PLUS: UNITED STATES MILITARY SECTION

EXCEPTIONAL PARENT
ep
PHYSICIAN • PATIENT

EXCEPTIONAL PARENT
MAGAZINE
MARCH 2018

INSIDE • GENETIC ALLIANCE:

FINDING CAMPS *for* CHILDREN *with* DISABILITIES

PLUS • AN EP EXCLUSIVE:

TURNING CAMP STAFF *and* VOLUNTEERS INTO CARING LEADERS

THE ANNUAL ISSUE:

SCHOOLS AND CAMPS

ENDREW F. SUPREME COURT CASE:

STRENGTHENING FAMILIES' VOICES *at* IEP MEETINGS

FROM THE AADMD:

GENETIC MANIPULATION *for* INDIVIDUALS *with* DISABILITIES

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Information and Support for the Special Needs Community

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

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On Becoming a Practitioner of the Gentle Art of Swedish Death Cleaning

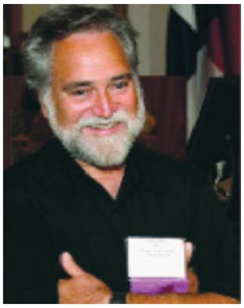
Exceptional parents have far too many artifacts to sift through and decide which pile to place them in. What do you do with early IEPs, MRI findings, Special Olympic medals, behavioral support plans, clinic appointment cards, support group newsletters, insurance explanation of coverage and conservatorship papers?

It started innocently enough.

My wife decided it was time to change the carpeting in our bedroom. It had outlived its place in our home. Relegating carpeting as a second-tier floor covering was difficult at the beginning. Like Woody Allen – who described his Jewish family and neighborhood as being from "the heart of the old world, their values are God and carpeting" – I always thought carpeting was the flooring you opted for when you "arrived." The die was cast and arrangements were made for the carpeting to be removed, and a new cork floor was scheduled for installation. I was instructed to clean out my closet to enable the installers to lay down the flooring, which included removing cabinets and drawers in my closet. This was a no-holds-barred strip down to the last unmatched sock, and to the T-shirts that announced that I participated in several sports car rallies when I was in college. It was long overdue and presented me with an opportunity to confront the accumulated mess of too many things that were taking up space. It also reminded me that I was three ball caps shy of being considered a hoarder.

The operative word for my initiative was "ruthless." Of course, being a physician, I quickly adopted the "triage model" – three piles designating "keep," "donate," or "junk." It quickly became apparent that the accumulated collection had become invisible to me. By the time I had cleaned out the closet (five bags of black heavy-duty contractors bags), I had reached the equivalent of a "runner's high." Throughout the process I had become a disciple of Kerri Richardson: "Clutter. Even the word feels heavy when you say it. We've become consumed by stuff and so inundated by things that we almost have nowhere to turn." (*What Your Clutter Is Trying to Tell You: Uncover the Message in the Mess and Reclaim Your Life*).

Feeling victorious from my conquering of closet clutter I started thinking of what other piles had become invisible. It was during this exploratory excursion that I found out about "the gentle art of Swedish death cleaning." Margareta Magnusson, who describes herself as being between "eighty and one hundred," has written the definitive book on "death cleaning."



Death cleaning comes in two waves. Initially it comes from inheriting "stuff" from your deceased parents. Old furniture, photos, clothes, art, collectibles, old Volvos, endless pieces of paper and the occasional arthritic Fox terrier. The full monty of emotions accompanies the inheritance. The question of what to do with the stuff becomes as difficult as

CLEAR THE WAY: *(Above)* "The operative word for my initiative was 'ruthless.' By the time I had cleaned out the closet (five bags of black heavy-duty contractors bags), I had reached the equivalent of a 'runner's high.'"

deciding if D-Day would be more successful if they waited for the weather to change.

The second wave of death cleaning comes when you are forced to confront what to do with your "own stuff." Death cleaning is not a sad endeavor, unless it paralyzes you. It stems from the wisdom of Einstein (who had the unique challenge of constantly having to declutter his thinking), "Out of clutter, find simplicity." We don't necessarily engage in death cleaning to save our offspring and spouses from the arduous task, when the time comes, of having to deal with our stuff (although that is a loving gift for sure), but simply to come to the realization that our lives could be made simpler if we learn to live with less.

> "Swedish death cleaning can be a very uplifting, invigorating and inspiring endeavor. It encourages you to reflect and reconstitute memories of people caring for, and about people. Sometimes we simply come to the realization that our lives could be made simpler if we learn to live with less."

Successful Swedish death cleaning suggests that you start to confront the big stuff first. Furniture is typically the easiest to deal with, and the monthly bills for the rental of a storage bin might remind you that it was enough to remember all the good times you had, watching the 16-inch black-and-white Dumont television without actually having to keep it. The same goes for the 40-year-old Remington typewriter that you remember your father toiling over in his attempt to write the next great American novel. Sentimentality is a wonderful and endearing quality, but there is something equally endearing to learn that you don't have to own something to appreciate and enjoy them.

The last thing to confront when you are death cleaning is photos. They fall into a very unique and challenging class. The American photographer Aaron Siskind said it best, "Photography is a way of feeling, of touching, of loving. What you have caught on film is captured forever… it remembers little things, long after you have forgotten everything." It is in that last concept that "it remembers little things," which can be reason enough not to relegate family photos to the "clutter pile." How could you discard things that prove, remind and testify that you came from somewhere; somewhere that no one else can claim?

Swedish death cleaning can be a very uplifting, invigorating and inspiring endeavor. It encourages you to reflect and reconstitute memories of people caring for, and about people.

For exceptional parents, death cleaning can have deep, significant and heartfelt emotions. They have far too many artifacts to sift through and decide which pile to place them in. What do you do with early IEPs, MRI findings, Special Olympic medals, behavioral support plans, clinic appointment cards, support group newsletters, insurance explanation of coverage and conservatorship papers?

Maybe the answer can be found in the insight of Anne Lamott, "Perfectionism means that you try not to leave so much mess to clean up. But the clutter and mess show us that life is being lived."

I love our new cork floor. •

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

NDSS Athlete Team to Run 250+ Miles for Down Syndrome Advocacy

The National Down Syndrome Society (NDSS), the leading human rights organization for all individuals with Down syndrome, proudly announces its official Athlete Team and Run Route for the Run for 3.21, a 250+ mile run from Washington D.C. to New York City. The run will serve as a major fundraiser for NDSS in 2018 and recognition of World Down Syndrome Day on March 21.

The National Down Syndrome Society (NDSS), the leading human rights organization for all individuals with Down syndrome, proudly announces its official Athlete Team and Run Route for the Run for 3.21, a 250+ mile run from Washington D.C. to New York City. The run will serve as a major fundraiser for NDSS in 2018 and recognition of World Down Syndrome Day on March 21.

This multi-day adventure kicks off at 6:00 a.m. on March 19 and travels from the steps of the nation's capitol, arriving at United Nations at 10:00 a.m. on March 21. Runners will be in motion for more than 50 hours to complete the course, which winds its way through rolling countryside, quaint downtowns and the heart of D.C., Wilmington, Baltimore, Philadelphia, Princeton and New York.

The National Down Syndrome Society is a human rights organization for all individuals with Down syndrome. NDSS provides state-of-the-art, comprehensive programming to all individuals with Down syndrome and their families with four main areas of programming which include: the National Advocacy & Policy Center, the Inclusive Health and Sports Programs, including the National Buddy Walk ® Program, Community Outreach and Resources and Public Awareness.

For more information visit www.ndss.org •

WHAT'S HAPPENING

CALLING ALL INNOVATORS FOR THE "CAREGIVERS SHARK TANK"

The National Caregivers Conference is inviting innovators, inventors, researchers and thought leaders to share their new ideas, products, technology's, or therapeutic concepts that aim to transform the health and role of family caregivers.

INNOVATION IS EVERYWHERE: The National Caregivers Conference is inviting innovators, inventors, researchers and thought leaders to share their new ideas, products, technologies, or therapeutic concepts that aim to transform the health and role of family caregivers.

The National Caregivers Conference is returning to New Jersey since Superstorm Sandy forced its cancellation in October 2012. This annual conference is renowned for its National level speakers, workshops and exhibitors who address both individual and national issues facing the caregiver community. The 2018 National Caregivers Conference, "Health, Technology, and the Family Caregiver", will bring innovative solutions to the increasing demand on the 40 million family caregivers across the nation while showcasing exciting projects that use technology to improve the health and quality of life of caregivers and their loved ones.

We are aware that innovators throughout the nation are developing new programs and products that aim to empower and positively impact activities of daily living for people with the greatest health needs and their caregivers. The Caregivers Shark Tank will present a platform to share these ideas with the "Sharks" who have the capacity to bring new models to the forefront of caregiving practice.

All finalists will be invited to present their new ideas, products, technology's, or therapeutic concepts at the National Caregivers Conference on October 11, 2018 in front of the panel of judges (Sharks), venture capitalists, leading industry investors, healthcare providers and caregivers.

The deadline for submitting an application to the Caregivers Shark Tank is April 30, 2018. For more information on the National Caregivers Conference and to submit an application to the Caregivers Shark Tank please visit www.nationalcaregiversconference.org

For over 40 years, we have helped thousands of New Jersey families with a variety of disabilities connect with resources and support services they need to live full and happy lives. The Family Resource Network (FRN) is a comprehensive, family-focused, organization designed to meet the growing need for community-based programs and services to this rising population. FRN's network agencies are: Autism Family Services of NJ, Caregivers of NJ, Epilepsy Foundation of NJ and the Family Support Center of NJ.

Please visit www.familyresourcenetwork.org for more information or call (800) 376-2345.

PA Summer Camp Hosts 100 Grieving Boys & Girls

WHAT: This summer, August 13 - 18, at **Camps Equinunk and Blue Ridge in Equinunk, PA, boys and girls will come together to spend a week at "Experience Camp."** Experience Camps provide free, one-week camps for children who have experienced the death of a parent, sibling or primary caregiver. Along with swimming, arts and crafts, and team sports, the kids take part in bereavement activities including sharing circles where they are encouraged to talk about their grief.

Currently accepting referrals and applications for boys entering grades 4-11 and girls entering grades 4-9 in the 18/19 school year.

WHY: **According to the U.S. Census Bureau, approximately 1.5 million children are living in a single-family household because of the death of one parent.** Grieving children are at higher risk than their non-grieving peers for depression, anxiety, poor school attendance or dropping out, isolation, behavior problems, lowered academic achievement, drug and/or alcohol abuse, incarceration or suicide. Experience Camps Help.

WHEN: August 13 - 18, 2018

WHERE: **Camps Equinunk and Blue Ridge in Equinunk, PA.** Experience Camps help grieving children feel "normal" and supported through friendship, teamwork, camp activities, and the common bond of loss. It is a safe environment where kids can explore their grief, break the isolation they may feel with their non-camp peers, and have a whole lot of fun. They have the opportunity to meet and connect with kids who are going through similar challenges, while getting all of the benefits of the traditional summer camp experience. In 2018, Experience Camps will have more than 500 campers at camps in Maine, California, Georgia, and New York.

For more information about Experience Camps, visit http://www.experience.camp

PHOTO COURTESY WWW.EXPERIENCE.CAMP

WHAT'S HAPPENING

THE KAUFMAN MUSIC CENTER'S SUMMER MUSICAL THEATER WORKSHOP

At Kaufman Music Center's five-week Summer Musical Theater Workshop, kids participate in all aspects of producing a show, which culminates in a full-scale production in Merkin Concert Hall. Professional theater directors, writers and composers work with groups of kids age 5-15 on seven brand new, original musicals inspired by a theme.

The children, who represent a diverse and enthusiastic group of NYC's youngest theater fans, will star in the musicals in three performances at Kaufman Music Center's Merkin Concert Hall. Broadway theater is a powerful educational tool. Musical theater can be a potent form of expression because it combines so many elements – visual, music, dance and song. It's a way of telling a story and captivating for children. It is important for children to be acquainted with a vibrant part of their heritage, and also to inspire them to participate in an art form they themselves can be part of, by acting, singing, dancing or writing. It is important for children to get away from their computers and video games and see live theater, he emphasizes. Introducing children to the arts is especially crucial at a time when education is increasingly narrowed down to testable functions. Theater gets kids interested and helps them understand life in a different way than, say, learning math and reading skills. Kids can be literate, but their imaginations can be starving.

ON WITH THE SHOW: "Spaceballs" *(Above left)* and "The Hitch-Hiker's Guide to the Galaxy" *(Above right)* were performed as part of "Far Out: 7 Original Science Fiction Musicals" on Aug 1, 2017 during the 2017 Summer Musical Theater Workshop at the Lucy Moses School at Kaufman Music Center. Campers work together with small groups based on their current grade. In the morning they take classes in acting, singing and movement. During the afternoon each group works with its director and interns to create its own musical play.

The 2018 Summer Musical Theater Workshop at Kaufman Music Center's Lucy Moses School runs from July 2 through August 2, 2018, Mon-Thu, 10 am-4 pm. Final performances in Merkin Concert Hall: Tue, July 31, 6:30 pm & Wed, Aug 1, 10:30 am & 6:30 pm.

– Sean Hartley, Summer Musical Theater Workshop and Broadway Playhouse

NEW PRODUCTS FOR LITTLE HANDS

SWITCH ADAPTED WALKING T-REX

The Switch Adapted Walking T-Rex is designed for use by children with upper extremity, severe physical or fine motor disabilities. This switch- adapted toy requires the user to continuously activate a switch (Dual Switch Latch & Timer #100DSLAT can be used in timed seconds or minutes mode if the user is unable to continuously activate a switch; switch and Dual SLAT not included). This toy is permanently adapted and requires one switch (switch not included). Requires three AA batteries (batteries not included). Color of toy may be different than what is shown.

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COLORFUL SENSORY BRUSH

The Colorful Sensory Brush is a tool designed for children or adults with sensory processing disorders to use. The brushes can be used for clinical or home use. They can be used for specific deep pressure protocol. Use for calming or before focused attention is required. Colors vary.

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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.

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

PLEASE JOIN US FOR THESE 2018 IES BRAIN RESEARCH EVENTS

DEDICATED TO THE MEMORY OF IRENE SIMON - THE "I" IN IES.

SAVE THE DATE

Monday, June 4th, 2018

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NEW PRODUCTS

MATCHING TEXTURES BAG

The Matching Textures Bag is a bag filled with different textured squares (scratchy, slippery, silky, soft, rough, bumpy, furry, and fuzzy) designed for children with learning disabilities ages 3 and up to promote tactile awareness and sensory exploration and to practice describing material. Includes a set of 20 squares (10 different pairs) of material with different textures packed in a drawstring cotton bag. Each textured pillow or patch is a 3-inch square in size to fit wellin small hands. Includes a "Tip Sheet" packed with fun activities that "touch" on matching, vocabulary, communication, and tactile discrimination skills. Develops descriptive vocabulary and matching skills.

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CHUNKY WOODEN PUZZLE SHAPES

The Melissa & Doug Chunky Wooden Puzzle Shapes are designed for use by individuals who have physical, cognitive or sensory disabilities. The shapes are featured in this extra-thick Wooden Puzzle with easy-grasp, chunky pieces. Each piece has a matching picture underneath and the shape's name is printed on the puzzle board. It encourages hand-eye coordination, fine motor skills, and visual perception skills.

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MUSICAL SQUARES

Musical Squares is a game designed for individuals with physical disabilities to allow them to practice a combination of gross motor skills and cause-and-effect and enhance their motor planning skills. This is a good addition to sensory rooms or to be used by itself in an active sensory play area. Make noises from touch.

Ten different themes are selectable using the blue button found on the front of the unit (0-9) on the display. The first two themes are interactive games (0-1) that will light one of the colored squares, then within a few seconds the user should press the corresponding color on the controller to receive a round of applause. If the color is wrong, they will hear a negative sound. If no color is selected the unit will go through a time out sound. Games "0' and "1" have the same function. However, the color square in game '1" appears for less time and a slightly faster response is required.

Themes 2-9 all consist of varying themes that will only operate if one of the colors is selected by the controller mat or buttons. The color square and theme sound will remain on for as long as it is pressed. Volume can be adjusted to suit.

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AMERICAN ACADEMY OF DEVELOPMENTAL MEDICINE & DENTISTRY

Genetic Manipulation for Individuals with Disabilities: Does CRISPR-Cas9 Provide a Magic Bullet?

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

> *"In 1972, WABC-TV in New York sent rookie reporter Geraldo Rivera to Staten Island to infiltrate the Willowbrook State School. Robert Kennedy had visited the mental institution in 1966 and declared: 'Willowbrook State School was not fit even for animals to live in.' Geraldo gained entry using a stolen key and documented the brutal horrific living conditions of its disabled residents, which included several children with mental limitations. The report led to an immediate government inquiry."* [1]

More than 45 years have passed since the investigative reporter Geraldo Rivera's documentary on Willowbrook State School in New York City revealed the gruesome and neglected conditions in which individuals with intellectual and physical disabilities lived under the protection of the state.

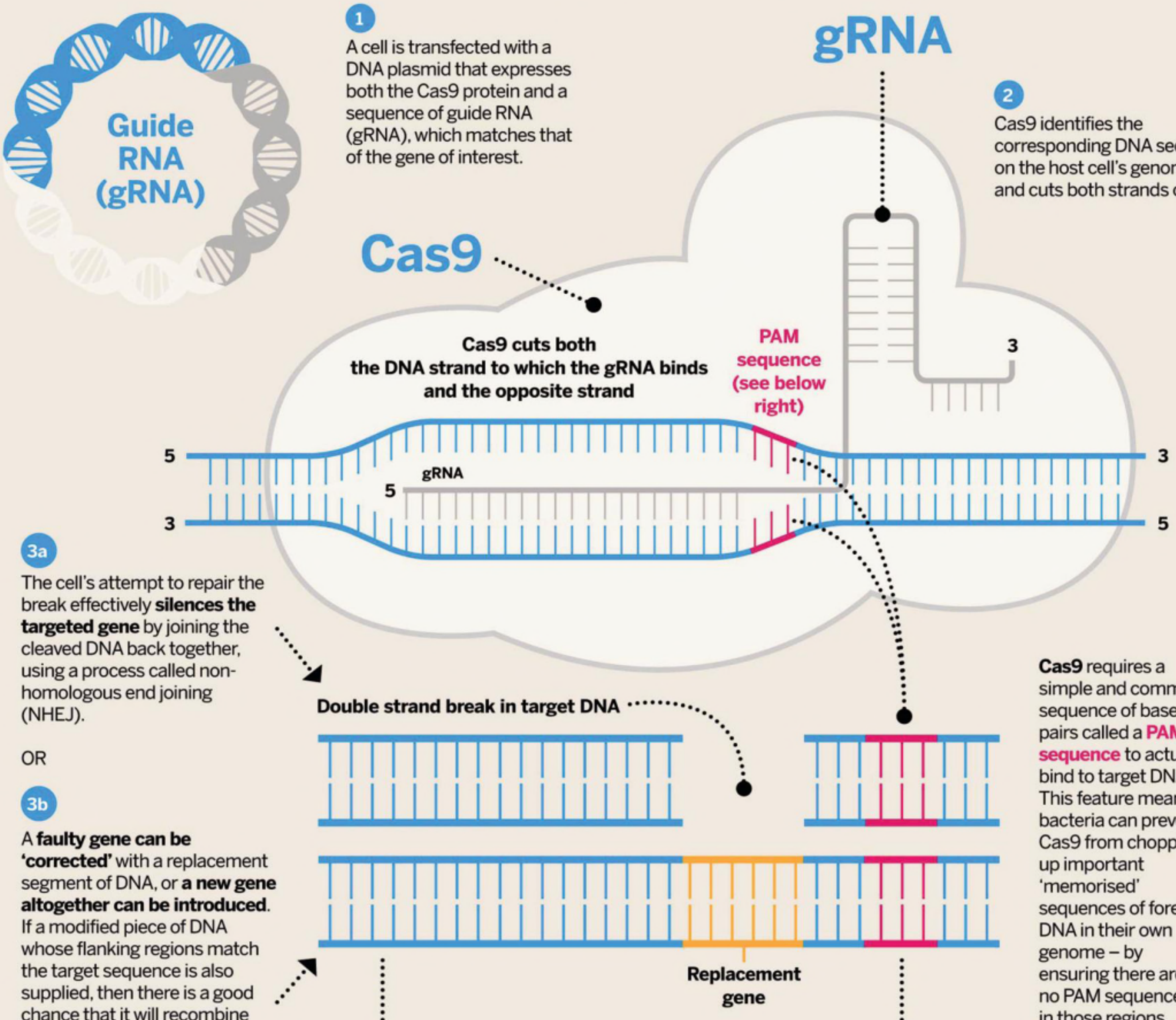
In the 1840s, activist Dorothea Dix lobbied for better living conditions for individuals with varied mental conditions after witnessing the dangerous and unhealthy conditions in which individuals with intellectual and physical disabilities were housed in jails. Over a 40-year period, Dix successfully persuaded the U.S. government to fund the building of 32 state hospitals for the care of these patients.

By the mid-1950s, a movement for deinstitutionalization and outpatient treatment for people with disabilities began in many countries, facilitated by the development of a variety of antipsychotic drugs. Deinstitutionalization efforts reflected a largely inter-

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.

CRISPR-Cas9 How the genome editor works



1 A cell is transfected with a DNA plasmid that expresses both the Cas9 protein and a sequence of guide RNA (gRNA), which matches that of the gene of interest.

2 Cas9 identifies the corresponding DNA sequence on the host cell's genome, and cuts both strands of DNA.

3a The cell's attempt to repair the break effectively **silences the targeted gene** by joining the cleaved DNA back together, using a process called non-homologous end joining (NHEJ).

OR

3b A **faulty gene can be 'corrected'** with a replacement segment of DNA, or **a new gene altogether can be introduced**. If a modified piece of DNA whose flanking regions match the target sequence is also supplied, then there is a good chance that it will recombine with the host DNA when the cut is made, thus introducing a new or replacement gene. This pathway is known as homology directed repair (HDR).

Cas9 requires a simple and common sequence of base pairs called a **PAM sequence** to actually bind to target DNA. This feature means bacteria can prevent Cas9 from chopping up important 'memorised' sequences of foreign DNA in their own genome – by ensuring there are no PAM sequences in those regions.

What next?

FOOD AND LIVESTOCK MODIFICATION

Researchers have already created plants and mammals with edited genomes. It is hoped such technology could help boost productivity and improve food security.

GENE DRIVE

Some genes are more likely to be passed on than others. If an 'edit' is linked to these genes, it will quickly spread through a wild population. That sounds alarming, but could help eradicate malaria-carrying mosquitos.

GENE THERAPY

Genetic disease could be treated by introducing gene editing systems into affected cells. Researchers in the USA are trialling this to treat HIV by knocking out the gene for the specific T-cell receptor that the virus targets.

HUMAN GERM LINE

Modifying human embryos, sperm or eggs would introduce changes to the genome of future generations. Some argue that other techniques, such as embryo screening, can just as effectively prevent genetic disease.

DESIGNER ORGANISMS AND MORE...

In future, could babies be 'designed' with a genome of our choosing? Could amateur biologists do their own gene editing outside regulatory systems?

IMAGE COURTESY J LEVIN WWW.CREATIVECOMMONS.ORG

national movement to reform the "asylum-based" mental health care system and move toward community delivery care. This movement was based on the belief that these patients would have a higher quality of life if assimilated and treated in their communities rather than in large, undifferentiated, and isolated mental hospitals.

SOME PAST DEVELOPMENTS

1. In 1907, Indiana was the first of more than 30 states to enact a compulsory sterilization law, allowing the state to "prevent procreation of confirmed criminals, idiots, imbeciles and rapists." By 1940, 18,552 people with mental illness were surgically sterilized.

2. In 1936, Dr. Walter Freeman and his colleague James Watt performed the first prefrontal lobotomy. By the late 1950s, an estimated 50,000 lobotomies were performed in the United States.

3. In 1954, Smith-Kline and French marketed Thorazine, chlorpromazine, the first antipsychotic drug approved by the Food and Drug Administration. It quickly becomes a staple in asylums.

4. In 1955, the number of people with mental illness in public psychiatric hospitals peaked at 560,000; reduced to 43,000 in 2010.[2]

5. Between 1977 and 2011, the total number of people with intellectual and developmental disabilities receiving residential services grew from almost 247,800 to 460,600 (an increase of 85.9%). There were important differences in the pattern of change, depending on the size of the institution and whether the setting was state or non-state operated. The number of people living in settings of 16 people or more declined from almost 207,400 in 1977 to 55,100 in 2011.[3]

IS THIS THE FUTURE

"Eager to speed developments of revolutionary treatments, the Food and Drug Administration recently announced that it would expedite approval of experimental gene therapies… The genes intended to fix a defect in the body are carried into each cell by a modified virus, usually a disabled version of an adenovirus or a lentivirus… If a company wanted to deliver a gene therapy to lung or liver, where the organ 'surface area is huge' the current price could be as much as $3 million per patient… it might cost a mere $30,000 for the viruses in the future."[4]

WHAT IS CRISPR-CAS9?

It is a unique technology that enables geneticists and researchers to edit part of the genome by removing, adding or altering sections of the DNA sequence. It is faster, cheaper and more accurate than previous techniques of editing DNA and has a wide range of potential applications.

The CRISPR-Cas9 system consists of two key molecules that introduce a mutation into the DNA. These are: 1) an enzyme called Cas9. This acts as a pair of molecular scissors that can cut the two strands of DNA at a specific location in the genome so that bits of DNA can then be added or removed; and 2) a piece of RNA which guides the Cas9 to the right part of the genome. This makes sure that the Cas9 enzyme cuts at the right point in the genome. At this stage, the cell recognizes that the DNA is damaged and tries to repair it.[5]

APPLICATIONS AND IMPLICATIONS

CRISPR-Cas9 has unlimited potential as a tool for treating a range of medical conditions that have a genetic component, including cancer, hepatitis B or even high cholesterol. Many of the proposed applications involve editing the genomes of somatic (non-reproductive) cells, but there has been interest in and debate about the potential to edit reproductive cells. However, any changes made in these cells will be passed on from generation to generation and, as such, have important ethical implications. Note: "Carrying out gene editing in germ line cells (e.g. a sperm or egg cells) is currently illegal in the UK and most other countries."[5] By contrast, the use of CRISPR-Cas9 and other gene editing technologies in somatic cells is uncontroversial. "Indeed they have already been used to treat human disease on a small number of exceptional and/or life threatening cases."[5]

CRISPR-CAS9 AND DISABILITIES

In the future, can CRISPR-Cas9 be a factor in reducing the great number of individuals with disabilities associated with generic aberrations? We already carry out procedures on prenatals in the uterus to correct abnormalities. But once again, CRISPR-Cas9 procedures on reproductive cells during early stages of pregnancy could be passed on to subsequent generations with unanticipated consequences.

On the other hand, given the technology to improve the life of a child and then as an adult, should such an ability be denied? But, one could image the act of some government office stepping in to deny (or even demand) such an action (in an effort to reduce long term healthcare costs). *(Note: Images of Big Brother from George Orwell's* 1984 *science fiction novel springs to mind. The reality is that the title of the book is the result of a change instituted by the publisher in an effort to better market the story by setting the events in the future when Big Brother* ***could happen.*** *The initial draft title of the book written in the 1940s was to be* ***1948.*** *The events* ***had already happened.*** *Who would have believed that?)*

The ability to modify genetic factors associated with the disabilities may not totally eliminate the full extent of the encumbrances faced by many individuals. It could, however, help to improve the life of the child and then adult, as well as reducing the lifelong economic burden for the individuals, their families, and even our communities. It might even increase the willingness of health practitioners to provide care for individuals with disabilities.•

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10,000 Steps Versus Exercise

Remember that you are also setting an example for your children. Demonstrating healthy habits will teach kids to incorporate these activities as they grow.

You may have heard about the studies that show sitting is worse for your health than smoking, and to combat this, getting a certain number of steps in per day is recommended. Our occupations are more sedentary than they used to be, and our pastimes are also getting less active as we sit at our computers and on our devices more often. Before Wall-E becomes our reality, health care providers are encouraging people to get at least 10,000 steps per day.

There are devices and apps that can count your steps; they can alert you when you are on track, or need a reminder to get moving. While this 10k steps per day is a great guideline, do not replace your exercise routine with getting your steps in. Walking is great – it gets you upright, boosts your circulation, and loosens up your muscles. However, remember that exercise is defined by intensity.

The definition of exercise is “physical activity that is planned, structured and repetitive for the purpose of conditioning any part of the body. Exercise is used to improve health, maintain fitness and is important as a means of physical rehabilitation.” The reason this is important is because exercise goes above and beyond your daily activities. Doing housework or yard work is physical activity, but it’s not exercise. Getting 10,000 steps in a day is actually a recommendation for your daily activity! It is meant to encourage you to walk rather than drive to a local store, and walk at the airport rather than riding the people mover. The difference between daily activities and exercise can often be clarified by considering the intensity at which you feel like you’re working.

Let’s focus on cardiovascular exercise, also known as aerobic exercise. This is pushing a wheelchair, swimming, cycling, dancing, etc. It’s activity that can be sustained and improves your endurance. Aerobic exercise enhances glucose regulation (i.e. helps manage or prevent diabetes,) improves blood pressure and improves arterial function. It can also help improve your memory and decrease depression and anxiety.

Heart rate is one way to monitor your intensity, however there are a number of factors that can impact your heart rate’s response to exercise. There are medications that may impact heart rate; if you have a condition that impacts your autonomic system, your heart rate response may not be reliable; etc. Rather than getting a heart rate monitor, or figuring out how to take your pulse while working out, there is a simple 1-10 scale that you can use.

1 = resting, probably how you feel now. 10 is that all out sprinting effort that can’t be sustained for very long. For aerobic exercise, you need to push yourself into the 4-6 range. It should feel effortful, and you may be short of breath, but could still have a conversation. If you’re not getting tired by the exercise, it probably is in that 2-3 range. Housework and yard work is in this 2-3 range.

Your level of effort is unique to you. Your 5 may be different than your spouse’s 5.

Think about this scale the next time you’re exercising – and if you are not reaching that 4-6 level, think about how to get up into that zone (safely!) As your fitness improves, it will take more work to get to the same intensity. That’s great! It means you’re getting stronger and reaping the benefits of your workouts. But it also means you can’t get complacent with your exercise routine, and you’ll need to step it up.

If you can push your walking to an intensity that constitutes exercise, fantastic! You can do this by walking faster, or by adding small weights to increase the effort. Still thinking about that 1-10 scale? You may feel a little short of breath, and it may be effortful to carry on a conversation – that is good! This is when you are getting the cardiac and neurological benefits.

While I agree with the importance of being upright as much as possible, taking 10,000 steps is not possible for everyone. Getting the steps does not lessen the need to push the intensity and get enough exercise!

Remember that you are also setting an example for your children. Demonstrating healthy habits will teach kids to incorporate these activities as they grow. Make it a family activity! Have challenges between family members to win something – like control over what plays in the car for a week, or picking the family dinner for three nights. Have fun with the exercising as well as the rewards.•

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 3 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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For many families, it can take months of planning to ensure as many needs as possible are met. To further complicate plans, most summer camps only last a week or a month, not the whole summer.

GENETIC ALLIANCE

The world's leading nonprofit health advocacy organization committed to transforming health through genetics and promoting an environment of openness centered on the health of individuals, families, and communities.

PHOTO PROVIDED BY GENETIC ALLIANCE

TRANSITIONING INTO Summer

Finding Camps for Children with Special Healthcare Needs

BY JEFFREY GIORGI AND AMELIA MULFORD

Summer camp can be a profound and transformative experience for children of all ages. Camp challenges us to interact with people we don't know, perform feats we didn't think we were capable of, and develop a stronger sense of self-reliance. But when the very act of moving around is a labored chore, summer camp experience can become less carefree and more stress-inducing, as in the case of five-year-old James.

"James is exceptionally resistant to change," shared his mother, Megan Thynge. "He's very protective of himself. He's so dependent on other people for help and getting around."

James was born with a rare genetic disorder, neurofibromatosis type 1 (NF1), which comes with a host of varied complications. James's biggest daily challenge is his physical disability. Unable to walk independently, James uses a wheelchair as his primary means of mobility. Even that little bit of mobility comes with the caveat that James is unable to get in or out of the chair without aid.

"He's our only child, so we spend a lot of time focusing on his needs, and, frankly, worrying about him," said Megan.

In the beginning, James spent his time in year-round daycare that specialized in an inclusion program, composed of classrooms filled with a mix of children with and without special needs. Daycare lasted all day and ran year-round.

"He received all of his therapy there and was just very well cared for," recounted Megan. "Once we got comfortable there, we really didn't have to worry about who was providing care."

HAPPY CAMPER: *(Left to right)* Megan Thynge, her son James, and husband Ben. "My child doesn't have any severe intellectual disability but faces constant physical challenges. Finding a camp that seemed like it would fit for James became a daunting challenge for us."

Megan says that building this rapport between child and caregiver is crucial and exists regardless of a child's specific physical, emotional, or occupational needs. If the child feels comfortable and trusts the individuals caring for them, uncertainty can be significantly easier to face. In Megan's experience, this is perhaps the single greatest factor in James's success in the year-round program.

> *"If a child feels comfortable and trusts the individuals caring for them, uncertainty can be significantly easier to face."*

When James turned four, his time in daycare came to an end. Depending on which state you live in, four is the age when school enrollment begins for most children.

Regardless of a child's needs, this type of transition can have ripple effects that aren't always immediately apparent. As families navigate the next steps of the transition and help their child stabilize, new questions arise: Where will the school be? Will they be able to accommodate specific needs? Will the child feel comfortable in his or her new surroundings?

"When the reality of him getting older and needing to actually attend school set in, it was panic-inducing," said Megan. "People that have known him all of his life and how to care for him are now gone." With the continuity of care disrupted during the transition period, the family faced the challenge of bringing James's new caregiver up to speed.

A family’s desire to have their child attend the best possible school for their needs is universal. However, in the Washington, D.C. region where Megan’s family lives, the school enrollment process is fairly unique. Many schools in the D.C. metro area are not required to be accessible to children with physical disabilities, as D.C. will find families a school with accommodations to meet the needs of individuals with disabilities. While helpful, it does not take into account other problems families may experience. Families must account for work schedules, commutes, cost. Finding the perfect place isn’t always as simple as finding accessible facilities.

Fortunately for Megan and her family, James was able to enroll in a school that could meet his specific needs both in and out of the classroom. Once a school was found, the family still had to consider the change in schedule. Leaving year-round daycare for more traditional schooling meant a new challenge to confront: summer vacation. Rather than planning vacations and getaways, for the Thynge family, summer meant finding care for James while school was out of session.

“The first six months were a learning process for everyone,” recalled Megan. “But then the second reality came in. The school doesn’t run year-round, what are we going to do for him all summer?”

Both Megan and her husband work full-time, without any wiggle room for one of them to take an extended leave from employment. With no immediate family in the area capable of taking care of James for an entire summer, their options became increasingly limited.

An unexpected interruption from work can be devastating under the most ideal of circumstances. Loss of hours means loss of income and a disturbance to home life. The snowball effect can accumulate until the burden seems insurmountable. If bills can’t be paid, camp becomes a distant dream.

“It was a pretty scary thought process. We didn’t know what to do,” said Megan.

Dismayed but not discouraged, Megan turned to some of her trusted resources: mothers and families with similar experiences. Using online communities, social networks, and parents she knew personally, Megan gathered a number of recommendations for her son. However, her hunt for information soon highlighted the frustration of trying to adapt broad-sweeping special needs resources to her child’s highly individualized situation.

“I find very few people in a similar situation as me, where my child doesn’t have any severe intellectual disability but faces constant physical challenges,” explained Megan. “Finding a camp that seemed like it would fit for James became a daunting challenge for us.”

“Rather than planning vacations, summer meant finding care for James while school was out of session.”

James may require assistance getting around, but he doesn’t necessarily need a lot of help engaging in the activities presented to him. He is capable of participating with developing children in many activities that aren’t driven by motor skills.

As fate would have it, James’s school decided they would use their own in-house after-care provider as a summer camp option for families of the school. Further, the school hired James’s one-on-one aide to help staff the summer camp.

“We found a unicorn!” exclaimed Megan. “We were extremely lucky.”

However, this stroke of luck far from represents the norm. Oftentimes, after-care is delivered separately from the school, with schools hiring independent contractors to fulfill the need. In James’s case, when he started school, the after-care provider initially refused to accept James as part of the program, saying they could not meet James’s needs. In the end, the school decided to

SEND A KID TO CAMP : FINDING THE RIGHT FIT FOR YOUR CHILD

For families ready to embark on the summer camp search, these resources are fantastic starting points. As with anything, it all comes down to personal needs. While circumstances may be similar from family to family, it is not always guaranteed that the right answer will found in any one place. It is important to cast a wide net and gather as much information as possible, from as many different sources as possible.

the YMCA

CHECK YOUR LOCAL YMCA

Many camps will make accommodations for children with special needs and scholarships may be available; Metropolitan Washington YMCA example

www.ymcadc.org/camp-registration-forms

Camp Carefree

CHRONIC ILLNESSES

(Free camp)

www.campcarefree.org

ASCO Cancer.Net

LISTINGS OF CAMPS FOR FAMILIES AND CHILDREN AFFECTED BY CANCER

www.cancer.net/navigating-cancer-care/children/camps-and-retreats-families-and-children-affected-cancer

Very Special Camps

SEARCHING FOR CAMPS RELATED TO SPECIFIC DISEASES OR BY AREAS

www.veryspecialcamps.com

take a different route, terminating the contractor and handling after-care and summer camp in-house.

Megan's family felt fortunate that James's school made the concessions that it did. Nevertheless, in many cases, parents will be forced to find alternative solutions for their children. Those alternatives often carry with them the burden of financial disruption and schedule overhauling.

What would the Thynge family have done if summer camp wasn't an option? "I don't have very much leave from work because I take a lot of time off for my son," said Megan. "We had thought about possibly having my husband take a bunch of leave over the summer as well."

Whatever solution was available, it would have meant asking for fewer hours, a part-time work schedule over the summer, or working from home. It would also have required the family to start from square one in the process of looking for camp that would be able to meet James's needs.

For many families, it can take months of planning to ensure as many needs as possible are met. To further complicate plans, most summer camps only last a week or a month, not the whole summer. In addition to turning the summer months into a jigsaw puzzle of summer camp placement, families have to take into account the constant unfamiliarity that their child will be exposed to and the unpredictability of how the child will respond to novel environment.

"I started to panic a little bit," Megan remembered, thinking about her son having to attend a new summer camp. "It's really scary to trust that somebody else is going to be able to do the right thing for him."

But for now, Megan can put her mind at ease for another year.

Megan knows how lucky she and her family are that things worked out the way they have. Although the camp search can present hurdles, Megan advised other families to not be discouraged.

"Keep trying. Even if one thing doesn't seem like it's going to work out, keep digging," said Megan. "Don't be afraid to ask as many people as possible. It can be really hard to ask for assistance finding things because we often ask people for so much already, but you kind of have to when it comes to your kids. Don't be afraid to keep putting yourself out there until you find the right thing for kid."•

> "Keep trying. Even if one thing doesn't seem like it's going to work out, keep digging, and ask as many people as possible."

ABOUT THE AUTHORS:

Jeffrey Giorgi is the Communications and Operations Assistant at Genetic Alliance, focusing his efforts on the behind-the-scenes work of the organization. Jeffrey is interested in the relationship between care providers and those they serve, and individuals' experience seeking care. He holds a BA from George Mason University and has worked in nonprofit organizations ever since.

Amelia Mulford is a Program Coordinator for Expecting Health, Genetic Alliance's maternal-health initiative. She is interested in the ways that health systems can support families and individuals as authorities in their own medical experience. She holds a BA in Psychology and Hispanic Studies from Lewis & Clark College and plans to pursue a career in genetic counseling.

"Cultivating a love of service and selflessness opens the window to a world that I want to live in, and one that provides experiences and memories of a lifetime for campers of every ability."

TURNING CAMP STAFF AND VOLUNTEERS INTO CARING LEADERS

BY LAURA WHITAKER

PHOTOS PROVIDED BY SUZANNE RUTLEDGE

As an eager freshman at the University of Georgia, I sought out opportunities to volunteer for organizations whose purposes were meaningful to me.

TRUE COLORS: Extra Special People hosts more than 300 campers of all abilities every summer. Staff and volunteers are trained to provide a transformative experience, and the organization aims to cultivate a a love of service and selflessness in its leaders.

Extra Special People (ESP) immediately caught my eye as a nonprofit serving youth and adults of all ages with special needs. I was trained as a summer camp volunteer and, after just one year of service, I was tapped to run programs when our founder lost her short battle with cancer. At age 19, I was training and equipping my peers whom I was serving alongside.

Thirteen years later, Extra Special People has grown to provide after-school programs and summer, day, and overnight camp experiences for hundreds of children and young adults with special needs across Northeast Georgia. I've had the privilege and perspective to serve not only as a volunteer, camp staffer, and coordinator, but also to lead in training eager young university student volunteers and staff much like myself. As time has passed, I've seen a shift in the behaviors, attitudes, and expectations of volunteers; I have had to adjust and innovate our training programs to continue engaging and inspiring young adults so that they can serve children of all abilities and give them the best camp experience of their life.

My staff and I do not take this responsibility lightly. We are caring for young boys and girls with disabilities ranging from autism to traumatic brain injuries to Down syndrome and other severe physical and developmental disabilities. But we recognize that these children deserve the chance to experience camp just as every other child in America does—without restrictions, limitations, or boundaries. Those opportunities to give our campers the experience of a lifetime come with the heavy responsibility of training up our staff and volunteers to serve each and every need while simultaneously offering a fantastic camp experience.

Since I am no longer running the programs on the ground as I did in my early years at ESP, my aim now is to train and motivate the Millennial generation to maintain the quality of our programming. Getting ahead of the curve is vital to training these young people to be great leaders and great people. I firmly believe that while collegiate volunteers need to enjoy their jobs and the camp experience, it is a job. It is employment. So, by teaching good practices—articulating insubordination, Human Resources-related issues, expectations, and ethics, I aim to provide leadership training that goes beyond their work at camp and into their lives as adults in society.

BRUNCH BOSS

When training students, a tried and true tactic for the start to a successful session is food. College students are always happy to be fed and a favorite among the Millennial generation is brunch. So, as we feed their bodies in our breakfast training sessions, I aim to also feed their souls. By developing their character, I believe we are setting them up for success in life, and not just as a camp employee. The caliber of student is extremely high at our recruiting field of the University of Georgia. Kids are very book smart, but they are still kids. In order for camp leadership to expect them to both be passionate and empathetic while also great employees, we are responsible for teaching expectations in a way that they can metabolize. In our case, that includes interactive sessions and brunch foods.

A WAFFLE LOT: Staff and volunteers love to learn on a full stomach. Waffle House caters the training session focused on "Leggo My Ego," a lesson on pride, humility and mentorship.

GET GRIT

The first session, entitled "Get Grit," focuses on endurance, work ethic, and HR-related terms such as time theft and insubordination. While the HR topics are not the most fun to discuss, the expectations laid out ahead of time give employees the understanding they need to be successful with their responses and their time. We discuss social media and personal time, and I calculate if every camp counselor was on Facebook for five minutes every day during paid hours what that cost to donors would be, as well as the cost to campers. Millennials in this age range see social media as an appendage, and often do not realize that personal time is a cost to the relationships they are developing face-to face with their campers, as well as the overall organization.

The time and effort topic leads to the discussion about grit. Camp life is difficult, taxing, often hot and emotionally, physically, and mentally draining. The definition of grit is, "a positive, non-cognitive trait based on an individual's passion for a particular long-term goal or end state, coupled with a powerful motivation to achieve their respective objective." Camp staff by nature are passionate, but the ability to hold on to that passion for a long-term goal (throughout the summer) is the mark of a person's character. Talking through scenarios when it could be easy to give up and lose passion helps counselors prepare themselves for those moments.

STARVE THE EGO

The second training session, "Leggo My Ego," includes waffles and focuses on a discussion of ego, humility, and growth. Pride prevents us from seeing our own mistakes. I stress the importance of recognizing, admitting, and learning from mistakes in improving ourselves. We ask that every employee owns his mistakes: when you mess up, fess up. This humility is vital to understanding our own shortcomings and therefore empathizing with the shortcomings of others. Our campers have abilities and disabilities of every kind. By understanding our own weaknesses, we can better understand the weaknesses of others—those we work with and those we serve.

Without pride, we are better able to approach situations with a willingness to learn. Our employees and volunteers love to learn, and we encourage them to come to us assuming they know nothing. This can be challenging because they are smart young adults who do know a lot, but accepting that they do not know everything about leading campers with special needs gives them the chance to open their ears and their minds to our training. Mentorship is an important aspect of growth and we encourage staff to begin the lifelong practice of finding and learning from mentors. If they soak in everything like a sponge, it miraculously creates a team that is bonded from the beginning under the same tenets and within the same culture.

Blame and belittling have no place at ESP, nor, I imagine, at any other camp in America. If employees and volunteers think they don't have to take responsibility for their actions or must degrade co-workers in order to feel secure in themselves, the culture becomes toxic. It may sound utopian, but we want to build a culture at ESP that creates "the best you," so that children and young adults can be served well. Finding a solution instead of placing or avoiding blame and being a mentor instead of belittling others offers growth and leadership for all. It cultivates not only a positive camp environment but a productive society beyond our campgrounds.

FEED THE SOUL

In *Leaders Eat Last: Why Some Teams Pull Together and Others Don't,* author Simon Sinek reminds us that selflessness is important, but taking time to care for one's self is equally vital so that you can pour into others. Being a counselor can leave you exhausted, both mentally and physically. In order to feed the soul, I try to teach our employees and volunteers to carve out alone time to refresh and revitalize their tired bodies and minds. This is important for both the employees to implement, but also for camp leadership to value and lead by example.

I also urge our trainees to seek out constructive feedback and ask, "What could I do better in this situation?" Learning from other, more experienced staff and asking for feedback is a sign of maturity, not lack of ability. I think it's important to stress that our young people should not be embarrassed of mistakes or questions. Rather, use them to grow their capabilities and experience, so that one day they, too, can be a mentor to others.

We have an incredible opportunity to train up tomorrow's leaders as we guide campers through the best summer experiences of their lives. That is our ultimate goal - to train staff and volunteers to serve with success so that each and every camper experiences the fruit of that work in the form of an incredible week of camp. Training up the heart, as well as the mind and body, provides a transformative experience for our friends with special needs. Cultivating a love of service and selflessness opens the window to a world that I want to live in, and one that provides experiences and memories of a lifetime for campers of every ability.•

GRIT AND GRACE: *(Left)* Humility and the ability to laugh at oneself are taught to the staff and volunteers at ESP. By understanding one's own weaknesses, one can better understand the weaknesses of others. *(Right)* Executive Director Laura Whitaker loves on a participant at Extra Special People. When training staff to serve campers, Whitaker stresses the importance of grit, the ability to maintain passion and commitment for the entire summer.

Learning from another recommended read, *The Happiness Advantage* by Shawn Achor, I encourage our team to find joy in everyday moments. The first day of camp is overflowing with excitement and adrenaline. By day five or six though, even the most enthusiastic and well-intentioned staffer can become depleted. Intentionally seeking out joyful moments, even in the mundane tasks and taking time out for oneself, can make or break a camp staffer and their overall work experience.

We implemented "Give 5" as an intentional practice of finding joy in the moment. Anyone can ask a staff person or volunteer at any time to list off five things for which they are grateful. They can be small, "My shoes are really comfortable/I had a really good lunch/Rey smiled at the pool today." By introducing this concept at training and practicing it throughout the summer, we find it teaches everyone to keep joy and positivity top of mind.

ABOUT THE AUTHOR:

Laura Whitaker began as a volunteer at Extra Special People in 2003. With her passion for enhancing the lives of children with developmental disabilities and her specialized education in this field, Laura was selected as the Executive Director in 2006. As Executive Director, Laura uses her leadership and management strengths to manage staff, oversee year-round programs and summer camps and raise millions of dollars for the organization. Her favorite part of the job is getting to hug the many children who walk through the ESP doors. For more information, visit www.extraspecialpeople.com and www.camphooray.com

LOOKING AT SCHOOL PLACEMENTS FROM BOTH SIDES OF THE TABLE

BY JOANNE DESIMONE

As the outreach coordinator for the Alliance of Private Special Education Schools of North Jersey, I help parents and district case managers find appropriate placement options for their students. As a special educator and parent of two children with disabilities, I use the knowledge I've acquired, sitting on both sides of the table. When parents call me for placement options, I especially lean on the experience I had with my younger son who is on the autistic spectrum. I found that the only thing worse than watching him struggle in a failing school placement, was feeling as though we'd run out of options.

After nine-and-a-half years, it is still easy to recall my son's long and difficult kindergarten experience. I knew what my son needed, and after months of school tours and rejected applications we finally found a good fit. But by the time we won our legal battle, all the available seats were filled. In desperation, we moved from our home state in order to accommodate our son's needs. Relocation made sense for us because we needed a wheelchair accessible home for our older son who has cerebral palsy. Yet, moving isn't feasible for everyone. While there's no perfect science to finding the right school, there are some key factors and questions to consider.

It's important to remember there is a continuum of placement options, including the general education classroom, integrated settings, resource room, self-contained classrooms, private special education schools, and home or hospital settings. School teams are legally required to consider all options and explain their recommendations. A good way for parents to engage as an equal member of their child's study team and ensure they can make

> “A GOOD WAY FOR PARENTS TO ENGAGE AS AN EQUAL MEMBER OF THEIR CHILD’S STUDY TEAM AND ENSURE THEY CAN MAKE FULLY INFORMED DECISIONS ABOUT PROGRAM RECOMMENDATIONS IS TO VISIT A VARIETY OF PLACEMENT OPTIONS.”

fully informed decisions about program recommendations is to visit a variety of placement options. Additionally, I suggest contacting the school’s SEPAG (Special Education Parent Advisory Group), PTA, and search for school parent groups on Facebook in order to get another parent’s perspective.

In an effort to develop and maintain a successful individual education plan, I strive to keep an open, ongoing dialogue with my sons’ teachers. Parents and teachers have different perspectives, insights, and skills. I remember, as a new teacher, thinking I understood all I needed to know about working with families. When my oldest son was diagnosed with cerebral palsy, I realized how little I knew about what it meant to have a child with a life-long disability. My naiveté didn’t come from a lack of care or dedication. I believe it came from lack of connection and dialogue. A teacher only knows what’s in a child’s chart and what a parent wishes to divulge.

AVOID THE “US AGAINST THEM” MENTALITY

When a child struggles in a school placement, it’s easy to adopt an “Us against Them” mentality. I find it’s easier to avoid this by reminding myself to foster that collaborative relationship with both my sons’ school teams all year long. I need their educational knowledge and they need my parenting expertise. In moments of tension I remind myself that we all have the same goal of supporting my sons in their efforts to succeed in school and beyond. I’ve found great success in approaching team members by saying, “We both want the same thing, now what can we do to make it happen?”

When a parent calls me for placement options, one of the first things I ask them to do is describe their ideal program. I find this strategy helps to hone in on the child’s learning style, recognize what strategies allow the child to be successful, and prioritize their needs. My goal is to get an accurate picture of the whole child, not just their classification and diagnosis. For every disability there is a spectrum of ability so the goal is to find a program that can accommodate the child, not the label placed on them.

I sometimes compare school tours to house tours. When you find the right home, you can feel it in your gut and you start imagining where your furniture will go. In the right school, you get a glimpse of your child belonging. While I enjoy when a school passes the gut-feeling test, the teacher in me likes to keep realistic expectations. I don’t expect a school to meet 100% of the items on my fantasy school wish list, but I do try to gauge if a program is forward thinking. When I toured a prospective school for my older son, the principal detailed plans for a vision therapy room and a sensory integration room. While the school’s strong sense of community had impressed me, I was more delighted by their progressive attitude. Children’s needs change over time. It’s good to know how flexible the school can be in order to meet a child’s growth.

TABLE TALK : SCHOOL PLACEMENT Q&A

When touring prospective programs, start with some basic questions.

- *What is the class size?*
- *What is the student-to-teacher ratio?*
- *What curriculum is used?*
- *What are the teachers’ qualifications?*
- *Do they provide Occupational, Speech, and Physical therapies? What about Counseling and behavior supports?*
- *Is the school clean and organized?*
- *What is the overall mood of the teachers and students?*
- *Are the students actively engaged?*
- *How is everyone interacting?*
- *Ask specific questions—such as “What would you do if?” –to get a sense of how academic or behavioral challenges are handled.*
- *Is there a full-time nurse on staff?*

The teacher in me also likes to know what supports and resources are available to the teachers.

- *Are there behavior specialists on site?*
- *Do teachers have access to learning disability consultants?*

It is often said that special education isn’t a place, but a service. I see this service as a fluid work in progress. Sometimes you have to pick your battles. Just because there’s one bad teacher or problematic situation doesn’t mean you have to give up entirely on a placement. By all means don’t ignore a problem, but like Mr. Rogers said, “Look for the helpers.” Hopefully, you have been able to maintain an ongoing, open communication with several team members. Rely on those positive relationships as much as you can.

My son had a situation where one teacher refused to follow his IEP modifications. I watched his grade plunge from week to week. Part of me worried that this teacher’s behavior would not be an exception and so I questioned the nature of his placement. But I had one team member working as hard as she could to rectify the problem. Together we came up with several options, presented them to my teenage son, and gave him the power to choose. Although I wasn’t happy with the situation and it didn’t work out the way I’d hoped, I used it as a teaching opportunity. Now my son has a better understanding of his IEP and how to advocate for himself without being adversarial.

DOCUMENT SCHOOL-RELATED INTERACTIONS

I do advise documenting all school-related interactions. Buy a big binder. Communicate as much as possible with your school team in writing, and save everything. Not only are you creating a running record that could be used at IEP meetings or a formal hearing, you will also have an accurate, detailed book of your child's educational history. Memory is a funny, unreliable thing. Give yourself a break by recording events as they happen.

Finding the right school fit is perhaps most stressful during the transitional years. Change is hard on a child, and it's no easier on parents. When a child is thriving and a parent has a good relationship with the school team, it's scary to move on to the unknown. If a child is struggling, it's difficult to imagine progress in light of ever increasing academic expectations. The goal is to meet the child where they are, but also to support and expect measureable progress.

Like many students, my younger son struggled in his first year of middle school. Uncertain about staying with his program, we toured a second in-district option. The choice was still unclear so I requested sample homework materials for both programs in several subject areas. Making side-by-side comparisons helped us to see which program would be most appropriate.

> "THE BETTER A TEAM UNDERSTANDS THE WHOLE CHILD, THE MORE LIKELY THE CORRECT SCHOOL PLACEMENT WILL BE FOUND."

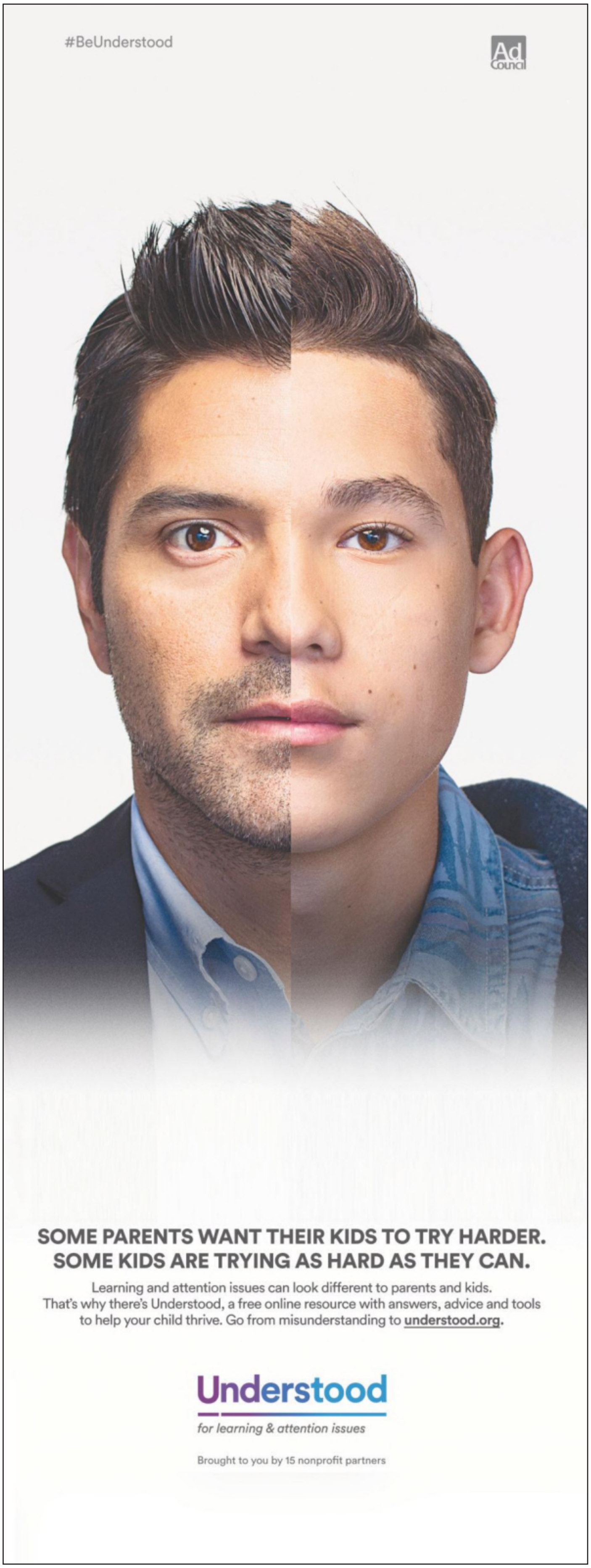
Another thing I did to lessen my anxiety during middle school and high school transitions was to work on giving his future school team the most accurate picture of my son. The truth is good teachers do more than just simply abide by an IEP. Think of all the things you do as a parent in order to make the day run smoothly. It's probably more than you give yourself credit for. I told his teachers, "Imagine a complete stranger reading this IEP and include everything you do that contributes to his current success."

For me, transitions were also difficult because as my sons got older I worried more about graduation and the future. While fostering independence has always been a goal, teaching self-advocacy takes a stronger priority by the time a child is in high school. My goals and my sons' goals aren't always the same and I've had to learn how to step back more and give them a stronger voice. After so many years of advocating, it takes a conscious effort to hand over responsibility to my children, but that's been the goal all along. The more they speak for themselves, the clearer their strengths and challenges are.

All of this is to say that the better a team understands the whole child, the more likely the correct school placement will be found.•

ABOUT THE AUTHOR:

Joanne De Simone is a special educator, advocate, and writer. Her essays have appeared in several publications including The Washington Post, The Huffington Post, Literary Mama, Brain, Child Magazine, and The New Jersey Council on Developmental Disabilities' Blog. She is working on a memoir about reconnecting to the lessons she learned as a modern dancer in order to balance her sons' medical and educational challenges. Joanne blogs about special needs parenting at Special-EducationMom.com



POLICE

People will throw names of schools out to you and all sorts of ideas.

But it comes down to your child and his or her needs — not what worked for someone else.

11 TIPS FOR SELECTING A SCHOOL FOR YOUR CHILD WITH SPECIAL NEEDS

BY AMI NEIBERGER-MILLER, APR, MA

Selecting a school for your child who is coping with special needs can be a daunting task for any parent or guardian. In this article, we talk with the staff at the Episcopal Center for Children (the Center) about what factors to consider when selecting a school for your child coping with special needs.

The Episcopal Center for Children is a nonprofit, nondenominational school and treatment program for children contending with emotional challenges from the greater Washington, D.C. metropolitan area. Accredited by the Joint Commission and certified by the District of Columbia Office of State Superintendent of Education, the Center serves children who are 5-14 years old in grades K-8. Their staff offer the following tips for selecting a school.

1. VISIT THE SCHOOL

There are specialized schools serving children with special needs that will look at your son's or daughter's paperwork and give you a yes or no answer about acceptance. This might make it easier for you to make a quick decision, but the staff encourage prospective parents to visit the campus.

Realize the staff is also looking at your child and his or her needs. Brittany Pratt works at the Center and is the director of positive behavior interventions & supports. "I look at the behavior concerns and try to get a sense of the intensity of the behavior. Sometimes the way it appears on paper, is not how it appears in person," said Pratt.

When you visit the school, bring your notes along and check off questions as you go. You may want to ask a lot of questions and that's okay. A list can help you stay on track.

> **"When you visit the school, bring your notes along & check off questions as you go. You may want to ask a lot of questions & that's okay."**

Observe students in one or more classrooms and watch how they interact with the teacher and other staff. Stay for more than just one or two minutes when watching the classroom. Notice how the teacher engages with the students and how they respond.

Linger a few minutes and consider if your child could learn and be successful in this classroom environment. Is there an objective posted in the classrooms you see? Is there an agenda being used by teachers and students? Stand in the classroom for a little while.

2. DO NOT BE AFRAID TO ASK A LOT OF QUESTIONS

Ask teachers about their approach to education. For example, if you talk with the reading specialist, ask what their method or approach is. They should tell you they are certified, but they may say we use the Lindamood-Bell Learning Processes, Wilson Reading System®, or a blended method for intensive reading instruction. Ask how their methods are applied in the classroom and how they might work with your child.

3. BE OBSERVANT

Do the students you see in the hallways or classrooms look happy? How are they interacting with the staff and teachers? Are older and younger students intermingled at some activities, like lunch? Look for the culture of the school in action. Do they call the place where students eat lunch the cafeteria or the dining room? What posters or signs are on the walls? Does it feel friendly and warm? Or cold and institutional?

Pratt encourages parents to ask if there is a peer group that can help the student be successful. Ask about schoolwide activities and events. Concerts, assemblies, a gardening club, sports, a makerspace and other activities are all opportunities for your child to celebrate, and be successful.

Probe about how the school supports positive behavior. "You will want to know what systems we have set up to facilitate a child's progress or behavior support systems," said Robert Chuthaset, coordinator of behavior support services at the Center.

4. DISCUSS DURING THE VISIT HOW THE SCHOOL RESPONDS TO CERTAIN BEHAVIORS THAT ARE SPECIFIC TO YOUR CHILD

For example, if you know your child is a runner or elopes out of classrooms, ask if the school has locked facilities. Find out what their policy is for how they handle children who run or elope out of classrooms.

If the school does physical restraints, ask if the staff are equipped with training in this area specifically, or if they have certifications or licenses for physical interventions. Ask what type of training the staff has. Is it just one staff member, or have all of the staff had the training? Find out what behaviors would warrant a physical restraint. Inquire about what happens after the child is restrained.

5. ASK WHAT SCHOOLWIDE AND CLASSROOM BEHAVIOR MANAGEMENT PLANS ARE IMPLEMENTED AT THE SCHOOL

Sometimes individual classrooms will have additional incentive and behavior management plans to keep students focused and decrease problem behaviors. You might ask what is specifically done to support positive behavior.

6. BRING YOUR CHILD ALONG FOR THE SCHOOL VISIT IF YOU CAN

Letting your child see the school and getting their impressions will be important for your decision about placement. Seeing your child in person really gives the school a different perspective too. "We have the child see the psychiatrist, psychologist and the social worker. The record is not always an accurate reflection of the whole child and may place more emphasis on behavior concerns," said Stefanie Nash, chief program officer at the Center.

A CLOSER LOOK: Be observant and look for the culture of the school in action. What posters or signs are on the walls? Does it feel friendly and warm? Or cold and institutional?

"Sometimes the way a child presents on paper – we never see here – because they are not in a classroom with 20 plus students (like at their home school). Their behavior may not have the same level of intensity that brought them here," said Nash.

It's also important to watch the interaction of staff with your child while you are on the visit. Note how they talk with your child and with other children.

Your child may not always articulate in words their feelings, but they will observe certain things. They might say the campus looks cool or lunch smells good. The big question is – is this the school that they could see themselves coming to? Can they see themselves here?

7. ASK ABOUT SERVICES AND SUPPORTS FOR THE ENTIRE FAMILY

Parenting a child coping with special needs can bring its own unique challenges for any family. Parents should also consider what types of services the school will offer for them and for the rest of the family. As a parent you have a right to know what your child does throughout the day. You want to feel like you are part of the process and part of the program. How does the school build those connections and help you?

8. ASK HOW THE SCHOOL ENSURES THAT WHAT IS GOING ON AT SCHOOL CARRIES OVER INTO THE HOME

Are there daily, weekly, or monthly updates? Will you be communicating with one person or several people? Because the Center communicates with a parent or guardian every day for each student, it's important that families be prepared for that communication.

CHOOSING WISELY : A CHECKLIST FOR SELECTING A SCHOOL

It can be challenging for parents to make a decision about a school placement. Parents should be an active part of the decision-making process, ask lots of questions, and make informed choices about what works best for their child.

- ☐ *What is the educational program at the school?*
- ☐ *What is the treatment program? What is the school's underlying philosophy about treatment or therapy?*
- ☐ *What are the behavior support systems the school uses? Do they use PBIS (Positive Behavior Intervention System) or another approach?*
- ☐ *How does the school manage difficult behavior?*
- ☐ *Is the facility locked or open?*
- ☐ *What is the environment and culture of the school? How does it feel to walk through the hallways?*
- ☐ *How do students transition throughout the day? What is a typical daily student schedule?*
- ☐ *What is the typical class size? What is the student to teacher ratio?*
- ☐ *What does the school do to excite students about learning?*
- ☐ *What is the school's policy on medication and administering medication?*
- ☐ *What types of training and certification does the staff have? In education? In behavior support? In treatment?*
- ☐ *Are there social workers at the school? Or other mental health professionals? Will they provide therapy and treatment? How often?*
- ☐ *What is unique to the school's program that is not offered in another school?*
- ☐ *How does the school communicate with the family? What is the expectation for me as a parent from the school to be involved? Are there meetings, calls? How often?*
- ☐ *What supports does the school provide for parents or guardians? For the family?*
- ☐ *Do you have a peer group for my child? Can my child have successful peer interactions?*
- ☐ *How long is the school year? If the school has an extended year, what is the program like?*
- ☐ *How long will my child be at this school? What's going to be the plan after they leave this school?*
- ☐ *What is my child's opinion about this school?*
- ☐ *How do the staff interact with my child?*
- ☐ *Do I feel comfortable with this school?*
- ☐ *Are the staff responsive to me? To my child?*
- ☐ *Can this school meet my child's needs?*
- ☐ *Can I see my child being successful at this school?*

9. TAKE A STRENGTHS-BASED APPROACH

So often when we talk about children receiving special education services, our conversations are about deficits and problems. Flip this perspective on its head, by considering your child's strengths. Think about your child's strengths and ask if there are things in the program that support those strengths.

"If you have a child that really loves music, sports, or the arts – and that's an area where they thrive – then look at what sort of programming they offer that speaks to your child's strengths," said Catherine Tafur, director of related services & activities and occupational therapist at ECC.

She says to consider the opportunities the school offers for children to succeed. "It's important to know the bones of the education, but they are kids – what's there to tend to the needs of the child? How do they provide opportunities for success and successful participation?"

10. THE STAFF SHOULD ALSO BE THINKING ABOUT YOUR CHILD AND HIS OR HER NEEDS, AND VISUALIZE HOW THAT CHILD CAN FIT INTO THE SCHOOL CULTURE

In her role, Tafur considers whether the Center has the capacity to meet the needs of prospective students.

11. MAKING YOUR FINAL DECISION

It can be challenging for parents to make a decision about a school placement. Nash notes that parents sometimes can find a school that "had my child's best interests at heart, but may not have offered needed programming."

She says it's important to look at all of the information you gather about the school you are considering and to make an informed choice. Nash encourages parents to be an active part of the decision-making process, ask lots of questions, and make decisions about what works best for their child.

"We know that parents have often been through a grinder and selecting a school can be nerve-wracking. People will throw names of schools out to you and all sorts of ideas. But it comes down to your child and his or her needs - not what worked for someone else. You want to look for what's right for what your child," said James Cowan, director of education at the Center.•

ABOUT THE AUTHOR:

Ami Neiberger-Miller, APR, MA is a writer, mother and foster parent living in Northern Virginia. She has worked with the Episcopal Center for Children for three years. She specializes in public relations for nonprofits and associations. More information about the Center can be found at www.ECCofDC.org

IDENTIFYING EDUCATIONAL APPROACHES TO SUPPORT STUDENTS WITH DYSLEXIA

BY ANGELA SHAW

In order to integrate a specialized academic focus to learners with dyslexia and other reading differences, it is essential to understand and integrate the six strategies noted in this article to increase support, understanding, and communication that is essential to a collaborative team of educational caregivers.

The International Dyslexia Association (IDA) suggests that as many as 15% to 20% of the general population could have some degree of dyslexia (2017). Dyslexia, a language-based learning disability that is characterized by difficulties with word recognition, spelling, and decoding due to a weakness in the phonological components of language, often significantly impacts reading comprehension, vocabulary growth, and academic achievement across the curriculum.

Reading is foundational to all academics and many social circumstances. In recent years, a growing awareness of individuals identified with dyslexia has increased our understanding of how to teach students who are confronted with learning to read in a different manner than students without a reading disability. In addition to requiring the reading methodologies recommended by the National Reading Panel's research evidence to include instruction in "The Big Five" interrelated skills critical to reading success—phonemic awareness, phonics, fluency, vocabulary, and comprehension (National Institute for Literacy)—students identified with dyslexia share common characteristics related to their learning profile, which require a specific and specialized scope of teaching. Assembly Bill (AB) 1369's call for educational service to address dyslexia concerns include the recommended teaching elements through multisensory, evidence-based, structured, sequential, explicit, and direct instruction.

As legislative updates have supported an increase in identified students with dyslexia, it is becoming more likely that teachers across our nation will become responsible for ensuring learning occurs for students with the unique learning profile relative to dyslexia. Moreover, since dyslexia manifests along a continuum of levels, from mild to severe, students identified with dyslexia are appropriately supported through an array of learning environments. Connected to appropriate services and eligibility are considerations by the Individualized Education Plan (IEP) team to include collaborative partnership with related service providers, such as Speech/Language Pathologists, Occupational Therapists, and Counselors. Communication and collaboration between all service providers, both special and general education, is necessary to provide intensive interventions needed by students with pervasive reading disabilities to access and attain the ability to read and learn within the walls of the classroom. Connection and communication between education professionals and families is a critical bridge to encourage and provide for generalization and increase of skills in the making. The following serves to guide teachers, related service providers and parents in addressing the critical elements recommended, in order to provide a specialized educational approach for students whose journey on the path to reading requires an alternate route.

MAKING THE CONNECTION: In recent years, a growing awareness of individuals identified with dyslexia has increased our understanding of how to teach students who are confronted with learning to read in a different manner than students without a reading disability.

MULTI-SENSORY

Although multi-sensory techniques have been discovered to be effective for all learners, this technique is particularly effective for students with dyslexia. Although multi-sensory techniques have been discovered to be effective for all learners, this technique is particularly effective for students with dyslexia. This instruction involves all of our senses, with a focus on visual, auditory, kinesthetic, and tactile elements.

When integrating various senses into the learning process, memory is enhanced and engagement is encouraged. It is when the learner begins to engage in multi-sensory experiences, that he or she can become aware of, or more in tune with, their own strengths with learning strategies; thereby beginning the journey toward life-long learning, both academically and emotionally. Educational caregivers are wise to watch for the cues that students provide us, as they journey through the experiences presented through a combination of learning channels. The short descriptions below provide a glance at the techniques that fall under the umbrella of multisensory learning strands.

- ***Visual:*** *The use of vision in teaching is a traditional approach, but goes beyond relying solely upon the activity of reading text. Visual learning occurs with the application of visual maps to include-timelines, flow charts, digital or print captions, graphs, posters, video, and more.*
- ***Auditory Techniques:*** *The use of listening is another traditional approach to teaching and learning, but listening to the teacher talk is only the beginning of this strategy. Use of music, singing, rhymes, lyrics, tapping, clapping, and discussion are some ways in which the ear is involved in the activity of learning.*
- ***Kinesthetic:*** *If you have ever referred to yourself as someone who learns by doing, then you are indicating a strength as a kinesthetic learning. Kinesthetic learning is performed through motion, using fine and gross motor skills. Air writing, using hand gestures or body motion cues to learn the alphabet, jumping on a number line for subtraction and addition, the act writing or drawing are a few examples of learning through movement.*
- ***Tactile:*** *Individuals who tend to touch fabrics or other items, for example, as they wander through the aisles of the department store, are learning and gaining information through the tactile channel of touch. Through the fine motor activities of using letter tiles to spell words, count coins, write letters in the sand, putting together puzzles, building with clay, etc. are utilizing the tactile technique.*

EVIDENCED-BASED

This is a type of intervention that has been proven effective through actual clinical trials. Oftentimes, the clinical trials are an outcome of the theoretic support referred to as research-based. (Yale Center). Evidence-based practice (EBP) are strategies grounded in research that can be learned and implemented. According to the Yale Center for Dyslexia and Creativity department, the ideal reading instruction provided to a student with dyslexia "…should be evidence-based, systematic, and delivered in a small group setting."

STRUCTURED

When providing structured literacy instruction, the distinctive principles of the targeted learning guides the lesson. The organization of the material presented will follow a logical order, relative to language rules. Additionally, lessons will be cumulative and each step will be based upon concepts previously learned. When providing learning from the perspective of structured literacy, concepts are taught deliberately and explicitly. Nothing is thrown to the chance that the learner implicitly knows or understands a concept. For example, just because a student knows his/her alphabet, it is not implied that they know the difference between the role of a consonant and the role of a vowel. Meeting the needs of an individual student is an essential element within the structure, in order to ensure the student masters the material to a degree of automaticity.

SEQUENTIAL

When following the principles of structured literacy instruction, sequential literacy instruction occurs, as the organization of material will follow the logical order of the language. The sequence will begin with the easiest and most basic concepts and elements and progress methodically to increasingly more rigorous concepts and elements, with each step building upon previous learning.

EXPLICIT

Deliberate teaching of all concepts with continuous student-teacher interaction ensures that no assumptions will be made for the learner to deduce or imply concepts on their own. This element is enfolded within the constructs of structured literacy instruction. Within the explicit strategies, instructional routines allow students to focus upon content through a shift away from question-based instruction that often includes additional language demands surrounding the content. Routines are built into presentation and interaction of teacher and learner through learned routines such as:

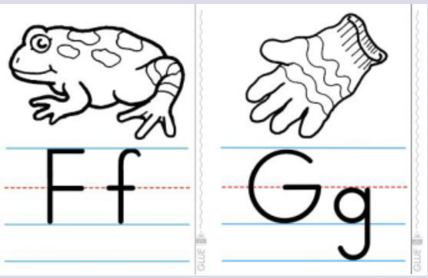
-**"My turn"** where teacher models.
-**"Do together"** where learners and teacher do together.
-**"Your turn"** where learner performs independently.

This routine inclusive response pattern provides from instruction to remain on target skills, active engagement, a steady pace, and lots of practice and repetition. Such an approach increases engagement and fun, as well was minimum transition.

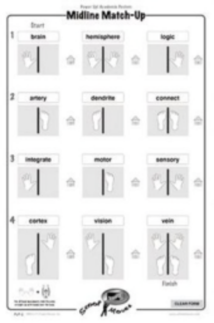
TOOLS OF THE TRADE | FOR SPECIALIZED METHODS OF INSTRUCTION

The more that is learned about how to reach and teach students with dyslexia to overcome the hurdles of their neurobiological difference in learning to read, the less overwhelming the situation will become. Included are some examples of simple, but effective scaffolds and structures that can be systematically implemented within an evidence-based and structured program tailored to learners who require specialized methods of instruction.

This **15-foot Coloring-Book Style Alphabet Banner** from superteacherworksheets.com, is differentiated to create an A,B,C book for kindergarten and first grade students who were identified with dyslexia. Dot the letters with liquid glue and have student trace the letter and say the sound or the letter name for a multi-sensory learning experience that spans sound, sight, and touch.



Visual scaffolds, such as the teacher-made template pictured here, support students' visual modality, as they complete the map. Additionally, as students move through the article that they are summarizing, the act of highlighting the ideas and transferring information to the map, engages their movement and fine motor modalities. Finally, listening to the verbal prompts provided supports their auditory modality. Once the template is complete, the load put on working memory and executive function is relieved and allows the student to transfer the information into a nicely presented paragraph. As one 3rd grade girl identified with a reading disability aptly expressed, "I love this. I couldn't put down my thoughts this well without this tool."



This **activity from S'cool moves**, integrates movement, vision, and auditory components, to scaffold and overlearn some consonant, vowel, consonant words from an explicitly taught, structured, and sequential reading program, not related to S'cool Moves. This movement-based program, includes the visual components of interactive posters and incorporates auditory learning with movement. S'cool Moves is the collaborative effort of a reading specialist and an occupational therapist. The program is built upon research from the fields of brain science, OT, PT, mind-body science, behavioral optometry, and best practices (https://www.schoolmoves.com/). Strategies used within the S'cool Moves program qualify as evidence-based practices (Wilson). S'cool moves meshes perfectly with multi-sensory practices, which encourages and focuses upon teaching through doing rather than just telling. Check out the website to learn more about this innovative manner of blending the health and educational models to create an engaging, multi-sensory learning experience that can be fused into a structured reading program, across a vast array of skills and grade levels.

ILLUSTRATIONS PROVIDED BY ANGELA SHAW

DIRECT INSTRUCTION (DI)

Through DI, inferential learning of any concept is not taken for granted (ldonline.org). The explicit teaching of a skill-set, using lectures and demonstrations of the material provides for an explicit, systematic instructional system based upon scripted lesson plans. Efficiency and pace of instruction are emphasized because of the purposeful acceleration of student progress, which DI programs are designed to provide. Oftentimes, professional development and coaching are provided to ensure that a high fidelity of implementation occurs.

Difficulty learning to read can be overwhelming and emotional for students and their parents. Families and educators often ask how they can help the student with dyslexia transform into a reader. In order to integrate a specialized academic focus to learners with dyslexia and other reading differences, it is essential to understand and integrate the six strategies noted above to increase support, understanding, and communication that is essential to a collaborative team of educational caregivers. •

ABOUT THE AUTHOR:

Angela Shaw is a special educator in So. California. She synthesizes her diverse education and experience to provide students learning that will grow for a lifetime. Her focus is upon special topics to include articles: "Simple 'Life Hacks' for Students with Dyslexia" (November, 2107, *Exceptional Parent* Magazine) and "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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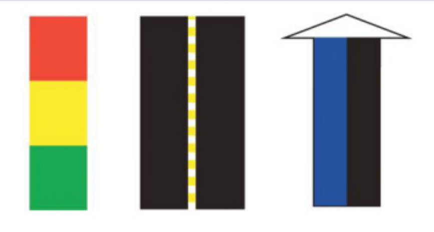
A word on Word Walls. In order to create effective Word Walls, they need to be explicitly and systematically taught. Additionally, they should be interactive and engaging. Word wall activities, as suggested by Reading Rockets, engage students from explaining key vocabulary to spelling words. Word wall activities engage students while they learn key vocabulary, whether it be learning to explain a word, to compare it to other key concepts, or to spell it. The one pictured, supports the reader in understanding and locating vowels through the use of red construction paper. Additionally, its purpose is to support students toward becoming independent writers through guiding students to discover similarities amongst words. For example, if a student is not sure how to spell the word cake, the teacher may guide him to discover the word make and change the beginning to /c/ or the letter "C". Additionally, the voiced sound /th/ and unvoiced sound of /th/ can be discovered and studied using the words on the wall. If a student writes the word camp as cap, help him or her discover that the nasal sound of /m/ appears in the word jump. Getting up close and personal with the word wall is important. There are many walls that you can build, to support vocabulary, literature, spelling, and so on. Check out www.readingrockets.org for some more great ideas on word walls.

This **work mat** presents a vast number of learning routines for multi-modal activities. Blending sounds into words is the initial topic of the visual support map. Tap out the sounds, starting with green, slowing in the middle at the yellow to hear the sound clearly, say the last sound at the end. Have the student do the tapping activity 2 or more times, before putting his or her finger on the "road" for blending into a word. The arrow does more than provide a visual to remind students of the left to right progression of the word. Place the work mat into a page protector and the student can transition into writing the presented word within the arrow lines using a dry-erase pen. For those students who have working memory needs, have them place letter tiles in the tapping sections when it is time for the writing/spelling activity. Remember to create and present this activity in a structured and sequential manner, with the sequence beginning at the easiest and most basic concept and building logically to an increased rigor. Direct Instruction methodology of "I do", "We do", "You do", will guide students to lessen the language load that purely verbal instructions sometimes present. Another great DI structure is to add the verbal prompts recommended by www.ottoolbox.com , such as "start the tall letters in the sky" or reminding the student "tail letters hang down underground."



Students with dyslexia can excel at math, but may require supports and strategies to address common math struggles that accompany dyslexia with regard to the language load of math (Woodin). Today's primary students begin conceptual and language-based mathematics practice, as they are introduced to the numeracy of addition and subtraction. The number bond is a paper-pencil based worksheet that can be broke down into multi-modal areas of seeing, hearing, and touching. Lots of practice at the table with a **divided dish, cubes, and an equation**, scaffolds and promotes overlearning, to support our students with dyslexia access conceptual applications of math beyond word problems.

Many parents have had an experience similar to the one faced by Endrew F.'s parents, in which their child's IEP goals don't vary each year and there is lack of progress.

ENDREW F. SUPREME COURT CASE:

STRENGTHENING THE VOICES OF FAMILIES AT IEP MEETINGS

BY DIANA AUTIN, MARIA DOCHERTY AND LAUREN AGORATUS, M.A.

The recent Supreme Court case, Endrew F. vs. Douglas County School District, has implications for parents participating in the IEP (Individualized Education Program) development for their child. The decision clarifies the rights of children with disabilities for a free, appropriate public education (FAPE) under the Individuals with Disabilities Education Act (IDEA).

This case is critical to ensuring that special education services meet the stated Congressional goal of IDEA: *"Improving educational results* for children with disabilities is an essential element of our national policy of ensuring equality of opportunity, full participation, independent living, and economic self-sufficiency for individuals with disabilities." It also supports the commitment of the US Department of Education "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.'"

The case also builds on the previous US Supreme Court case in Rowley, in which the Court held that students who require special education have a substantive right to receive free, appropriate public education (FAPE). The Court indicated at that time that this is met "if the child's IEP sets out an educational program that is 'reasonably calculated' to enable the child to receive educational benefit" that is more than de minimus (trivial). How much more than de minimus benefit is required is at the heart of the Endrew F. case.

WHAT WAS THE CASE?

Endrew F. is a student with autism and challenging behaviors. His parents thought he had made little progress with the same goals year after year in a Colorado public school. They enrolled him in a

private school for students with autism. His behaviors improved and he began learning at a faster rate.

WHAT WAS AT STAKE?

The argument centered on what is meant by FAPE. It explained what constitutes an appropriate education and to what extent students with disabilities are entitled to progress in and benefit from their education under IDEA (Individuals with Disabilities Education Act.) The main question was: "Must schools provide a meaningful education in which children show significant progress and are given substantially equal opportunities as typical children, or can they provide an education that results in just some improvement?"

WHAT DID THE COURT DECIDE?

The Supreme Court overturned the Tenth Circuit's decision that Endrew was only entitled to an educational program that provided "merely more than *de minimis"* (i.e. minimal) educational benefit. Under the Tenth Circuit's ruling, the district only had to show that Endrew F.'s IEP was designed to provide more than trivial or minor educational benefit in order to meet its FAPE obligations. The US Supreme Court's unanimous decision requires that IEPs must have goals that are *"appropriately ambitious"* and that districts must be able to offer a *"cogent and responsive explanation"* for their proposed IEPs that show that each IEP *"is reasonably calculated to enable the child to make progress appropriate in light of his circumstances."* The Court held that each child with an IEP is entitled to *"the chance to meet challenging objectives."*

HOW DOES IT AFFECT CHILDREN IN SPECIAL EDUCATION AND THEIR FAMILIES?

This decision clearly stated that FAPE under IDEA is a substantive right to an education that is designed to support student learning, and reinforced the importance of realistic but high expectations for students with disabilities. The outcome of the Endrew F. case reinforces the rights of students with disabilities and…

- *Spelled out the standards for determining FAPE.*
- *Increases focus on student centered IEPs considering unique needs, abilities and circumstances.*
- *Supports rationale to request more intensive, specialized and related services if needed for appropriately ambitious, challenging objectives.*
- *When parents and districts disagree, the district has a responsibility to provide a cogent and responsive explanation for the proposed IEP that demonstrates that it is appropriately ambitious and that it provides the chance to meet challenging objectives.*

Many parents have had an experience similar to the one faced by Endrew F.'s parents, in which their child's IEP goals don't vary each year and there is lack of progress. This court decision reinforces that IEPs must include annual goals (and as stated previously challenging objectives) that aim to improve educational results and functional performance for every child with a disability. The IEP must be aligned to both State academic content standards and ambitious goals.

For students with the most significant cognitive disabilities, alternate academic achievement ambitious standards must be aligned with the State's grade-level content standards. Goals for these students must also be appropriately ambitious, based on the State's content standards, and again "reasonably calculated to enable the child to make progress appropriate in light of the child's circumstances."

IEP Teams must implement policies, procedures, and practices related to:

(1) *present levels of academic achievement and functional performance;*

(2) *measurable annual goals, including academic and functional goals;*

(3) *how a child's progress toward meeting*

annual goals will be measured and reported, so that the Endrew F. standard is met.

Families must always remember that they are part of the IEP team. This new standard will require a "prospective judgment by school officials" that "will be ***informed*** not only by the expertise of school officials, but also ***by the input of the child's parents and guardians.***"

IEP IMPLEMENTATION TIPS

Questions asked during an IEP meeting should include:

- Have we given "careful consideration to this student's present levels of achievement, disability, and potential for growth?"
- Have we considered this student's "previous rate of academic growth, whether the student is on track to achieve or exceed grade-level proficiency, any behaviors interfering with the student's progress, and the parents' information and input?"
- Have we ensured this IEP includes challenging goals? Are these sufficiently challenging? Are they appropriately ambitious?
- Will this IEP allow this student to progress academically and functionally?
- Have we considered performance problems from the past year and parents' concerns in writing the goals, objectives and assessing what services are needed?
- How is this IEP reasonably calculated to enable this student to achieve passing marks and advance for grade to grade? And if that is not a reasonable expectation for this student, how is this IEP reasonably calculated to enable this student to make progress appropriate in light of his strengths and needs?

IEP Team members should consider how special education and related services have been provided, including ***the effectiveness of instructional strategies and supports and services with the student.*** The Team should consider ***the child's previous rate of academic growth, whether the child is on track to achieve or exceed grade-level proficiency, any behaviors interfering with the child's progress, and additional information and input provided by the child's parents.*** The IEP team must give "careful consideration to the child's present levels of achievement, disability, and potential for growth."

The IEP itself must aim to enable the child to make progress. It is an individualized determination that is unique to each child. The IEP should be reviewed at least annually to determine progress with periodic meetings throughout the year if warranted. ***If a child is not making expected progress toward annual goals, the IEP Team must review and revise the IEP. The parents of a child with a disability have the right to request an IEP Team meeting at any time.***

THE IEP AND YOU : RESOURCES FOR THE ENDREW F. DECISION

CENTER FOR PARENT INFORMATION AND RESOURCES: Endrew F.
www.parentcenterhub.org/endrew-qa
Find your Parent Center
www.parentcenterhub.org/find-your-center

U. S. DEPARTMENT OF EDUCATION
Endrew F.
Questions and Answers
www2.ed.gov/policy/speced/guid/idea/memosdcltrs/qa-endrewcase-12-07-2017.pdf

UNDERSTOOD.ORG TOOLKIT FOR FAMILIES
www.understood.org/en/school-learning/your-childs-rights/basics-about-childs-rights/download-endrew-f-advocacy-toolkit

NATIONAL PLACE
(PARENT LEADERSHIP, ADVOCACY, & COMMUNITY EMPOWERMENT) WEBINAR
www.parentsatthetable.org/storage/app/media/resources/Main%20Resources/?dir=Endrew%20F.%20Webinar

As in the case of Endrew F., behavioral supports are also essential for successful outcomes. IEPs must include consideration of behavioral needs in the development, review, and revision of IEPs in order to provide FAPE. IEP Teams must consider behavioral goals and objectives and services and supports in the IEPs of children whose behavior impedes their own learning or the learning of their peers.

In summary, the Supreme Court's Endrew F. decision will help parents make sure that their child's IEP goals and objectives lead to better outcomes. Students with disabilities are entitled to FAPE and appropriately high expectations should be in place for all children.

"To meet its substantive obligation under the IDEA, a school must offer an IEP reasonably calculated to enable a child to make progress appropriate in light of the child's circumstances." (U.S. Department of Education quote)

TAKE-AWAYS

- Parents need to fully understand that their child is entitled to an IEP that enables their child to make academic progress - which means for most children, the opportunity to advance from grade to grade.
- Progress must be appropriate in light of the child's circumstances.
- The adequacy of a given IEP turns on the unique circumstances of the child.
- Every child should have the chance to meet challenging objectives.
- The Supreme Court clearly articulated a shift to higher expectations for children with disabilities.
- Advocacy begins and ends with the families directly impacted and the family organizations that educate and support them.

ABOUT THE AUTHORS:

Diana Autin is the Executive Co-Director of the Statewide Parent Advocacy Network (SPAN.)
Maria Docherty is the Director of Technical Assistance for SPAN.
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.

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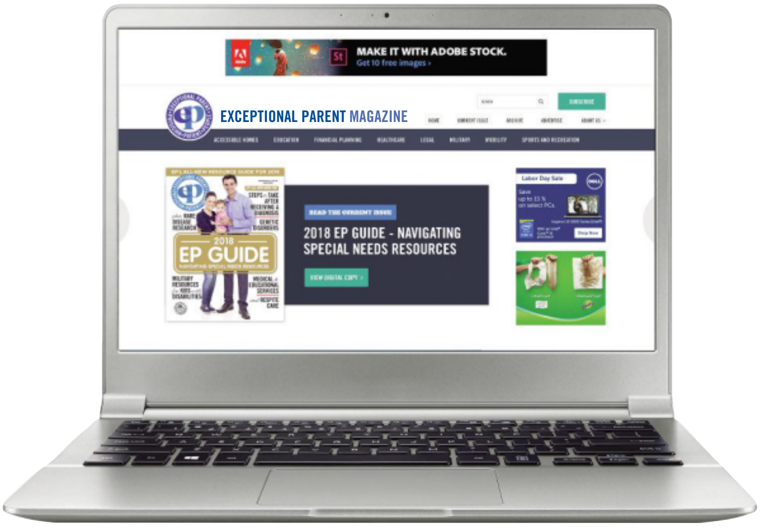

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Exceptional Parent Magazine is proud to announce the launch of www.ep-magazine.com – our all new website which coincides with our expanding role as a leader in the field of special needs publishing and communications.

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

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

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

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

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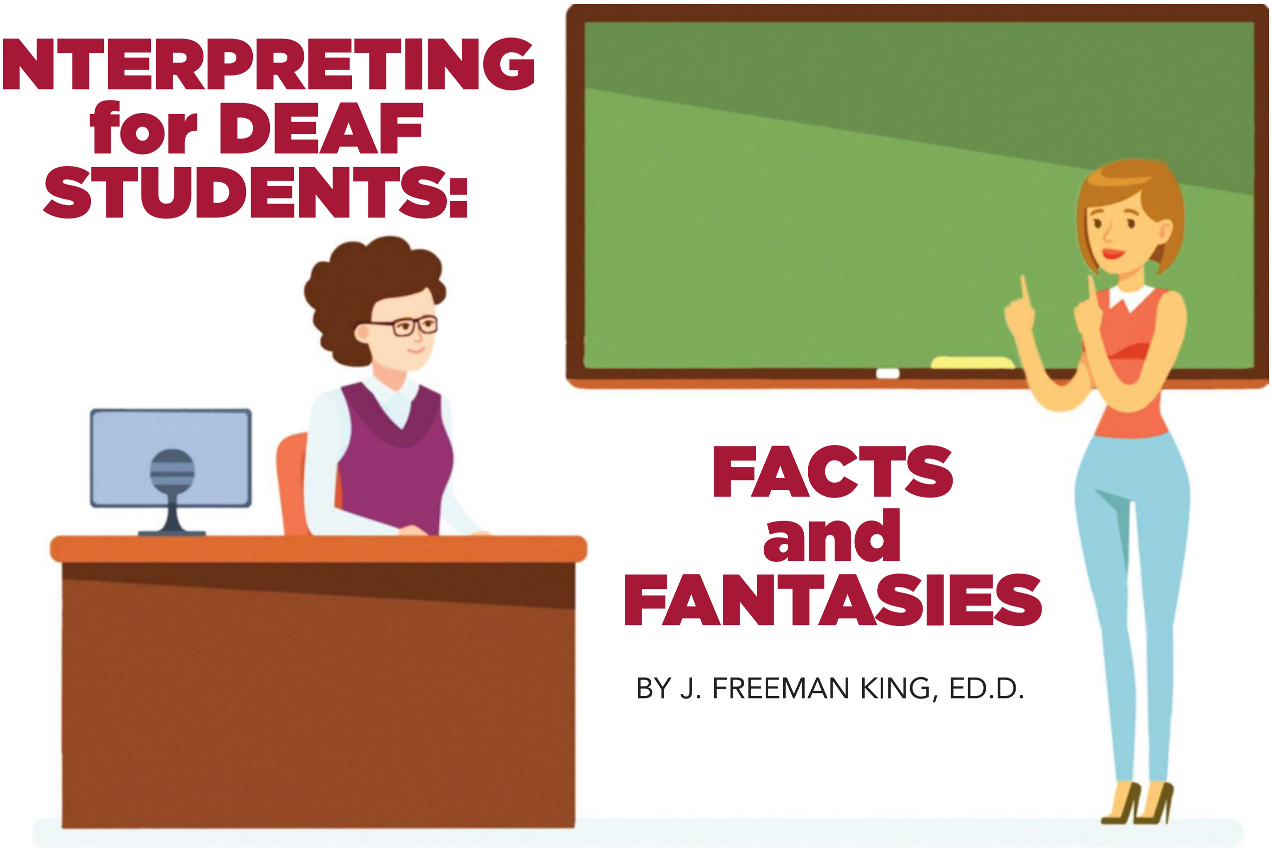
***EP-MAGAZINE*.COM: AN ALL-NEW DIGITAL HOME FOR THE SPECIAL NEEDS COMMUNITY**

Students who benefit from the services of an interpreter also have to be developmentally, cognitively, and socially accustomed to navigating the educational experience.

INTERPRETING for DEAF STUDENTS: FACTS and FANTASIES



BY J. FREEMAN KING, ED.D.

Parents, school districts, teachers, audiologists, and speech-language pathologists involved in education of deaf children are often ill advised regarding the effectiveness of interpreters in public school mainstreamed classes. Even though interpreting services are often recommended in the deaf student's Individualized Education Plan (IEP), what is overlooked is the fact that many deaf children, especially preschool, kindergarten, and elementary-aged do not have a fully developed and meaningful visual language, without which the interpreter's effectiveness is greatly diminished or non-existent.

Many of these younger students are only in the beginning stages of visual language acquisition and do not yet have the expressive and receptive skills to benefit from an interpreter. Also, middle school and high school students can be impacted if the students do not have the needed language skills and incidental learning access to adequately understand the teacher's message as relayed by the interpreter.

Visual language competency and use is not the only factor that contributes to a deaf student being unable to benefit from the use of an interpreter. Students who benefit from the services of an interpreter also have to be developmentally, cognitively, and socially accustomed to navigating the educational experience. Quite often, school districts believe that the provision of an interpreter automatically provides the deaf student access, participation, and membership into the hearing educational environment. More times than not, this does not happen.

The Individuals with Disabilities Education Act (IDEA) affirms that, based on assessment, interpreting services for deaf and hard of hearing students should be appropriate and will effectively serve the student. For many of these students, interpreting is the primary support service, and often the interpreter is the only sign language model the deaf student has access to. If the student is still acquiring foundational language, making linguistic strides through interpretation alone is in itself challenging, if not impossible. When this is the case, the educational team must consider alternate or additional roles/positions with language-fluent staff who are trained to provide language planning and instruction that leads the student to having a foundational language in which interpreting can be beneficial.

Often, deaf students state that they prefer direct communication with their classroom teachers in the K–12 setting that is more efficient, effective, and empowering than with interpreted communication. Thus, the Individualized Education Program (IEP) team must consider the restrictiveness of the recommenced placement site for the student. With assessment data and anecdotal evidence from the educational team, IEP teams should consider whether or not direct instruction from a qualified educator or from an interpreter would best assure an appropriate and least restrictive educational environment. When direct communication cannot be made available for all or part of the educational process, it is critical that quality standards for interpreters and other members of the educational team be implemented.

Interpreters should not be required to perform in roles in which they are not trained and qualified: as tutors, Deaf Education-related specialists, counselors, or teachers. This can lead to confusion and misunderstanding among colleagues, parents, and students. Interpreters should never be expected to unilaterally decide educational supports that students might need. Interpreter preparation programs generally provide training from a community interpreting perspective, not how to match the language needs of a child whose language is still emerging. If an interpreter is expected to serve an expanded role, it should be formalized and discussed with the instructional staff, the parents, and the student, and all instructional supports should be guided and monitored by a qualified educator and included in the Individual Education Program (IEP).

Even though interpreting services can be valuable to deaf and hard of hearing students who possess a high level of linguistic skills, these services are a complicated process; yet, they remain a predominant provision for deaf and hard of hearing students who attend public school programs. Certainly, not all students are prepared to access educational programs in this manner. Therefore, in order to provide a truly least restrictive education in the most appropriate environment, decisions made by the Individual Education Program team regarding interpreting must be carefully and judiciously made. •

The following questions are presented for consideration by all educational programs that are considering the use of interpreting services:

In what manner do educational programs assess a student's linguistic competency in sign language and make programming decisions accordingly?

Only teachers of the deaf, speech-language pathologists or diagnosticians who possess expertise in a receptive and expressive visual language, such as American Sign Language (ASL), should be entrusted with the responsibility of assessing student sign language competency. If this expertise is not evident, the school district or the program must assure that it is.

Do interpreting services provide a restrictive environment or a least restrictive environment?

If a student is not linguistically prepared, the IEP team needs to implement programming that provides a natural language environment for its facilitation. Natural sign language environments should include native sign language users (well qualified deaf individuals) or hearing professionals who are competent in the visual language. Also, students will benefit socially and linguistically from age-appropriate peers and adult language models. Adult language models can serve as classroom teachers, teacher aides, and tutors.

ABOUT THE AUTHOR:

J. Freeman King, Ed.D. is Professor, Deaf Education, Utah State University, Logan, Utah.

In recent years, Health Promotion has been spreading outside the screening "tent" and to the field of play and community with Special Olympics Athletes serving as health leaders.

A LIFETIME OF GOOD HEALTH

BY PEYTON PURCELL, MPH

Like any athlete, Special Olympics athletes who are fit, at a healthy weight, have strong bone density and normal blood pressure are better able to compete in their sport, contribute at work and enjoy activities in their daily lives. But people with intellectual disabilities (ID) have higher rates of obesity, bone fractures and untreated hypertension (high blood pressure), leading to chronic disease and, for many, a shorter life expectancy. One of the largest discrepancies between individuals with ID and the general population exists in obesity. In Special Olympics athletes, 31% of the adult population globally were obese (BMI ≥30) as compared to 13% of the general population. In the United States, the rates are even higher—45.8% of US Special Olympics athletes were obese in comparison to 30.4% of the general US adult population.

Since 2003, Special Olympics has offered Health Promotion events to help combat this disparity by providing free screening to Special Olympics athletes, as well as training healthcare providers in how to provide care and resources to individuals with ID in their own clinics and communities. "Special Olympics Health Promotion changes lives around the world by delivery of interactive, and fun education activities that promote healthy behaviors and provides opportunities for athletes to learn about and practice behaviors that enhance their health and prevent chronic disease," said Mary Pittaway, a registered Dietitian and Special Olympics Global Clinical Advisor for Health Promotion.

In Health Promotion events around the world, volunteer physicians, nurses, nutritionists and health educators provide clinical screenings in four key areas: (1) bone density (for athletes age 20+), (2) blood pressure, (3) Body Mass Index (BMI), and (4) a self-report survey on current health habits. Based on the screening results and the athletes' needs, volunteers also provide critical education in areas such as nutrition, sun safety, and tobacco cessation to convey and reinforce key concepts on healthy living, healthy lifestyle choices, and locally specific health issues.

Special Olympics health programming works to address wellness and health promotion across the continuum – from the individual athlete to the family who supports them, and the community they live in, to the health system. At a Health Promotion screen-

PHOTOS PROVIDED BY STEPHANIE CORKETT/SPECIAL OLYMPICS

LEADING THE CHARGE: *(Above left)* Renate Nekolar from Austria gets her blood pressure checked. *(Above right)* An athlete in Indonesia learns the difference between healthy and unhealthy foods. *(Opposite page)* Gabriele, center in yellow, has lost over 22 pounds after being motivated to get healthier after attending Health Promotion.

ing, the focus is the athlete themselves. “We teach athletes behaviors they can do for themselves, rather than having to depend on others. Athletes are empowered to choose healthier foods and beverages. They are taught how to protect themselves from getting sunburn, while still getting enough vitamin D. They are shown ways to add physical activity into their daily lives, outside of their sports time. They learn to protect themselves from communicable diseases by practicing good handwashing,” explains Pittaway.

“Often, athletes share that the nutrition information they receive at Health Promotion, such as drinking more water and less sugar-sweetened beverages, has helped them to achieve a healthy weight and improve their sport performance. We talk about small changes to enhance the athlete’s health and sports enjoyment,” shared Alice Lenihan, a registered dietitian and Special Olympics Global Clinical Advisor for Health Promotion. The athletes are eager to learn and apply the knowledge they gain from Health Promotion.

At a 2014 Health Promotion event in Italy, Gabriele, a Special Olympics soccer athlete, spoke with Health Promotion Clinical Director and Nutritionist, Roberto Vennarucci. They discussed how Gabriele might be able to run faster and meet his athletic goals if he improved his nutrition and healthy habits. Roberto recalled that Gabriele’s mother explained, “no matter how hard she tried, Gabriele didn’t seem to care about what he ate.” However, after attending the Health Promotion event, Gabriele decided to track his weight, control the amount of salt and seasoning in his cooking, and replace sugary beverages with water. Within several months he had already lost 22 pounds. Even better, he maintained that weight loss for more than a year when he reconnected with Roberto and the volunteers who first inspired him to work toward this health goal at another Health Promotion event.

In recent years, Health Promotion has been spreading outside the screening “tent” and to the field of play and community with Special Olympics Athletes serving as health leaders. Athletes are leading “sun safety squads,” passing out sunscreen and providing sun safety education to their fellow athletes and fans in the stands; they are leading cooking demonstrations at community events; and they are speaking to legislators and industry leaders. Through their actions, and with support from Special Olympics, these athletes are leading the charge to create inclusive communities that are improving the health not only of themselves and their fellow athletes, but having a ripple effect on their families and communities and inspiring us all to make our own behavior change and healthy lifestyle decisions. •

Learn more about Special Olympics, Healthy Athletes and Health Promotion and wellness programming at http://www.specialolympics.org/health

ABOUT THE AUTHOR:

Peyton Purcell, MPH is Senior Manager of Health Promotion and MedFest, Special Olympics International.

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I decided it was time to come out of the genetic disease closest and own my disease: go from hidden-HD Seth to a new Seth with no secrets.

MY HUNTINGTON'S DISEASE JOURNEY

BY SETH ROTBERG

When I was about 12, I started noticing something wrong with my mom. She wobbled from poor balance, often tripping and falling over, as if she were drunk. She had severe mood swings; one minute she was fine and the next, she was angry, frustrated, or depressed. I was confused as to what was going on and the doctors just labeled it as her being bipolar and having major depression. But we knew it had to be more than that.

A few years later, when I was 15 and my sister was off at college in Arizona, my dad and I were still trying to figure out the problem with my mom. My mom needed help and we were running out of options. After countless doctor's visits and evaluations, we found out my mom had the rare, neurological, genetic disease known as Huntington's Disease.

Huntington's Disease, which is also known as HD, slowly deteriorates a person's physical and cognitive abilities. The cognitive decline includes a loss of short-term memory, decision-making, concentration, among other things. But the worst part about the disease is that there is no cure. Once the symptoms start, the average life span is 10 to 20 years.

When my parents sat me down to tell me my mom had HD, I still did not understand what that meant. So, I did what any other 15-year-old kid would do – I Googled, "What is Huntington's Disease?" Even though I learned more about the disease, I was still in denial and was often embarrassed by my mom's slurred speech and wobbly movements. I would even stay at my friends' houses, just to get away. I wanted to be "normal." Yet, I did not realize that HD takes away the possibility of that "normal".

It was not until college that I understood the genetic component of HD affected *me* as well - I was at a 50/50 chance of inheriting the disease and ending up like my mom. A coin-flip. I thought: heads I win, tails I lose. I just didn't know which it was going to be, because to know, you need a genetic test.

Regardless, I felt like I needed to do *something.* I began to realize that all those past years of my mom acting differently was truly not her fault and it was actually the HD that caused my family so much stress. Part of me felt guilty for how I treated her and wanted to do something to make up for it. My friend, Max, and I decided to

SLOW TO SHARE: Seth with his sister, Julie, his dad, Alan, and his mom, Debbie. "Coming out of the testing process, I told a few friends. But, apart from them, I'd put myself in a genetic disease closet, closed the door, and hid my results from everyone else."

PHOTOS PROVIDED BY SETH ROTBERG

organize a 3-on-3 basketball fundraiser called Hoops for Huntington's to raise money and awareness for Huntington's Disease. You could also say this was my way of coping with the disease and keeping my mind off of wondering what my genetic fate would be.

However, I could not help but think about testing because of the impact it will have on my future. I wanted to make sure I could plan my future accordingly, no matter what happened. Without knowing my gene status, I would not be able to better plan what lies ahead for me such as a wife, kids, a house, and career. I became exhausted and drained on a daily basis and I ultimately decided I did not want to live with the unknown.

A FAMLY INSPIRED: Seth's mom prior to showing signs of Huntington's Disease. Seth and his family at the annual Huntington's Disease Society of America National Convention. *(Left to right)* Debby Miller, Mike Miller, Steve Miller, Seth Rotberg, Alan Rotberg, Julie Rotberg and Ann Miller

After deciding to get tested, I felt that I should not tell my family. My mom was still alive, and, if I tested positively, I did not want her to feel devastated and guilty that she passed HD down to her son. At the time, my dad was the caregiver to my mom and I did not want to feel like another burden to him. And since HD is a genetic disease, my older sister is also at risk and I did not want her to feel stressed or pressured to get tested. But ultimately, I did not want my mom to ever find out. I was afraid my dad, sister, or extended family may accidentally say something to her.

I walked into the exam room feeling a bit nervous, yet calm. My neurologist introduced me to the genetic counselor who was not at my first appointment. I realized it must mean bad news. He then said "Seth, your genetic test came back positive for Huntington's Disease." I had already known, deep down, that I had the disease, but now this was confirmation that it was for real. I was in shock.

Coming out of the testing process, I told a few friends and I was very fortunate for their support throughout the whole process. Yet, apart from those friends, I'd put myself in a genetic disease closet, closed the door, and hid my results from everyone else.

Knowing I had Huntington's did give me extra motivation in life. I joined a few HD organizations and was supporting young people and families impacted by the disease. I started doing more fundraising and helping with advocacy efforts. I was feeling pretty good about how things were going.

In 2013, my life hit a turning point. My senior year of college, the day before my last semester, my good friend, Jake, unexpectedly died in an accident. His favorite quote – he even had it in his yearbook – became inscribed on his headstone: "Live as if you were to die tomorrow, learn as if you were to live forever." I thought to myself "How can I keep his memory alive by living my own life to the fullest?" As I still mulled this over for some time, I lost another friend, Meghan, who had a version of HD that took her life at the age of 26. Meghan had always shared her story to raise money and awareness for the disease. She never hid her disease, but instead used it to inspire others.

It made me think more about my HD

TALKING THE TALK: "Navigating Genetic Disease Testing: A Personal Story" | Seth Rotberg | TEDxNatick; https://www.youtube.com/watch?v=5_O5TfMVqD8&feature=youtu.be

A WAY FORWARD: Seth and his mom in the late stages of Huntington's Disease. Seth being honored Heroes Among US award at the Boston Celtics game in 2016.

secret. Why keep going on in life keeping a part of me hidden from the world? Despite Jake and Meghan's circumstances, their positive outlook on life inspired me. Jake's legacy wanted me to make the most out of life. Meghan's example showed me I could be open and use my own disease to accomplish that. I decided it was time to come out of the genetic disease closest and own my disease: go from hidden-HD Seth to a new Seth with no secrets.

Before I could do that, I needed to tell my dad and sister. I told them separately, starting with my dad. I walked into the living room, sat across the couch from him and told him I had something important to say. I could not get the words out. After a long silence, he looked at me and said, "Why are you so nervous? What is it? Come out with it?" I said, "Dad I've tested positive for Huntington's Disease."

I was expecting him to be upset and even frustrated for keeping this from him. Yet, I have never seen someone so calm. He simply said "Okay." I was in disbelief: "That's it?" He explained that he was not worried based on all the research happening. He said it is important to stay positive because, soon enough, there will be a cure for it. It was reassuring to know my dad was going to stick by my side just like he did with my mom.

I then told my sister and I feared telling my sister wasn't going to be as easy as telling my dad. But of course, I was wrong. After telling her she asked some questions about it but was very supportive. Mostly, she was just shocked, like so many others, that I had kept this a secret for two whole years.

If I could go back in time and do it all over again, I would probably only change one thing: tell my sister and dad how I wanted to test for HD and have them go through the testing process with me. Few people can say they have very supportive friends like me, and I think it is important to have as many resources as possible when going through the testing process.

After telling them, I felt so relieved. I was finally out of my closet – people were now aware of my hidden secret: the HD. And better yet I knew my life purpose: sharing my HD journey and mentor young people facing adversity in life. Whether it is HD related or another challenging circumstance, helping young people is what makes me happy and who I am today.

Instead of letting HD define and defeat me, I found ways to use my disease to improve my life and the lives of others. Over the past couple years, I've met people I never would have met, been involved in organizations I never would have helped, and had experiences that my hidden-HD Seth never would have had the opportunity to enjoy. In 2015, I was awarded the HDSA Youth of the Year award, and in 2016 I was a recipient of the Heroes Among Us Award from the Boston Celtics. Even though I am still fairly young, I sit on the Board of Trustees for the Huntington's Disease Youth Organization (HDYO), whose mission is to support young people around the world impacted by HD. The past couple of years, I've been able to help out at the HDYO Youth Camp and actively and intimately help young people affected by HD learn how to make their life better as well.

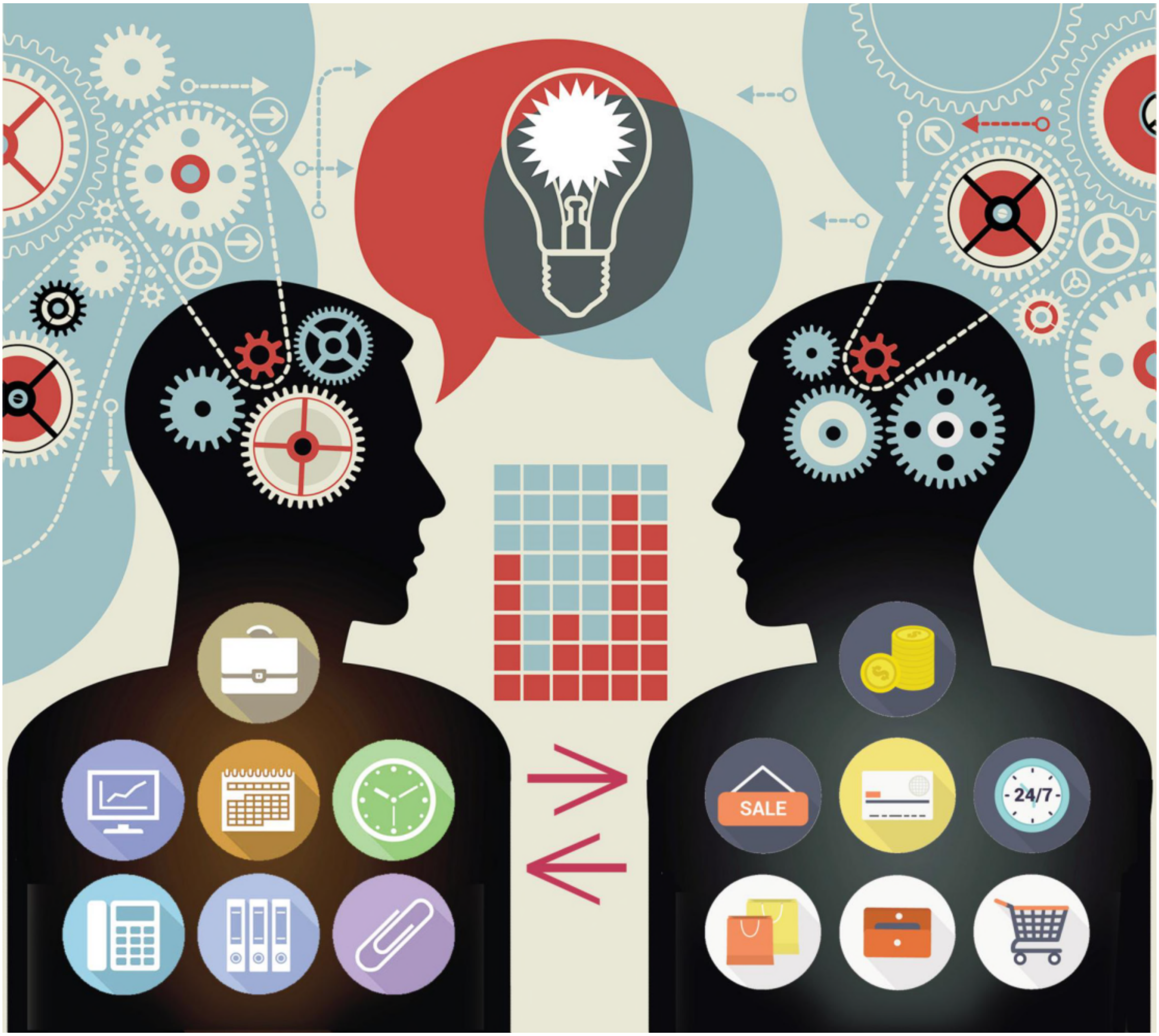
Recently, I was invited to speak at TEDxNatick and share my HD story to inspire others. It was an unbelievable opportunity to meet and listen to so many other people's experiences. I hope to continue finding opportunities to use my experience to help others learn more about HD and find ways to make life better, no matter where they are at now.

Each day is a new day and you have the opportunity to make the most of it. What's your next step to a better tomorrow going to be? •

ABOUT THE AUTHOR:

Seth Rotberg is currently pursuing a master's in nonprofit management at DePaul University in Chicago. He is passionate about bringing his personal experience to working for non-profit organizations. He has more than seven years of experience working and volunteering with a variety of youth development nonprofits. Contact: Seth@hdyo.org; 508-988-5888

Companies are starting to recognize and celebrate the need for a neurodiverse workforce. And this isn't just a hunch. Real work has been done to demonstrate the strengths of a subset of this workforce: those with I/DD and learning disabilities.



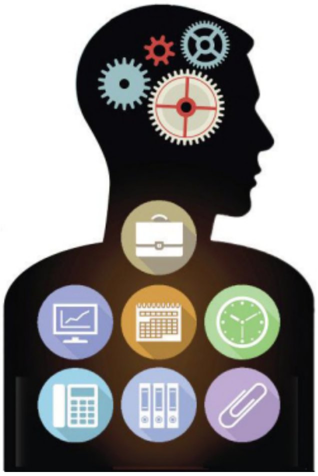
NEURODIVERSITY IN THE WORKPLACE

EXCITING OPPORTUNITIES ON THE HORIZON

BY ANGELA NELSON, MS, BCBA

The question that pops into nearly all parents' minds at some point – what will my child's future look like – yields a wide array of aspirations… and even more questions. Some, clear as day, while others, foggy. And what if you have a child with an intellectual or developmental disability (I/DD)? What will his or her future hold? The good news is, today, it's not just Mom and Dad who are the advocates helping to carve out meaningful employment for their children. It's the future employers, too. But a little context first…

We've heard the statistics about employment among the I/DD population, and the numbers are staggering. The ARC surveyed families raising children with an I/DD for a 2010 study, and they reported only 15% of their children were employed. These data were similar to many other surveys, including the National Core Indicators (NCI) Data Brief, which highlighted the high underemployment or unemployment rates of people with an I/DD along with what type of housing they resided in (e.g., 33% of those living independently had employment vs 17% living with parents, etc.), whether they liked their jobs (92% of those working in the community said "Yes"), and the type of work they did (30% cleaning/maintenance, 18% retail, etc.). Certainly, we have the Americans with Disabilities Act (ADA), a civil rights law prohibiting discrimination based on disability in all areas of public life, as well as the U.S. Equal Employment Opportunity Commission (EEOC), which specifically enforces that employers not discriminate against qualified individuals with disabilities during interviewing, hiring, training, or firing. While these laws and groups are crucial for our employed population, how are we getting more people with I/DD *into* the workforce in the first place? And how are we supporting their work to facilitate their success?



"Companies such as Microsoft, SAP, Willis Towers Watson, Hewlett Packard Enterprise (HPE), and Ford have all examined their human resources practices to better access and accommodate neurodiverse talent."

Enter the word "Neurodiversity." This is still a fairly new term, and while its definition will continue to evolve, most agree it refers to the concept that we are all wired differently. The tech industries have taken particular interest in this concept. Companies such as Microsoft, SAP, Willis Towers Watson, Hewlett Packard Enterprise (HPE), and Ford have all examined their human resources practices to better access and accommodate neurodiverse talent. Microsoft even has their own "Neurodiversity in the High Tech Workforce Conference." Companies are starting to recognize and celebrate the need for a neurodiverse workforce. And this isn't just a hunch. Real work has been done to demonstrate the strengths of a subset of this workforce: those with I/DD and learning disabilities. HPE's program has placed over 30 individuals from within this "neurodiverse subset" in roles testing software at Australia's Department of Human Services, and this subset was found to be 30% more productive than colleagues without a disability. Israel's Defense Force has a "Visual Intelligence Division," which employs many individuals with autism as image analysts and even recruits high school students for strong visual thinking and attention to detail. These are the students that would otherwise receive an exception letter from participating in the Israeli Army due to their disability.

This is encouraging news for parents to hear, so why isn't every company doing this? And why are people with disabilities still so underemployed when we know they have so much to contribute? Many times, it comes down to just getting past the interview. If you aren't making eye contact, your conversation goes off on a tangent, you focus on the interviewer's earrings or the picture of their dog on the desk and keep circling back to those topics, for example, this can be confusing to someone who has never supported an employee with a disability before. They may even assume you're uninterested or underprepared and, therefore, not an appropriate fit for the job. The result – another "We're sorry" response, and it's back to square one. Or let's say you *are* hired but are having difficulty prioritizing tasks and staying focused on your work. You get distracted by people coming and going alongside your desk, the side conversations you overhear are always derailing your concentration, and those fluorescent light bulbs are almost unbearable. Never mind the fact that you can't keep all those projects organized. You may eventually find yourself getting fired because you missed too many deadlines. Or let's say you exceed expectations when it comes to your tasks, but when it comes to interacting with your colleagues, you find it agonizing. Knowing you must give that presentation in front of even three people looms over you and makes you sweat more than anything in the world. The anticipation of talking to others at that upcoming holiday party makes you nauseated for weeks. And conflict resolution? You don't know where to begin. Even though you produce superior work, you may find yourself leaving your job because the social expectations are too much to bear.

We know people are facing challenges like these daily, all over the world. Where's the disconnect, and thus, the opportunity for the company?

Awareness and training for managers and employees to better support a neurodiverse workforce.

Companies are required to provide *reasonable* accommodations to their employees with disabilities unless that accommodation would cause the business undue hardship. A Job Accommodation Network (JAN) study found that the majority of accommodations were completely free, or if there was a cost, it averaged only around $500. The benefit? Increased morale and productivity, better retention rates, reducing workers' compensation and training costs, and increasing diversity throughout the company. With awareness and training, managers and "neurotypical" employees can support their colleagues who may benefit from even the simplest of tweaks to their job duties. Let's look at a few examples:

Challenges with communication/ speaking	• Allow a written response instead of verbal • Provide advanced notice of topics for practice purposes • Allow a colleague to present material on the employee's behalf
Challenges with organization/ prioritization	• Assist with a color coding system for files and projects • Work with the employee to create daily/weekly To-Do list • Assign a mentor to assist the employee • Provide a timer to assist with time allocation
Challenges with social interactions with coworkers	• Provide sensitivity training • Allow telecommuting if needed • Assign a mentor to assist the employee • Provide clear expectations of appropriate behavior and examples to explain inappropriate behavior • Provide positive reinforcement for appropriate social behavior
Challenges with sensory issues	• Allow noise canceling headphones • Provide sound absorption panels • Provide a sound machine • Relocate the employee's workspace • Redesign the employee's workspace to reduce distractions

At Rethink, our mission is to inspire and empower individuals with developmental disabilities and those who support them. In partnering with companies, large and small, to provide training and resources to their employees raising children with an I/DD, it became clear that these companies were invested in the overall wellness of their population. Having to manage a job while simultaneously juggling therapy visits, assessments, IEP meetings, the stress, and all the extra considerations that come with having a child with a disability are not overlooked. Companies appreciate the unique needs of their employees and, more and more, are providing them in-depth support. An area of introspection among companies now is – are we, the HR managers, supervisors, mentors – equipped, right here in the office, to accommodate neurodiversity? We are providing support to the caregivers, but what about our employees who may be struggling? And what about the valuable employees we may never have the pleasure of working with because we are not providing an accessible path to employment? What about that talented employee who just couldn't meet deadlines that we had to fire? What about the employee who left us last month because he felt uncomfortable with the amount of social interaction we have here? Where do we go from here?

Awareness and training for managers and employees is a viable option to facilitate a *successful* neurodiverse workforce. Rethink has incorporated the hardships shared by both people with I/DD, as well as employers, to create a meaningful solution:

- *E-Learning – modules to train managers and employees*
- *Teleconsultation – calls and videoconference with master's and doctoral-level board certified behavior analysts (BCBAs) to provide guidance*

The E-learning modules focus on improving awareness and job productivity for all employees. The modules are five to ten minutes, focus on employee strengths, and are full of easy, practical solutions to implement on the job. Specifically, the trainings promote active participation through guided notes, short review quizzes, and discussion guides. Many resources are provided in the form of printed material to facilitate implementation of strategies such as checklists and visual supports. There are also follow-up activities, which serve as guides for self-reflection, as well as additional reading and research content.

The teleconsultation services focus on personalized supports and troubleshooting for workplace issues. For example, a manager may want to discuss how to implement newly learned ideas around using checklists and color coding to better support an employee who is struggling with task completion and organization. Or an employee has just learned that her colleague is on the autism spectrum, and she wants to talk through ways to be most helpful to him. Teleconsultations allow for a confidential dialogue about usually difficult situations and how to solve them proactively and with care.

"Having to manage a job while simultaneously juggling therapy visits, assessments, IEP meetings, the stress, and all the extra considerations that come with having a child with a disability are not overlooked."

We applaud companies for striving to create a more inclusive workplace. Not one that's just neurodiverse, but one that ensures everyone is successful, accommodation or not. Workplaces that celebrate our differences and believe that a disability shouldn't exempt you from meaningful employment. These truly are exciting opportunities on the horizon for our children. •

ABOUT THE AUTHOR:

Angela Nelson, MS, BCBA is a board certified behavior analyst (BCBA) and has a master's degree in educational psychology and counseling. She is the Executive Director of Family and Clinical Services at Rethink, a healthcare technology company that provides resources, training, and support to parents, special educators, and clinicians. Angela's division, Rethink Benefits, provides teleconsultation services and guidance to parents utilizing Rethink as a free health and wellness benefit from their employers. To learn more about Rethink, visit www.rethinkbenefits.com

HOW TO TEACH GOOD ORAL HYGIENE TO YOUR CHILD WITH SPECIAL NEEDS

BY RICHARD MUNGO, DDS

Trying to get any child to lay off the candy and brush their teeth can be a challenge. Yet, for parents with a special needs child, it can be even more problematic as there are other variables that put them at high risk for dental problems. A child's physical, mental and intellectual abilities will all factor in their ability to comprehend and practice good oral hygiene. With some conditions, such as cerebral palsy and seizure disorders, it might be physically challenging for the child to brush or floss. Then there are special needs children that must adhere to a diet high in carbohydrates and sugars. Others require medications that cause dry mouth and gum growth or are missing teeth, which is common among special needs children.

According to the American Academy of Pediatrics (AAP), dental care is the most common unmet need among children with special needs. Because cavities left untreated could spread to other parts of the body that may already be compromised by a preexisting condition, it's important that parents instill good oral hygiene with their child. Following are some time-tested strategies to help parents with the process.

START EARLY

Like any good habit or routine, you want to introduce the importance of good oral hygiene early. Even before the first tooth, you should consider wiping your child's gums with a special toothbrush or washcloth. Later, as your child's teeth start to come in, you'll want to introduce him or her to the actual process of brushing. Remember to avoid fluoridated toothpaste until the age of 3.

As soon as teeth become visible in the mouth, brush the teeth with a small, soft-bristle toothbrush. Make brushing in the morning and evening a part of your child's daily routine.

If your child has sensory issues, you may want to break down the process. You can start by touching your child's cheek with the toothbrush, and then lips, before moving to actual brushing. You'll always want to do it at a time when the child is least cranky and will be most cooperative.

AVOID SUGARY FOODS & NIGHT BOTTLES

Limit your special needs child consumption of candy, soda, and snacks. Often parents will use sweets to placate a whining child, award a child for good behavior or to avoid mealtime food battles.

It's equally important that your bedtime routine doesn't involve a bottle. The sugars in milk and juice have the potential to decay teeth. Such habits can be setting up your special needs child for lifelong dental problems.

MAKE BRUSHING FUN

Once teeth become visible you'll want to introduce your child to brushing twice daily. Start with a soft-bristle toothbrush. If your child has physical limitations that make it difficult for him to hold or maneuver small things, consider attaching something to the handle.

The aim is to make brushing seem less like a chore, but something fun and enjoyable. Try putting on your child's favorite song or creating a game out of the process.

FIND A GOOD DENTIST

It is recommended a child starts visiting a pediatric dentist on their first birthday. This will help to normalize the process and identify any dental issues that require intervention.

For a child with sensory issues, the sight or feel of dental instruments and the bright office lights can be frightening. It's important the dentist has extensive experience treating children with special needs, including developmental disorders, physical disabilities, and special behavioral and emotional needs. The office should radiate calm and be equipped with the latest technology that allows the doctor to perform a full range of dental procedures – from X-rays to crowns – in one place.

Be sure to bring the toys and games to distract your during the wait. Some parents find giving their child earphones and allowing them to listen to their favorite music during drilling helps limit anxiety.

STAY POSITIVE

Children pick up on their parents' emotions. They are also quick to mimic what they see at home. A parent's own oral hygiene practice and attitude about personal dentist visits will inevitably influence the child's thoughts and actions.

ABOUT THE AUTHOR:

Richard Mungo, D.D.S., is chair of pediatric dentistry at CHOC Children's, a pediatric healthcare system in Orange County, California. Dr. Mungo's philosophy of care is to provide the highest quality of oral health care for the children in an atmosphere that is culturally sensitive and fully attentive to patients' needs.

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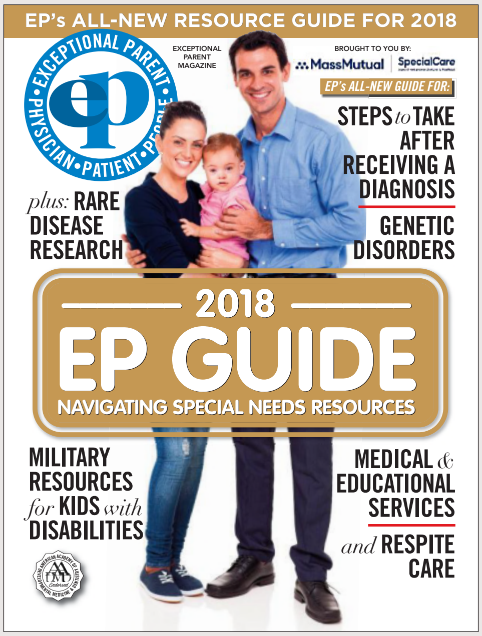

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FAMILY FITNESS *with* YOUNG CHILDREN

As a parent of young children, your time may not always feel like your own. Despite your best efforts, it may seem like there's always another mess to clean. Finding time to exercise ... well, let's just say it might not make it to the top of your to-do list. But here's the thing: you don't have to choose between spending time with your children and physical fitness. Regardless of your current fitness level, there are ways to include your family in your active lifestyle, which ultimately sets a positive, healthy example for your kids. Try these ideas for exercising if you have young children.

FITNESS WITH A BABY

- **Put your baby in a stroller and take a brisk walk.** You'll get some exercise, your child will enjoy a change of scenery, and you'll both get some fresh air.
- **Invest in a jogging stroller.** Once your child is old enough, a jogging stroller is a great way to pick up the pace and improve your cardiovascular fitness.
- **Check out upcoming walks, fun runs or races.** See if your community or Morale, Welfare and Recreation program (www.militaryinstallations.dod.mil/MOS/f?p=MI:ENTRY:0) offers a stroller-friendly option.
- **Hike with a baby carrier.** There are numerous options on the market that allow you to safely strap your child to your chest or back, so you can enjoy a hike.
- **Look for a parent and baby fitness class.** Check with your installation's fitness center to see if it offers classes designed for parents with young children.

FITNESS WITH A TODDLER OR YOUNG CHILD

Take a trip to the park. Visit the playground on your installation or find a park in your surrounding community where you and your child can run, climb, swing and jump.

- **Go for a bike ride.** Attach a child's seat to your bike and get ready for a good time. Make sure you have the proper safety equipment (like a helmet) before you set out.
- **Rent sports equipment.** Check with Morale, Welfare and Recreation on your installation to see what equipment is available if you aren't yet sure of your child's unique interests. This is a way to introduce your child to a wide range of sporting options without spending a lot.
- **Go bowling.** Not only does bowling provide a great way to get some activity, but your installation's bowling alley may even offer a family discount.
- **Go for a swim.** Spend an afternoon splashing around with your child and teaching them swimming basics, like floating and treading water. You can even check with Morale, Welfare and Recreation about swimming lessons.
- **Have a dance party.** Fitness doesn't have to be a formal activity to be good for your body. Turn on some music and have a family dance party at home.

Remember, every little bit of activity counts — whether it's doing jumping jacks during television commercial breaks or playing a game of tag with your children in the backyard. Use whatever time and equipment you have at your disposal to prioritize your fitness while still spending time with your family. Not only will your family's health improve, but your children will learn the types of healthy habits that last a lifetime.

Check with Morale, Welfare and Recreation on your installation for a schedule of swimming lessons, or reach out to Health and Wellness Coaching (www.militaryonesource.mil/health-wellness-coaching) for other ideas for family fitness activities.

– Military One Source

FAMILIES WHO WALK TOGETHER TALK TOGETHER

Family time is precious to service members and their families, so make the most of it by looking beyond phones and screens for simple activities together. Make family time count and try something as simple as going for a walk . It will pay off in more ways than one.

- *Take a family walk or visit a Morale, Welfare and Recreation fitness facility together.*
- *Hike in a national park, or search for family excursions through your local Information, Tickets and Travel.*
- *Walk around your installation and become familiar with it.*
- *Find other families to walk with, especially if you just moved to the area.*
- *Start a military family walking club that meets once a week for a nice, long stroll.*

Staying healthy together can strengthen your bodies and your family bonds. Read more to find out how getting fit as a family can help your communication and relationships. Swap out your daily screen time for an exercise session and get these benefits:

- *Open communication with your family: Talk while you walk, (or run, skate or hike) and it may be easier to have those tough conversations or just learn something new about each other.*
- *Better health: Teach good habits that will last a lifetime. Your kids will thank you for it later.*
- *Improved moods: Feel those endorphins as a family, and create happy memories that'll get you through the toughest times apart.*
- *Accountability: Working out as a family is much more motivating, and you'll be less likely to wind up on the couch if you plan group activities.*

Reach out to your Morale, Welfare and Recreation facility to find out more about local fitness options, or simply for great recommendations on where to take your next walk. Take the first step toward family bonding.

– Military One Source

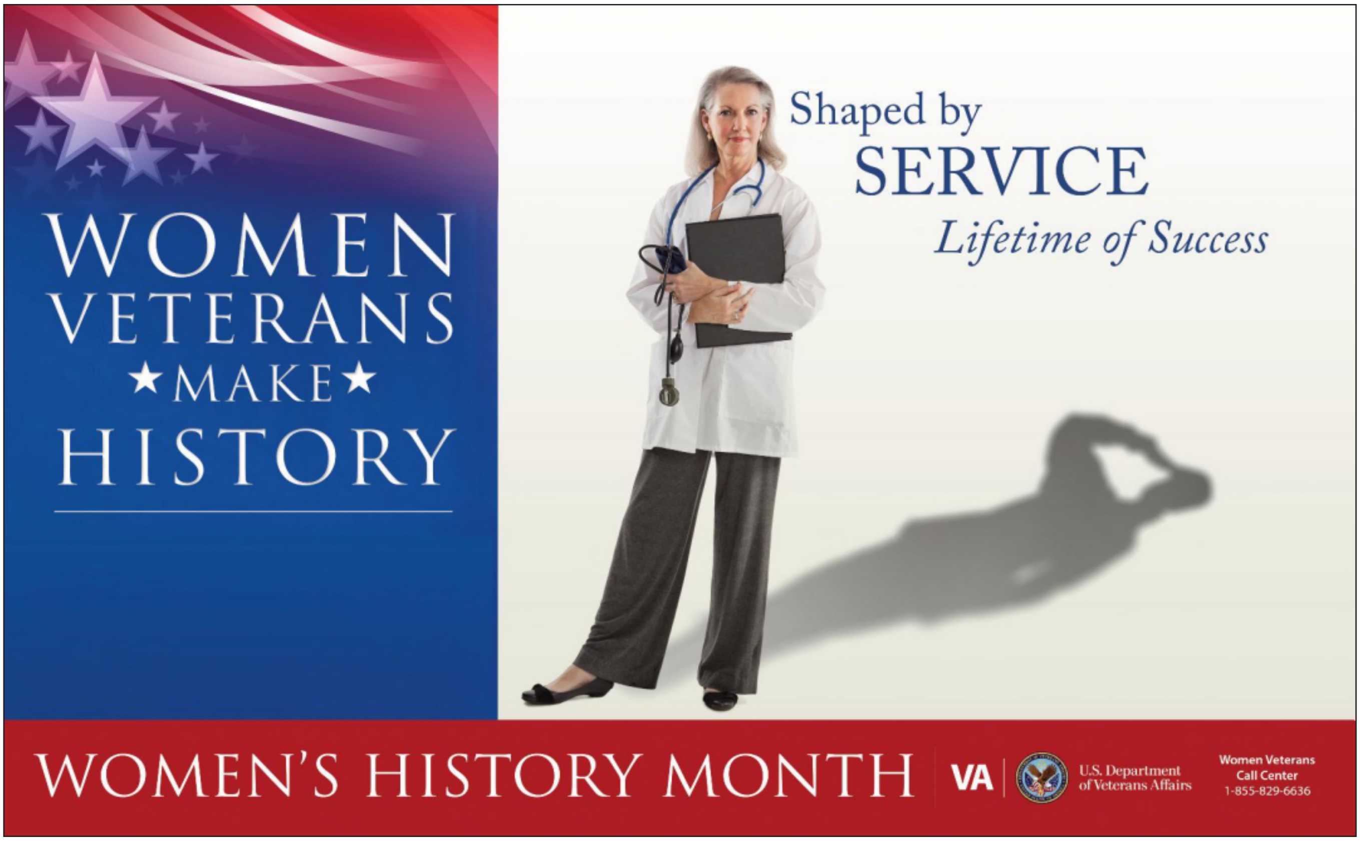

PHOTO COURTESY U.S. ARMY/DAVID VERGUN

Knowing What He'll Miss

The dream I had the other night was not for me. I think the dream was what I felt inside for Broden. He will miss it. He will miss the feeling of excitement of asking a girl to the dance and hearing her say yes.

I had a strange dream the other night. I walked into an empty locker room to change my clothes. I grew frustrated because I couldn't find anything that was mine. After being in the locker room for what seemed like eternity, I walked out to the gym only to realize that I had missed the event. Everyone was smiling, laughing and hugging each other in celebration after the event. The scary thing was that no one had noticed that I had missed it. I tried to analyze the dream because I felt so alone when I woke up and I had such a hollow feeling in my chest that I couldn't seem to get over. After thinking about it these past few weeks, maybe this dream has nothing to do with me. Maybe it has to do about how I feel about my son, Broden.

Last weekend, Mark and I decided to do what we always say we are going to do, but really never do. We cleaned out Broden's bedroom. We found things like parts of toys that we thought we would never see again, the other sock that is married to the one that was collecting dust in our basement on the washer. As I dug through his drawers, I found a pair of size 4 shorts. When I read the size out loud to Mark, we sat there in disbelief. Broden's birthday is in March. He'll be 12 years old. After saying his age out loud to each other again, we started to throw more things away. I kept thinking, "He's 12 years old. Why am I putting that shirt on him?" or "He's 12 years old, when was the last time he read that book?" When I called Broden back into his room after our overhaul, he ran in and jumped on the bed as he slowly scanned his room. He could tell things were different and based on his smile, I'd like to think that he wanted to tell us, "Thank you for doing this because I'm going to be 12 years old."

A few days after reorganizing his room, I took him to a doctor's appointment for a check-up. After the woman at the front office asked me his date of birth, she told me there were a few more surveys that needed to be filled out on his health. After opening them up, I approached the front desk and tried to convince her there must be a misunderstanding because Broden was given sex and drug surveys. She told me there was no mix up. Since Broden was going to be 12 years old, he needed to take the surveys. I continued to argue with her, "How can Broden take these surveys? He doesn't even know how to take a freakin' survey, much less answer questions about sex and drugs!?"

She would not budge and I was told to take the surveys for him. In the waiting room I went through each question as I rolled my eyes. I would ask Broden, “Have you had sex? If so, how often?” He would look at me with a blank stare. I was thinking to myself, “I don’t think he’s taking meth.”

> “I mourn for Broden knowing that he doesn’t even know what he will miss. Maybe that is his only saving grace and what I need to remind myself. ”

After filling out the surveys, kicking them back to the nurse and rolling my eyes like the smarty pants that I am, I was educated later that day on the reasons why they provide those surveys to typical 12 year olds. A friend of mine told me that there are many 12 year olds that would fill the two surveys out a lot differently than I did for Broden. She reminded me that kids are growing up way too fast and we need to be proactive and ask the right questions to create appropriate dialog.

I looked at Broden as he watched his Nemo video, and it hit me. Broden’s path and a typical child’s age path are growing farther and farther apart. It is no longer just focused on basic communication of his wants and needs. Typical kids are creating more complex relationships that are far beyond Broden’s capabilities and he most likely will never experience it.

Yesterday, I was driving my oldest son, Hayden, to school in the morning. It was the first day of school after the Valentines Day dance. He had asked a girl to the dance and she had said yes. I remember his face when he saw her for the first time at the dance as he gave her a flower. He was smitten. As we pulled around to the front door of the school that Monday morning, he anxiously opened the door and scanned his eyes around the front of the school. I knew who he was looking for that morning. He was looking for her.

The dream I had the other night was not for me. I think the dream was what I felt inside for Broden. He will miss it. He will miss the feeling of excitement of asking a girl to the dance and hearing her say yes. He’ll miss the feeling of his heart pounding the first time the girl he likes wants to hold his hand. I mourn for him knowing that he doesn’t even know what he will miss. Maybe that is his only saving grace and what I need to remind myself. He will know what he knows, but will never know what he is missing. •

PUZZLES & CAMO

Shelley Huhtanen is an Army wife with two children, one with autism, whose husband is currently stationed at Fort Benning, GA. She is an autism advocate and currently the parent liaison for the Academy for Exceptional Learners.

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