of health insurance or by the type of insurance, such as TennCare/Medicaid.*
- *Health care providers may have concerns about issues of consent and conservatorship for the individual with IDD.*
- *Lack of a primary care provider may lead to people using the Emergency Room for most of their care, which is not cost-effective, convenient or suitable for routine care.*
- *Clinicians may allow an individual's diagnosis of autism, Down syndrome or other developmental disability to "overshadow" other possible diagnoses of physical or mental health conditions.*
- *Reimbursement issues, since treating patients with disabilities may take longer than a "typical" office visit would take.*

One of the "hats" I wear here at the Vanderbilt Kennedy Center is serving as the program coordinator for the IDD Toolkit, www.iddtoolkit.org, an online resource for medical professionals to better serve adults with intellectual and developmental disabilities. The tools include Health Watch Tables for autism, Down syndrome, Prader-Willi, fragile X, fetal alcohol spectrum disorder, and other developmental disabilities as well as tools on mental and behavioral

health. (Please check it out!) The IDD Toolkit project, which was funded by a grant from the WITH Foundation (<https://withfoundation.org>), has also led us to create online training for medical professionals as well as for individuals with disabilities, family members and caregivers (<https://ucedd.vkclearing.org>) about the special facets of health care for adults with IDD.

The online training was a collaboration with the Department of Intellectual and Developmental Disabilities and the Bureau of TennCare. And we've done several telehealth sessions (live video-conferences) with community health care providers, offering sessions on such topics as epilepsy, autism spectrum disorder, the special physical health care needs and behavioral health needs of adults with IDD. This, too, was funded by the WITH Foundation.

I recently was able to attend the annual conference of the American Academy of Developmental Medicine and Dentistry, an organization that was organized in 2002 to provide a forum for health care professionals who provide clinical care to people with neurodevelopmental disorders and intellectual disabilities. The AADMD mission is "to improve the quality of healthcare for individuals with neurodevelopmental disorders and intellectual disabilities."

The conference was held in Seattle, WA, in conjunction with the Special Olympics National Games, which helped launched the Center for Inclusive Health (<https://inclusivehealth.specialolympics.org>). According to the website, inclusive health is "the inclusion of all people, including people with intellectual disabilities (ID), in mainstream health policies and laws, programming, and services, training

Folks with IDD have often experienced trauma in the past, including trauma related to health care professionals and medical procedures, and they may be reluctant to seek medical care or resistant to exams and treatments.

programs, research, and funding streams." This effort includes encouraging fitness and wellness centers to become more inclusive as well, and for individuals to take charge of their health and fitness.

Many of you may not be aware that for more than 20 years,

Special Olympics, with help from the Golisano Foundation, (www.golisanofoundation.org) has had a program called Healthy Athletes (www.specialolympics.org/health.aspx?src=navwhat), in which athletes who are coming to a venue to compete are given health screenings. Since that time, Special Olympics Healthy Athletes has provided more than 2.1 million health screenings and trained more than 240,000 health care professionals in more than 135 countries.

Healthy Athletes screenings by volunteer health professionals are offered in vision, dentistry, podiatry, physical therapy and general fitness, audiology, healthy lifestyles and medical/sports physicals.

In 1995, the first year the screenings were done at the World Games, 15% of the athletes who were there to compete and were screened had such dramatic health conditions that they had to be referred to the emergency room for urgent care.

One of the big initiatives of AADMD, Special Olympics and other disability-related organizations has been to have people with intel-

lectual and developmental disabilities designated by the federal government as a “medically underserved population.” There are multiple benefits that come from having this population named an MUP. For a fuller understanding of the reasons for seeking such a designation, please see the Autistic Self Advocacy Network’s policy brief (http://autisticadvocacy.org/wp-content/uploads/2014/04/MUP_ASAN_PolicyBrief_20140329.pdf).

The benefits include:

- *Medical school loan forgiveness or reductions*
- *Special visas for foreign medical school graduates*
- *Expansion of physician and dentist training in the care of patients with IDD*
- *Funding for more preventive care and screenings for those with IDD*
- *Community health center grants to provide care specifically to this population*
- *Prioritization in research of issues affecting people with IDD*



TRICKY TRANSITION: For years I have heard families and individuals with disabilities say how much they love their pediatrician, and how difficult it was to find an adult health care provider who knew about their disability – and who was willing to take them as a patient.

The best ways to advocate for such a designation are contacting the governor and our two U.S. senators. But with the election coming up in November, you may just want to wait.

For years I have heard families and individuals with disabilities say how much they love their pediatrician, and how difficult it is (or was) to find an adult health care provider who knew about their disability – and who was willing to take them as a patient. And who was willing to take their insurance, which is very often TennCare/Medicaid. My son has experienced all those things. So, having the opportunity to spend two days with a whole crowd of people—physicians, nurses, dentists, medical students and other health care professionals—who have the knowledge, the training, the experience and the DESIRE to serve adults with IDD was wonderful and energizing for me.

I heard about efforts at several medical schools (<https://www.disabilitycoop.com/2018/03/12/medical-schools-focus-dd/24838/>) to incorporate courses about providing health care to people with IDD into the medical schools’ curriculums, since most do not currently have such courses for those training to care for adults. I also learned about a Federally Qualified Health Center that focuses on serving people with IDD in Colorado Springs, CO, called the Developmental Disabilities Health Center (<http://www.peakvista.org/locations/ddhc>). I heard about a nurse who makes sure that adults with disabilities at her

hospital in Stockton, CA, have the equipment they need and the things they like in an effort to keep them comfortable, engaged and calm while in the hospital. She, with the help of grant funding, gets specialized wheelchairs, so that those patients who may have had to leave their chairs at home can at least get out of bed. She also procures weighted blankets and coloring books and fidget toys.

One of the very few benefits of people with intellectual and developmental disabilities living in institutional or congregate settings was that a team of health care clinicians and therapists were able to specialize to provide multidisciplinary, coordinated care to these patients. One key, longtime member of the IDD Toolkit team, Dr. Tom Cheetham, the deputy commissioner of health services for the Tennessee Department of Intellectual and Developmental Disabilities, got his start working in a large developmental center in Ontario, Canada. He embraced the challenges and the rewards of working with this population, and in the years since those developmental centers closed, he has worked tirelessly to persuade other medical professionals to find their passion to care for adults with IDD.

As people have moved out of the developmental centers and into our homes, into our neighborhood schools and into our communities, these moves toward inclusion must include inclusive health and health care. I would encourage you to check out the Center for Inclusive Health and see if there are things that you might want to try.

These issues of health disparities for people with intellectual and developmental disabilities are issues that I and the folks at the Vanderbilt Kennedy Center are working to address through the IDD Toolkit project, our

University Center for Excellence in Developmental Disabilities, our Leadership Education in Neurodevelopmental Disabilities training, and numerous other activities at the VKC. This work also happens through partnerships with state government and community organizations like Tennessee Academy of Family Physicians, the American Academy of Developmental Medicine and Dentistry and Special Olympics.

I would invite you to share ideas, opportunities, comments or questions about these efforts. Please email me at janet.shouse@vumc.org. May we all strive to take care of our health and may we all be able to find and access appropriate health care. •

(Republished from TennesseeWorks with author’s permission.)

ABOUT THE AUTHOR:



Janet Shouse is a parent of a young adult with autism, and she is passionate about inclusion, employment of people with disabilities, medical issues related to developmental disabilities, supports and services, public policy, legislative initiatives, advocacy, and the intersection of faith and disability. She wears many hats at the Vanderbilt Kennedy Center, including one as a disability employment specialist for TennesseeWorks. If you have a question you want answered about employment for people with disabilities or other mysteries of the world of

work, please email me at janet.shouse@vumc.org

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LEARNING AT THE LEE SPECIALTY CLINIC

BY MINDY DOGMANITS

When I was offered the opportunity to visit the Lee Specialty Clinic in Louisville, I was excited to spend time in a facility that fulfills one of my career goals – specializing in treating individuals with intellectual and developmental disabilities (IDD). Grateful for the opportunity, I told my husband, “I’m going to Kentucky!” I booked my flights from Buffalo to Louisville, with only one week left of summer break, before I would have to return to the University at Buffalo School of Dental Medicine for my fourth and final year of dental school.

On the first day of my week-long trip, I observed the Dental Department at the Lee Specialty Clinic, which appeared just like any other dental clinic. During the daily morning meeting, Dr. Kristin Compton, the Developmental Dentistry Director, discussed important details about patients and procedures, particularly regarding the root canal treatment that the dental resident would be performing that morning.

I learned that root canal treatment is routinely performed at their clinic, and I am embarrassed to admit that I was somewhat surprised. We are often advised that tedious treatment, such as a root canal, is often too difficult to accomplish in patients with neurodevelopmental disabilities. Some providers are more inclined to take patients with disabilities to the operating room for dental work, a setting in which time does not permit for such procedures. Other providers may, instead, offer alternatives to treatment or temporary solutions that can be performed in the office more easily. The spe-

cial challenges pertaining to the dental treatment for this population requires both a particular skill set, as well as a philosophy about the best course of treatment.

I was exposed to both at the Lee Specialty Clinic, where the providers do not hesitate to offer a vast array of procedures, while considering patients’ personal needs. I watched them treat patients that need more time, more breaks, sensory toys, a mechanical lift out of their wheelchair, medical immobilization/protective stabilization, or simply compassionate reassurance. My admiration for Dr. Compton and the entire dental team grew exponentially throughout the week.

When Dr. Compton asked me about my post-graduate plans, I confessed that originally, I expected to attend a residency program in Pediatric Dentistry. I explained that I wanted to work with adults with special needs, but also with children. Pediatric dentists may be more equipped to deal with difficult or defiant behaviors, but this is not the only reason why many adults with special needs still visit a pediatric dentist. There is a widespread shortage of general dentists willing or competent to see these patients in their practice.

I explained to Dr. Compton that I did not want to be a general dentist, because I didn’t want to do extensive “esthetic work,” implying cosmetic elective cases. She responded, informing me that they do a lot of esthetic work at the Lee Specialty Clinic. Patients with IDD may need dental work on their front teeth, which would be considered “esthetic.”

It may sound cliché to have had a “life-altering moment,” but I had one. I realized that my top priority is the patient. Personally, the

ABOUT EP MAGAZINE’S NEW SERIES

One of the ways clinical students (medical and dental) learn is at teaching rounds. These occur when the students, accompanied by their teachers, professors and instructors, learn at the bedside and chair side. Real patients are used to emphasizing what are known as “clinical pearls,” those life-long lessons that provide insights, observations and deductions that improve patient outcomes. *EP Magazine’s* new series, Teaching Rounds, will share articles about the ongoing teaching rounds conducted by members of the American Academy of Developmental Medicine and Dentistry (AADMD) in various teaching settings.

– Rick Rader, MD, Editor in Chief



most rewarding aspect of dental care is establishing and maintaining a good rapport with patients. As a dental student, I have been trained to perfect my abilities in procedures and techniques. However, as I move closer to my residency, I recognize the value in selecting the best procedure for each patient's unique needs.

Therefore, I plan to focus my practice of dentistry by specializing in treating individuals that require additional attention or behavioral guidance during treatment. This refers to both individuals with intellectual and developmental disabilities (IDD) and children.

It was during this epiphany that I was able to put Pediatric Dentistry into perspective. If I intend to treat adults, I need to be a dentist for adults. I have since applied to General Practice Residency programs for next year, which will allow me to enhance my skills in general dentistry and provide higher quality care to my adult patients, before proceeding with the pediatric specialty.

Throughout the week, I also had the opportunity to engage with Dr. Henry Hood, Director of the Lee Specialty Clinic, and co-founder of the American Academy of Developmental Medicine and Dentistry (AADMD). Dr. Hood developed a series of five one-on-one lectures, during which I learned more about neurodevelopmental disorders and the history of disabilities. Though I've learned about intellectual and neurodevelopmental disabilities throughout my education, this information was given in a different cultural context with unique perspectives, teaching me something completely new.

Aside from enhancing my formal education and dental knowledge, I also explored other areas of healthcare. The observation of a multi-disciplinary integrative approach to care was the most outstanding aspect of this experience. Moreover, some of the most memorable moments occurred while I ventured into these new territories.

I was also given the opportunity to participate in a session of integrative physical therapy and speech therapy. Truthfully, this was one of the most enjoyable hours of my entire week. The session began with the patient reading "knock-knock" jokes aloud to practice his speech, and we all shared laughs at the punchlines. His

INTEGRATIVE APPROACH: At the Lee Specialty Clinic, the providers do not hesitate to offer a vast array of procedures while considering patients' personal needs. My admiration for Dr. Compton and the entire dental team grew exponentially throughout the week.

shirt and pants pockets were stuffed with snacks that he took with him from the group home, just before his sister picked him up for the appointment. With each lively chuckle, he had to adjust the jiggling crackers. Throughout the session, he taught me how to do wall push-ups and showed off as his skills tossing balls into a barrel and riding the stationary bike. At the end of the appointment, the physical and speech therapists remarked how impressed they were with his progress. His sister also mentioned that he did more at that appointment than ever before! Then she whispered to me, "He was showing off for you." I was not only flattered, but also inspired by his motivation to work hard.

Aside from enhancing my formal education and dental knowledge, I also explored other areas of healthcare. The observation of a multi-disciplinary integrative approach to care was the most outstanding aspect of this experience.

I am so grateful to have had this rare and meaningful opportunity. All of the people I met, the moments I shared with patients, and the striking revelations I had, will forever be impressed upon my heart and soul. The Lee

Specialty Clinic feels like one of a kind, but I hope to discover more wonderful facilities like this one, and certainly emulate their establishment throughout my career •

"Funding for the Lee Specialty Clinic is provided by the Centers for Medicare and Medicaid Services and the Kentucky Cabinet Health and Family Services — Department for Behavioral Health, Developmental and Intellectual Disabilities"

ABOUT THE AUTHOR:

Mindy Dogmanits is a fourth-year dental student at the University of Buffalo School of Dental Medicine and an active member in the student chapter of the American Academy of Developmental Medicine and Dentistry (AADMD). After graduation, she intends to provide oral health care to children, as well as individuals with intellectual and developmental disabilities. Her clerkship at the Lee Specialty Clinic cemented her interest in special care dentistry.



Empowerment and Fun Through Play

BY JACKIE SCHWABE

I grew up loving the music of the 80's. "Girls Just Wanna Have Fun" was one of my favorites. While I don't listen to Cindi Lauper very much these days, I still think that all girls really want is to have fun. For that matter, most children just want to have fun. Yet, having fun isn't always as easy as it sounds if you have special needs children.

I have more than one child at home. Several of my children would be considered typically developing, one has an autism diagnosis, and another has a dyslexia diagnosis. Yet, regardless of their diagnosis, each of them wants to spend family time doing something fun. We had to figure out how to have fun with our family at a price we could afford. We also wanted our kids to feel empowered when they went into other environments to play games that might be found at their friends' homes. The end result was learning how to adapt existing commercially available card or board games to fit the needs of all of our children. The rest of this



Learning to adapt existing games has carried over into other things in our life. We are not the type of family that sits and waits for others to tell us how we can have fun anymore. We have learned to be investigators, adapt to our situation, and make fun happen.

TOYS AS TOOLS

I realized after observing Zoe's therapists for four years during her Applied Behavior Analysis (ABA) therapy that she learned a little differently than our other children. I considered if applying some of the same techniques we learned in therapy would apply to teaching her how to play a game of UNO. The concept of toys as tools for fun emerged in our family.

THE INVESTIGATOR

The first thing to consider when adapting a new game for your child is to investigate if they have some of the basic skills needed for the game. The idea is to remove all the extra stuff and identify if they can perform a specific skill and to what level they are able to perform it. For example, a key component of UNO is to match colors and numbers to one another. Yet, that is actually two skills, one is matching colors and the other is matching numbers. So, we isolated the first investigation to test if she was able to match colors. We also didn't do these tests with all the other children around. We are not playing the game with the entire family yet, we are just trying to see how we could best adapt the game, so Zoe could be included. On a side note, we did find that as we did this type of investigation more and more often, that we could play the "investigation" game. This game allowed all the other family members to be the investigator that found out how much their sister knew. Our kids are now master investigators and game adaptation consultants.

GOOD DEAL: Investigate if your child is able to draw cards from a stack of cards or if you need to have the cards spread out in a pile to make them easier to pick up. If teaching taking turns and drawing a new card are too much for one pregame session, then you can do each during different times.

article describes how we modified UNO to meet our family's needs and a few suggestions on how you too might adapt other games, save some money by avoiding expensive special need-only toys, and use toys as tools for fun, engagement, and family time.

UNO CAUSED A MELTDOWN

Uno is a game that we played as kids with our parents at the dinner table. It was simple enough; the goal was to get rid of all of your cards and when you had one left in your hand you would yell UNO to warn the rest of the players you were about to win. The game was a bit more complex than this description as there were skip, reverse and other action cards to make the game a bit more fun. However, the first time we tried to play Uno with Zoe, our child with an autism diagnosis, we found out pretty quickly that it wasn't as simple as we originally thought. Since it wasn't as simple as we thought, it was also not as fun for her as we thought, and it ended in a major meltdown that wasn't fun for anyone.

PROCESS OF ADDITION

Once we decided to test matching with colors, we then had to find out how many cards she could see at one time and not be overwhelmed. We started with only three cards. Two of the cards were the same and one was unique. We asked her to match the colors. Lucky for us, she was able to do that with ease. We included the color matching until we got to seven cards. We called this the process of addition. We didn't eliminate options, we kept adding a little at a time. We selected seven because that is the number cards in an UNO hand. However, if you child can do four cards and no more, then stop at four. You are making up your own adapted rules right now to see how you can best play the game.

Rules for Common Card Games

When we are at home, we like to spend time enjoying family fun, so we learned how to adapt existing commercially available card or board games to fit the needs of all of our children. We modified UNO to meet our family's needs, and we adapted some other games to avoid expensive special needs-only toys. Now, we use toys as tools for fun, engagement, and family time.



UNO

www.unorules.com



GO FISH

www.bicyclecards.com/how-to-play/go-fish

BINGO

www.bicyclecards.com/how-to-play/bingo



YAHTZEE

www.hasbro.com/common/instruct/Yahtzee.pdf

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AHEAD OF THE GAME: Talk to your other family members to advise them about new adapted game rules before you play so there are no surprises when you play together.

POWER OF SAFETY

You can also do the same test for matching numbers. If you find out your child can only match the colors or only the numbers, then adapt the family game to only match on that item. Two great things have already happened. You already played with your child and prepared them for matching in the family game and you did it in a safe way where they do not feel overwhelmed or embarrassed for not understanding the rules. We made it safe for her to learn. The power of safety does amazing things for self-esteem, or at least it did in our home. You can even consider matching only colors or only numbers the first time to really keep things simple for your child as they learn new skills.

ADAPTATIONS FOR FINGERS

Another adaptation we use was to have everyone's cards face up in front of them instead of being held in their hands. Some children, including our child, have dexterity limitations – and we didn't want her to get frustrated with that and miss out of the fun.

LEARNING SOCIAL SKILLS LIKE TAKING TURNS

Taking turns is also an important skill for playing a card game. Doing a one-on-one investigation with your child to play the matching game where you take a turn and they take a turn is a good practice before

the family game as well. You can also find out at this time if they are able to draw cards from a stack of cards or if you need to have the cards spread out in a pile to make it easier to pick up. If teaching taking turns and drawing a new card are too much for one pregame session, then you can do each during different times. The key is to have fun each time and build on skills each time you play. The big win will be playing your family's own personal game with your child being fully included in the social experience.

SENSE OF CONTROL: CONTINUE WITH SENSE OF SAFETY

Now you are ready to play with the family. It is a good time to talk to your other family members, including other children, to advise the new adapted game rules before you play so there are no surprises when you play together. You want to encourage your child to pick from a few games that you have done pregame warm up with. This gives them a sense of control and empowerment. Provide only two to three choices so you don't overwhelm them during your first game together.

MEET THEM WHERE THEY ARE

Once they select the game to play, setup the game to work the way you adapted it to work. If you are playing UNO, remove all of the action cards so you only have the cards with colors and numbers. Play on a surface

that is clear of other distractions. Explain the rules in a simply way, but do not oversimplify. If your child can handle a more complex explanation, use words they are comfortable using. Meet your child where they are. Focus on only the number of steps that your child is able to follow and only explain that many. For example, our daughter could only follow two-step instructions when we did this the first time, so we only provided two details at one time. Our daughter also has a seven to ten second processing delay, so we let time pass before we explained more as well.

EMPOWERMENT THROUGH PLAY

We found the more we empowered Zoe to make choices about the adaptations, the more fun she had and the more ownership she took. Zoe decided she didn't want to say UNO, she wanted to say Poppy. Then the new rule in our house was that the winner got to pick the special word we yelled when we had one card left. I am happy to say that she is now able to play by the standard rules of UNO, as well as the family rules. Turns out that the family rules ended up being more fun in some cases.

LESSONS FROM THE FIELD

A few great lessons came out of learning how to adapt games to allow our daughter to play with us. First, we stopped buying a lot of special games that were just for her. Early on we purchased a lot of things that we couldn't use or didn't use and then we didn't know what to do with them. Also, our other children felt that their sister got a lot of fun toys and they didn't get anything. They seemed to understand the non-toy like purchases, but the games and toys were a different story.

Second, we were able to play games together as a family. Let's face it, things can be difficult raising children and trying to keep everyone connected. We were trying to play board games or do other things that

would allow family time, but it was really difficult. Once we figured out how to adapt games, we were all able to spend time together. We were able to work on our daughter's social skills too.

Third, we were able to play with a purpose. What I mean is we were able to use toys as tools to encourage cognitive skills, identify number, identify colors, matching, counting, and strategic thinking.

Fourth, we empowered all of our children to find innovative solutions to solve their own problems. Our child with dyslexia preferred games that didn't have a lot of reading. Our child with an autism diagnosis turned out to be a great reader, so she was able to help adapt things for her older brother.

“We empowered all of our children to find innovative solutions to solve their own problems.”

HOW WILL YOU MAKE FUN HAPPEN TODAY?

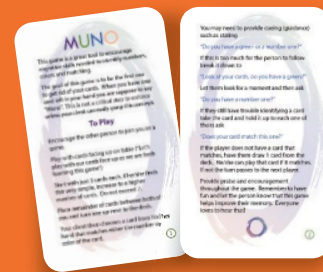
Sometimes we can get caught up in all the things we or our children cannot do. We want to have fun and we want them to have fun too. My kids have taught me more than any degree I have even obtained, and any job I have ever worked. Learning to adapt existing games has carried over into other things in our life as well. We are not the type of family that sits and waits for others to tell us how we can have fun anymore. We have learned to be investigators, adapt to our situation, and make fun happen. How will you make fun happened today? •

ABOUT THE AUTHOR:

Jackie Schwabe is co-founder and CEO of Mindlight, LLC and Vice President of Leadership Research at North of Center. She is a certified Caregiving Presenter, Certified Caregiving Consultant, and Certified Caregiving Educator. She received her BA in Management Computer Systems from the University of Wisconsin – Whitewater and her MBA in Technology Project Management from the University of Phoenix. She has been active in the area of healthcare integration, healthcare IT, telemedicine, product development, and product management for over 20 years. She has been a cross-sector, cross-discipline leadership practitioner her entire career. Her mission is to provide the tools, opportunities, and connections people need to be their best self.

Empowerment Fun, and Toys as Tools

Our family was trying to play board games or do other things that would allow family time, but it was difficult until we figured out how to adapt games. Once we did, we were able to spend time together, and work on our daughter's social skills too. MUNO is an adapted game that helps to encourage the cognitive skills needed to identify numbers, colors and matching. The goal of this game is to be the first one to get rid of your cards.



MUNO: A CARD GAME FOR MATCHING COLORS AND NUMBERS

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Participate in fundraising to support the Champions Together team.





SPECIAL OLYMPICS A VIEW FROM THE INSIDE

BY RENEE DEASE

Hi, my name is Renee Dease. I have worked at the headquarters of Special Olympics for 35 years! I was the very first receptionist that the Special Olympics office ever had. I have filled many roles during my time at Special Olympics and have had the opportunity to see the organiza-

tion change and grow into what it is today. As a young adult, I went to the District of Columbia Arc and trained for two years to be an administrative assistant. I interviewed with Mrs. Eunice Kennedy Shriver, the founder of Special Olympics in 1978 and got the job, and the rest is history.



MORE THAN A GOOD SPELLER: *(Opposite page)*

Renee helps train Health Messengers to spread the word about Special Olympics Health; *(above, clockwise)* with daughter Bridget, who is earning her Master's degree in Playwriting; celebrating Halloween with staff members; and giving a speech at the Kennedy compound in Hyannis Port, MA for the 50th anniversary of Special Olympics.

When I first met Mrs. Shriver, I thought she was very kind. When I met her, she told me, “Renee, I hear you’re a good speller and we need more good spellers in the office.” I was so excited to be working with Mrs. Shriver. Her brother, former U.S. President John F. Kennedy, had passed so many bills to help people with intellectual disabilities I couldn’t believe I could work side by side with this influential woman and her family. Mrs. Shriver had so much energy and she cared so much for people. I admire how she saw that sports and recreation promoted confidence in people with intellectual disabilities (ID). She would have Special Olympics athletes come to her house to swim in her pool.

Before working at Special Olympics, I was an assistant coach for athletics and a spokesperson for Special Olympics DC. I helped athletes write speeches for events and was the MC for the annual Athlete of the Year ceremony. I was a board member of Special Olympics DC and co-wrote a play for Special Olympics DC athletes to perform called *On the Road to Success*, which was inspired by *The Wiz*.

Working at Special Olympics was much different 35 years ago. The floor we worked on had four offices for about 15 people. Staff would run down the hall always in a hurry to get everything done. We’d also yell across the hallway to each other.

My current role at Special Olympics is Coordinator of Healthy Athletes. In this position, I support Healthy Athletes events. I interview Special Olympics athletes from around the world about their health and wellness, and leadership activities. I have a record of more than 20 years of athlete interviews!

In July of 2018, Special Olympics started a year-long celebration of the 50th anniversary of the first Special Olympics Games in Chicago, Illinois. I was proud to attend and see how Mrs. Shriver’s legacy is being carried on. In 50 years, Special Olympics athletes have more opportunities to be leaders in the Movement. I saw families come together to support each other and learn more about Special Olympics. I’m proud that Special Olympics is working with

schools to make sure that the next generation will include people with intellectual disabilities in their lives. Seeing unified sports take off is also amazing. I love that when people with intellectual disabilities play sports with people who don’t have disabilities, it gives everyone a chance to work on the same team and to have an equal share in play.

With Special Olympics, in 1981 I had the chance to have my first plane ride to go visit the Special Olympics Ohio Program. In my 35 years at Special Olympics, much has changed. I went to college and received an Associate’s degree in Liberal Studies. My lifelong career dream is to use my writing and communication skills so I can educate people around the world about Special Olympics, and to teach them what motivation, determination and courage people with intellectual disabilities have. In my spare time, I love to write poetry and I’m successfully starting a garden at my house. I have a beautiful daughter, Bridget, who is going to school to get her Master’s degree in playwriting next year.

The Special Olympics office has grown from 15 people to having several offices around the world. As for me, I learned how to use a computer and don’t need to holler down the hallway for people any more. What hasn’t changed is that people with intellectual disabilities still don’t have the same rights and benefits as people without disabilities. I’ll continue my work with Special Olympics to ensure that in the future, the world will be more accepting of people with disabilities and my job won’t be needed anymore. •

ABOUT THE AUTHOR:

Renee Dease has worked at the headquarters of Special Olympics for 35 years. Starting out as their very first receptionist, she currently is Coordinator of Special Olympics’ Healthy Athletes. In this position, Renee interviews Special Olympics athletes from around the world about their health, wellness and leadership activities.

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Dominique Dawes, 3-time Olympic gymnast, co-chair of the President's Council on Fitness, Sports & Nutrition



UPS & DOWNS

A SPECIAL OLYMPIAN'S
JOURNEY TO GREATNESS

BY OLIVIA BATCHELOR, OTS

In the small town of Russellville, KY, Lee Dockins is a local celebrity. The 31-year-old with Down syndrome has far surpassed everyone's expectations for her life and continues to strive for greatness. With 222 medals and 4 first-place ribbons from the Special Olympics, this gymnast has made her hometown proud. Recently, though, Lee's successes have also been noted on a national stage, as she was one of four athletes chosen to represent the Special Olympics at their 50th Anniversary exhibit in Washington D.C.. When asked about her journey, Lee was speechless, affirming that the entire experience has been simply unbelievable.

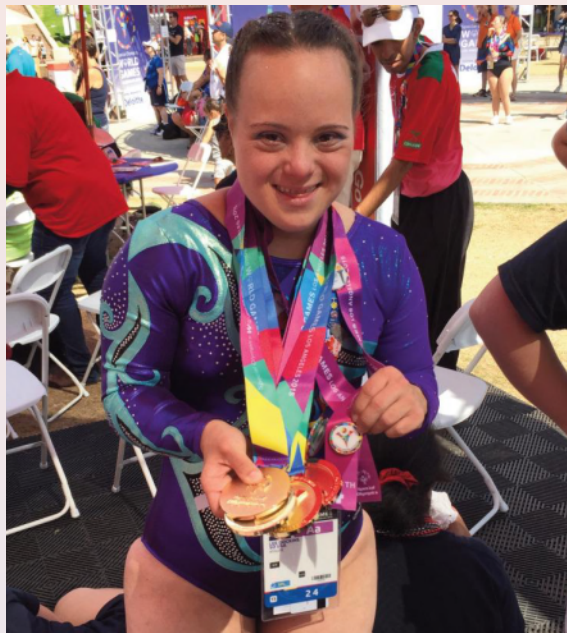
According to her mother, Sharon, Lee was destined to be a gymnast. When she was still an infant, Sharon walked into Lee's room to check on her only to find her sound asleep in the splits position. By the time she was five, the family decided to enroll her in Logan County Gymnastics, a brand-new gym in their hometown. Owners Donnie and Polly Porter worked with Lee for many years and continue to train her to this day. "Skill by skill,

I learned," she reflected fondly. At 31, Lee is the longest standing member of the gym.

Lee's journey with Special Olympics began at age eight when her teacher, Mrs. Karen Milliken, encouraged her to compete at the area games in Bowling Green, KY. Mrs. Milliken stayed involved in Lee's career long after she left her classroom, joining the family at their first USA games in Ames, Iowa and even accompanying them to

China for Lee's first world competition. According to her mother, it is these individuals that have made all the difference in her daughter's life. "Lee epitomizes the idea that it takes a village to raise a child," she shared, "She really is an example of that with teachers, family, church, coaches... Everybody's helped to raise Lee."

With so many supporters over the years, Lee's success has been remarkable. She has competed multiple times on the national stage and has travelled to the world games in China, Greece, and Los Angeles, even having the opportunity to participate in a rhythmic gymnastics exhibition event in Switzerland called Gymnaestrada. Snippets of Lee's journey have been highlighted in Sports Illustrated magazine and in segments on ESPN. This summer in Seattle, Lee earned her first Best All Around gold medal and was eager to show it off. "It's just unbelievable," she said of the whole experience, "I can't believe how cool it is!"



MORE UPS THAN DOWNS: (Left) Lee took the all-around gold in her artistic gymnastics division at the Seattle games; (Right) Lee is featured prominently among five stars of Special Olympics' first half-century at the Smithsonian Institute.

At this point, Lee competes at Level 3 (of 4 total levels) in both artistic and rhythmic gymnastics. Within the Special Olympics, competitive levels are determined by skill level, with more difficult skills being expected as the levels increase. As a Level 3 gymnast, Lee is expected to be able to cartwheel dismount off the beam and complete a handstand vault. However great these stellar accomplishments are, they are not the end goal for our celebrated gymnast. When asked about the future, Lee voiced her desire to compete as a Level 4 gymnast. On practicing these new skills, she had this to say: "It's a little harder, but I'm still doing it because I love it. It's scary, but I'm cool with it," to which her mother replied, "Oh, you're not scared of anything; you're fearless." In light of all her successes over the years, it is difficult to disagree.

Over the years, gymnastics has become more than just a sport for Lee. In recent years, she has taken on a role as assistant coach at Logan County Gymnastics. For five years, she has been helping the three- to four-year old class, and she is now transitioning to a role where she will begin helping older gymnasts with rhythmic skills. In addition to this, she also participates in the ambassador and global messenger programs through the state office of Kentucky Special Olympics. In this role, she learns about many of the social aspects of athletics such as giving speeches and meeting new peo-

ple. According to Sharon, seeing Lee grow into these roles has truly given her competition purpose.

When asked about their favorite memories over the years Sharon noted that, on top of her list, it would be the experience of working with curators at the Smithsonian museum put together Lee's portion of the exhibit. For the next year, the museum will display the leotard that Lee wore while competing in China and the hand grips that she used at the Greece games. Once the display is taken down, Lee's memorabilia will be kept in the vault alongside those of Olympic greats.

As for Lee's favorite memories, she says meeting Olympic speed skater Apollo Ohno on two separate occasions has been a highlight of her experience. The pair met first at the World Games in Los Angeles in 2015 and were reunited after Lee's knee buckled during competition at the USA Games this summer in Seattle. "He cheered

me up," Lee shared, "I put the ice on my knee and he said, 'Good job, Lee. I'm very proud of you.'"

In terms of advice for anyone who is considering participating in Special Olympics, Sharon Dockins had this to say to parents: "Anytime you can get your child involved athletically, it helps them. It obviously helps them physically, but it also helps them socially... Get behind them, support them, and do whatever it takes."

Sharon also affirmed the added benefits that gymnastics has given Lee in terms of muscle tone, strength, coordination, and grace. Lee herself had similar advice for future athletes, discussing the many skills she has learned over the years and repeating Special Olympics' Oath as her personal motto: "Let me win. But if I cannot win, let me be brave in the attempt."

Both mother and daughter commended the Special Olympics platform for promoting the idea of inclusion to the general public. This year's slogan rings out as a personal challenge from Lee and Sharon to us all: "Rise with Us."•

ABOUT THE AUTHOR:

Olivia Batchelor, OTS is a Graduate Assistant at The University of Tennessee at Chattanooga.



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FROM OUR FAMILIES... TO YOUR FAMILIES

MILITARY SECTION

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By Shelly Huhtanen



AN OVERVIEW OF *Special Education*

At-home activities, beyond paper and pencil, are another critical element that can bolster learning along the way.

Special education is designed to meet unique needs of children with special needs, ages 3 through 21. Military OneSource offers tools and resources to help you navigate the system. Start here to learn about the special education process, including eligibility, relevant laws and regulations, moving (including overseas) and graduating or leaving school.

About the Individuals with Disabilities Education Act

The Individuals with Disabilities Education Act (<http://idea.ed.gov>) ensures that all children with special needs have access to a “free appropriate public education” (www2.ed.gov/about/offices/list/ocr/docs/edlite-FAPE504.html) and they have the necessary tools to meet their educational goals. The act governs how states and public agencies, including the Department of Defense, provide early intervention, special education and related services to eligible children with disabilities, ages birth through 21.

Eligibility

The Individuals with Disabilities Education Act assists with early intervention services for eligible children, birth to age 3, and special education services for eligible children, ages 3 to 21, in three specific areas:

- Identification
- Evaluation
- Delivery

Children qualify for special education based on guidelines set by the state and Department of Defense.

Relevant Regulations

The U.S. Department of Education uses specific regulations that implement the Individuals with Disabilities Education Act (www.militaryonesource.mil/products#!/detail/194) in public schools in the United States and its territories. States then create guidance to supplement these regulations. You can find state regulations on state education agency websites.

The Department of Defense school system operates under Department of Defense policy as outlined in Department of Defense Instruction 1342.12, “Implementation of Early Intervention and Special Education Services to Eligible DoD Dependents,” June 17, 2015 (www.esd.whs.mil/Portals/54/Documents/DD/issuances/dodm/134212m.pdf).

It includes these guiding principles:

- **Free appropriate public education.** *This principle makes sure every child, regardless of disability, has the right to attend a public school and receive an education tailored to achieve his or her highest potential.*
- **Appropriate evaluation.** *The testing process is regulated so children receive the best individualized education placement and services.*
- **The individualized education program, or IEP.** *This written document is created for every child in the public school system who’s eligible for special education. It’s drafted by an interdisciplinary team and reviewed every year.*
- **Least restrictive environment.** *This principle requires that students with disabilities share the same setting, as much as possible while still meeting their needs, with students who do not have disabilities.*



SCREEN FOR QUALITY: Do not give up screen time, but rather help your child manage it. Share screens. No matter your child's age, watch and listen to books on devices together. Discuss as you go. Re-watch and share a laugh or a tear.

- **Parent and teacher participation.** This principle establishes the importance of parents and teachers working together to achieve their children's educational goals.
- **Procedural safeguards.** These are in place to protect the rights of families with special needs.

Moving with an IEP

The act also protects your child's educational progress when you move to a new school district. School districts must provide comparable services that honor the previous school's IEP. Keep in mind, the new school district may not necessarily recreate the same program.

When a student with an IEP transfers, the new school must:

- Provide free and appropriate public education
- Include services comparable to those in your child's current IEP

Resources vary according to location. In some cases, they may be better than those available at your last duty station. Reach out to the school's counselors and teachers who will develop a new IEP for your child after your move.

Bring current copies of your child's IEP and eligibility records before transferring to start similar services immediately in your new location.

See Moving With an IEP for more information (http://download.militaryonesource.mil/12038/EFMP/eLearning/MoveIEP_508/MoveIEP_508/slide01.html).

Moving Overseas

The Department of Defense Education Activity special education website (www.dodea.edu/Curriculum/specialEduc/index.cfm) lists special education relocation suggestions and contacts for families moving overseas. Parents should contact the responsible spe-

cial education coordinator if a child receiving special education also requires:

- Special equipment
- Assistive technology
- Individualized paraprofessional support

If you need help with a PCS, be sure to reach out to your local installation's EFMP Military Family Support Center.

Graduating or Leaving School

Young adults with disabilities can find a number of continuing education and work opportunities within their communities. You can help find these opportunities by calling your local state vocational rehabilitation program. Learn how to advocate for your child within the school system by contacting your Center for Parent Information and Resources (www.parentcenterhub.org/find-your-center).

No matter what stage of life, individuals with special needs deserve a quality education just like everyone else. The Individuals with Disabilities Education Act is in place to open classroom doors to every child and help all students to be their best academically. The Exceptional Family Member Program provides family support, education and much more.

Contact a Military OneSource special needs consultant (www.militaryonesource.mil/special-needs1) if you have any questions or concerns regarding the care and education of your family member with special needs.

See the Special Education Fact Sheet for more information (www.militaryonesource.mil/products#!/detail/203).

– Military One Source



MILITARY LIFE

PERSON-CENTERED PLANNING

Person-center planning helps individuals with disabilities direct their own lives -- with options to plan housing, work, finances and more. Here are some questions and answers that can help you better understand person-centered planning, how it can help and how you might fit into the process.

WHAT IS PERSON-CENTERED PLANNING?

- Brings the individual together with a team of family, friends, neighbors, employers, community members and healthcare professionals to find out what is important to the person with the disability, now and in the future
- Matches the wants and needs of a person with a disability (www.militaryonesource.mil/-/an-overview-of-adults-with-special-needs) to existing services, adapts existing services to better suit the person or creates new services if required
- Gives people with disabilities and their families more control over services and the direction of their lives
- Helps people with disabilities accomplish their goals and fit in and contribute to society in a personalized way, rather than passively accepting services based solely on their diagnosis and condition
- Finds ways for the person with the disability to develop the skills and abilities needed to work toward achieving his or her goals and having more control in his or her life

WHAT ARE THE BENEFITS?

- Focuses on the person with the disabilities, not the planner
- Focuses on the person's strengths, not deficits
- Helps alleviate isolation, stigmatizing labels, loss of opportunity and loss of hope

WHAT ARE SOME BASIC PLANNING OBJECTIVES?

Person-centered planning aims to help the person with disabilities do the following:

- Live in the community
- Choose his or her own services and housing
- Develop his or her own skills and interests
- Be treated with respect
- Find a valued social role
- Find meaningful independent relationships

WHO MAKES UP THE PLANNING TEAM?

- An unbiased facilitator: Facilitators encourage brainstorming during the meeting and help identify friends, family or professionals that can help keep the plan on track.
- Advocates: Disability service advocates can help find resources, discuss options, help with evaluating plans and services, and assist the person with the disability become a self-advocate. In some cases, this may be a person with knowledge of disability law.

- Family members and friends: Immediate and extended family members and close friends can weigh options and help with informed decision making.

HOW DO YOU BUILD A TEAM OF ADVOCATES?

- Your installation Exceptional Family Member Program (www.militaryonesource.mil/-/exceptional-family-member-program-family-support) Military Family Support Center and Military OneSource can assist with finding person-centered planning facilitators and resources. Although facilitators and related resources will most likely come with a fee, a consultation with your installation Exceptional Family Member Program or Military OneSource is free. Call 800-342-9647 to speak with a consultant and be connected to experts on a wide range of topics relevant to families with special needs including education, independent living and more. (www.militaryonesource.mil/-/special-needs-consultations)
- State-Provided Resources: State-provided adult services specialists may be available in some states. You can search for programs and organizations providing advocacy at Disability.gov by entering "advocate" and your state.
- University Centers for Excellence in Developmental Disabilities: A Center for Excellence is another great resource for finding person-centered planning facilitators. To locate a center in your state, visit the Administration on Intellectual and Developmental Disabilities website (www.acl.gov/programs/aidd/index.aspx).

HOW CAN YOU HELP?

The more you know about how you fit into the planning process, the more you can help meet the goals of the person with the disability. To assist with planning, it's useful to become familiar with some of the following:

- Preparation: An Internet search for "person-centered planning toolkit" should provide resources to help you prepare for the planning meeting.
- Organization: Get organized with the Special Care Organizational Record for Adults With Special Health Care Needs (www.militaryonesource.mil/products#!detail/142).
- Disability services and rights: People with disabilities have certain rights under the law (www.militaryonesource.mil/-/understanding-the-americans-with-disabilities-act).
- Many benefits are available for people with disabilities. Visit Disability.gov to find out what Social Security benefits, medical services, employment, housing, transportation, respite care and other forms of assistance are available at the federal level. The site also has links to state benefits.

Military OneSource special needs consultants (www.militaryonesource.mil/special-needs1) can answer your questions and concerns about the care and education of your child or adult family member with special needs. Call us at 800-342-9647.

– Military One Source

I AM A VETERAN AND THIS IS MY VICTORY.

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Baggage

Broden’s team has not only helped him, but they have also helped me. As his team encourages him to grow, it is also giving me strength to let the past go.

“Your journey will be lighter and easier if you don’t carry your past with you.” I was reminded of this recently when I was approached by one of Broden’s RBT’s (Registered Behavior Technicians) about modifying how I pack his lunches each day. She sat me down when I arrived at the clinic at the end of the day. “Shelly, we need to talk. I talked to Broden’s team and we need to take another step with Broden’s food plan. Broden is 12 years old.” The RBT who presented the new plan for meal preparation is the one who reminds me that Broden is a child first, who just happens to have autism.

“Why don’t you try sending Broden’s lunch similar to a typical 12-year-old boy?” I was confused at first and she knew that she would have to spell it out for me. She tilted her head down and looked me in the eye, “Do you need to cut up his hot dogs and apples into little squares?” I told her that I was scared that he would choke. She then smirked and responded, “You cut his grapes in half! You cut his blackberries in half!” I started

to see her point. Since Broden had started his food intervention at two years old, I had continued to cut up every food item that I put into his lunch.

I sat in the chair and started to look at the floor. At that moment I came to the conclusion that the problem had resided with me over the last decade and it had everything to do with guilt. My obsession over packing his lunch and making sure every food item could be ingested by a two- year-old stems from a choking incident that happened when he was two (from a piece of chicken) and the feeling of approval that I am good enough to be his mom.

About ten years ago, our family was staying in a hotel traveling from Alaska to Kansas. During dinner in the hotel room, I let Broden sit between my legs on the floor and he started to choke. I didn’t notice at first that he was choking because he was sitting with his back to me. Mark was the one who noticed. I tried to help Broden, but was unsuccessful



ful so Mark grabbed him and was able to do the Heimlich to free Broden’s airway. I became frantic and felt helpless as I stood there not being able to do anything as I watched Mark try to open Broden’s airway. My sense of helplessness was too much to bear. Not think-

ing clearly, I opened up the door and ran down the hall screaming. Still, to this day, my actions are trivial to me, but at the time it seemed to be the only thing I could do. That feeling of helplessness has haunted me for years. Even to this day, I will not leave the house if an adult is not watching Broden eating anything that I think could be a potential choking hazard.

My feelings of helplessness and not feeling like I could measure up as a parent continued. Months later after the choking incident, Broden’s screaming at night had escalated. We were settled into our house at Fort Leavenworth and I could tell something wasn’t quite right with Broden. During nights when Broden

would scream, Mark and I would have the flashlight in his mouth to rule out possible strep. We would apply pressure to his abdomen and would notice it felt tight. Was it his appendix? We would never know because Broden couldn't tell us. The only thing we did know was that he was in pain. Many times, we would make the decision to take him to the local ER to

have him checked because if it was serious and it went overlooked, we would never forgive ourselves.

One night, Broden had been screaming and was in so much pain, he grabbed his hair

and pulled it out and then grabbed mine and pulled mine out. Mark said, "Take him in. He's in pain." Normally they would tell us it was gas, drug him up, and then send him home. This time, it just seemed different. Was it strep? We weren't sure so I put him in the car in the middle of the night and rushed him to the ER. Broden was hysterical. The doctor checked him out and then left the room.

"Broden's RBT turned to me and said, 'You are Broden's mom, so he's going to be just fine. Don't worry.' I needed to hear that."

Minutes later, the doctor came back in, looked at me and said, "I don't know, mom. I've looked at your son's records. I'm about to turn you in to social services." I was shocked. He accused me of trying to hurt my son. He left the room again and I called Mark right away. His parents were in town so they were able to watch Hayden. Mark came up to the

ER for support. The doctor stepped into the room to see Mark there ready to confront him. The doctor turned around and walked out of the room. We never saw him again. A week later,

Broden was diagnosed with autism and severe food allergies. At least we had answers and could move forward with helping him.

The road has been long, but I'm grateful that Broden has responded to his food intervention and his weight is steady. Broden's team has not only helped him, but they have also helped me. I am glad that I felt comfortable with his RBT and

confessed to her as to why I had been so overbearing with his food. As his team encourages him to grow, it is also giving me strength to let the past go. After we both agreed that Broden needed to move forward with his eating plan, his RBT started to walk out of the waiting room. She turned to me and said, "You are Broden's mom, so he's going to be just fine. Don't worry." I needed to hear that.

There's a popular quote that states, "Everyone comes with baggage. Find someone who cares for you enough to help you unpack." Thankfully I'm surrounded around people who care. •

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.

Inclusion *drives* Innovation

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SAY TO ALL OF YOU IS
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RON WHITCOMB SGT US ARMY 1968 - 1969 SQUAD LEADER, VIETNAM

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