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# EXCEPTIONAL PARENT

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EXCEPTIONAL PARENT
MAGAZINE
DECEMBER 2021
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## ANXIETY & THE HOLIDAYS

FAMILY, COMMUNITY & THE HOLIDAYS:

## SPARKING HOLIDAY CHEER

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AMERICAN ACADEMY OF DEVELOPMENTAL MEDICINE & DENTISTRY
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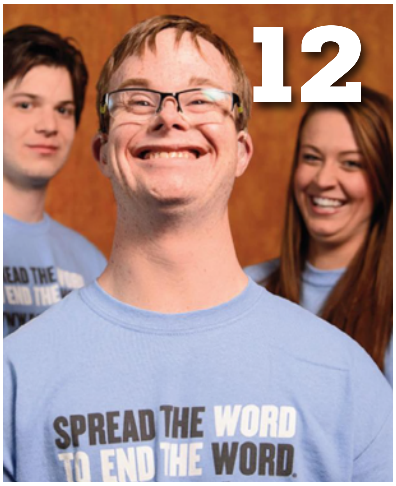

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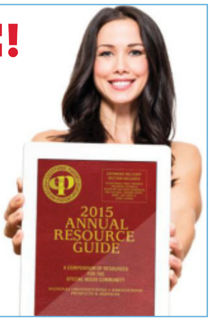

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**Note from the Editor-in-chief:** EP World, Inc. advocates for the dignity of all citizens with disabilities including the use of "people first language" where possible. We do not normally edit articles and submissions that do not reflect this language,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

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

# On the Joy Derived from Head Tilting

I was curious to learn more about what connects the head tilt to the human reaction of instantaneous enhanced attraction and how it might relate to intellect. So I enlisted my trusted inner circle of folks I spend my days with at the Orange Grove Center.

If truth be told, I was delighted to hear that my two-hour Zoom call was canceled at the last minute. So I fell into Plan B, which is implemented whenever I get more than 15 minutes of free time at work. I clean up stuff.

I have impressive looking piles of files, each begging for recognition as to their importance. On one counter we have,"REQUIRES REVIEW," which in right next to "REQUIRES REVIEW AND RESPONSE," which is next to "DO NOT LEAVE THE OFFICE UNTIL THIS IS REVIEWED," which of course is on top of "DO NOT LEAVE THE OFFICE UNTIL THIS IS REVIEWED AND RESPONDED TO".

Those piles are too toxic for me to deal with, especially the ones that are dated 2017; so I opt for going through some stacks with less intimidating labels. I finally find a pile that I can negotiate, it's a stack of old Norman Rockwell calendars where each month is accompanied by a painting by America's most loved artist. Of course, holding true to my ritual of looking at everything before I feel comfortable dumping them, I thumb through Rockwell's depiction of an America that is no longer recognizable.

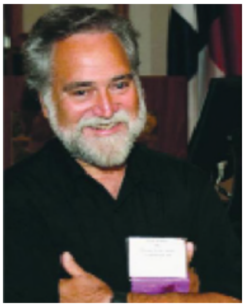
Illustrations of factory workers walking with lunch boxes, umpires officiating at Little League baseball games, school teachers running after students who left their scarves at their desks, and little boys staring at the framed diplomas while their family doctors warms his stethoscope with his hands.

While going through three of the calendars (before I can bring myself to tossing them) one thing resonates. Rockwell sure loved to paint dogs. Dogs of all ages, all breeds, all sizes and all energy levels seemed to find themselves in many of his renderings.

The dog theme was formally acknowledged when the Norman Rockwell Museum in Stockbridge, Mass. organized a special exhibit called "It's a Dog's Life: Norman Rockwell Paints Man's Best Friend."

According to Joyce Schiller, curator for the Rockwell Center, "Rockwell didn't say much about his habit of including dogs in his work publicly or in his correspondence," but he did include a little on the subject in an advanced illustration course written in the 1940s and included in *Rockwell on Rockwell: How I Make a Picture.*

"Animals are often the center of interest in story-telling pictures and at other times they can be included naturally in a picture. In such cases, they are very appealing and helpful." He goes on to qualify the suggestion by later adding, "I do not like to see an appealing animal put into a picture just to save the job." By this time I was becoming a Rockwell scholar and my deep research found his true sentiment in a quote, "If a picture wasn't going very well, I'd put a puppy in it."



Upon further review of his work, I came up with an additional perspective and imagined him sharing it with his closest confidants, "If putting in the puppy didn't work, I would simply tilt his head." That was a tactic that you could take to the bank. It appears that humans cannot resist a dog when they tilt their heads.

Dogs may have integrated this into their behavioral repertoire. Many dog owners may have been on the brink of scolding a puppy for not becoming housebroken faster when the puppy tilted their heads and noticed that the human cancelled the expected punishment. Saved by the tilt of a head.

It's also hard to predict how the "head tilt" may have been the deciding factor when visitors to dog shelters have picked one dog from the others.

**FULL TILT:** "There are several speculative reasons that account for the maneuver; by altering the position of the ears, it helps dogs better determine where a sound is coming from."

There are several speculative reasons that have accounted for the maneuver. According to Stephanie Gibeault of the American Kennel Club, "By altering the position of the ears, it helps dogs better determine where a sound is coming from. Despite being able to hear an incredible range of frequencies, dogs can't locate the source of a sound as well as humans can."

Considering the motion might be sensory-based, it has been hypothesized that vision is a possible cause of head tilts. Researcher Pam Hair reminds us that dogs rely heavily on body language and have an affinity for accurately "reading" human faces. "Their muzzle limits their field of vision. Make a fist and put your thumb against your nose and look out. This gives you some idea of what a dog sees. When he looks at you straight on, he can't see your mouth. But if he tilts his head a little, he can get a better view of your whole face and use that input, along with your tone and your words, to better understand what you're telling him."

One doesn't have to have a degree in canine cognition to appreciate how "cute" dogs (at any age) are when they tilt their heads. Dog owners react in identical ways when parents see their newborn babies smile (and tilt their heads). They "coo" at them, smile back at them, stroke them and reassure them that they are loved and adored (and can virtually get away with anything). Dogs are smart creatures and understand cause and effect. My money is on that this is a learned behavior and probably has its roots in survival tactics.

Perhaps canines learned it from observing humans. If you seek out a compassionate friend or loved one and share a problem you are having, here is what you can expect…"Their face softens, their mouth relaxes and they tilt their heads."

I was curious to learn more about what connects the head tilt to the human reaction of instantaneous enhanced attraction and how it might relate to intellect. So I enlisted my trusted inner circle of folks I spend my days with at the Orange Grove Center. They consented to getting together with me for some coffee, Moon Pies and their opinions. And while I tried to explain to them the standards of protecting volunteers in research according to the Nuremberg Trials, the Helsinki Accord and the Belmont Report, they all told me to stow it and hand out the Moon Pies.

> "My unscientific scientific study demonstrates that you don't have to have a three-digit IQ to understand, appreciate and embrace a tilted head."

My 10 volunteers all had a diagnosis of having an intellectual disability. I showed them 10 sets of photos of dogs, with each pair being depicted with a straight head shot and one of the same dog with a head tilt. They were each asked which one they liked better. It was unanimous; they all selected the photo of the dog tilting their head. Thus, my unscientific scientific study demonstrates that you don't have to have a three-digit IQ to understand, appreciate and embrace a tilted head.

We finished the research session with a group hug and with their determination to remember to tilt their heads when the opportunity arises.

They thought that the head tilt could be the new high-five and that they wanted to start the movement.

They asked why more people didn't tilt their heads if they knew it made people feel joyous, warm and happy. None of them thought the dogs would mind if we stole their secret.

As with most research studies conclude, "more research is needed in this area."•

**ANCORA IMPARO**

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

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

# WHAT'S HAPPENING

# BRAILLE INSTITUTE OF AMERICA'S UNIQUE HOLIDAY GIFT IDEAS

Braille Institute's HOLIDAY GIFT LIST includes descriptions of unique gift items for adults and children. Visit brailleinstitute.org.holiday-gift-list to see the full list of items.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① Large Print Keyboard is one of the most practical gifts anyone with visual impairments can receive and one they will likely use every day. The letters and characters on each key are enlarged and the keyboard is bright yellow for added contrast. Vistas Store Item #21712 - $36.95

② Talking clocks allow those who are blind and visually impaired to hear the time with the simple push of a button. A talking watch is also a great option for those who want to keep time on the go. Vistas Store Item #29907 - $14.95

③ Large Print or Braille Measuring Cups or Spoons allow a loved one to keep cooking in the kitchen. The large measurement print allows those with low vision to see the numbers. The braille cups and spoons allow them to feel the amounts. Vistas Store Item #26459 (cups) - $11.95, #26556 (spoons) - $8.95

④ Stay healthy and safe with a Talking Thermometer that lets those who are visually impaired take their own temperature and hear the results. Let's face it, taking one's temperature has become more common than it used to be. The thermometers are also available in Spanish. Vistas Store Item #21675 - $21.95

⑤ Large print playing cards enable those who are losing their vision to keep playing Bridge, Poker, and other card games they love with others. The holidays are all about bring people together and one of the best ways to do that is playing card games. Vistas Store Item # 24047 - $9.50

## FOR CHILDREN

⑥ Enjoy games such as Bingo, Scrabble and Uno in braille and low vision versions. Games are a great way for everyone in the family to get together and participate. Vistas Store Item #24016 (Scrabble) - $62.95, #24064 (Uno) - $15.95

⑦ Wikki Stix are a fun and constructive gift for younger children. The material is tactile which helps with sensory awareness. This is an easy way to bring educational and recreational to children who are blind or visually impaired. Vistas Store Item #30336 - $3.95

⑧ Beeping Foam Ball is an interactive way for young children to play and stay active. Soft foam balls make a beeping sound to help with tracking where the ball is. The foam material makes it safe to use indoors and outdoors. Available at **MaxiAIDS.com**

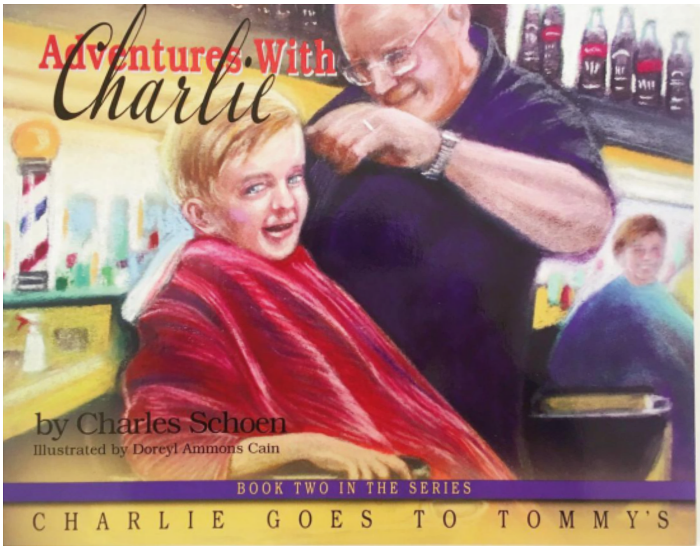
# WHAT'S HAPPENING

## NEW CHILDREN'S BOOK SERIES DELIVERS UPLIFTING MESSAGES OF INCLUSION

When his son Charlie was just three months old, author Charles Schoen threw away the "what to expect" books for new parents and focused on what his severely disabled child could do.

Charlie wasn't going to reach all the milestones that other children do, but Schoen was determined to help his son live a full, happy life.

Schoen's compelling new children's book series, Adventures with Charlie, was inspired by his real-life experiences raising a child with special needs. Written for preschoolers and early readers, *Adventures with Charlie* serves as both an inspiration to families confronting the challenges of physical and/or mental disabilities, while also introducing typical peers to children with differences.



**A CUT ABOVE:** Readers can learn from the ways in which Charlie interacts and makes friends in his community, growing through new experiences.

"Charlie is nonjudgmental. He doesn't see anybody with judgement like we do," Schoen said in a recent interview. "And so, he literally is an example of loving everyone just for being there – as opposed to who they are or what they do or what they look like."

Through *Adventures with Charlie,* parents and children can follow Charlie as he learns and grows through new experiences.

In the first book of the series, *Charlie Goes to School,* readers get to explore a day of school from Charlie's perspective, as he travels on the wind of his wheelchair, meets his friends, gathers knowledge and arrives back home flying through the air. In *Charlie Goes to Tommy's Barber Shop* and *Charlie Goes to Waffle House,* children can learn from the ways in which Charlie interacts and makes friends in his community. *Charlie Plays Baseball* shares the motivational story of a baseball league that caters to children with special needs and physical challenges. *And Charlie and the Half-Marathon* will have readers cheering as Charlie and his father team-up for this exciting new adventure.

"Children need to have stories that illustrate the idea that 'being different from typical peers' can have some special rewards," Schoen said.

The Adventures with Charlie series emphasizes what children CAN do in the face of physical or developmental challenges, and along the way, points out that when communities embrace and lift up all children, everyone wins.

Charles Schoen is the Executive Director of The Adaptive Learning Center, a preschool inclusion program in Atlanta, Georgia. He has three children. His oldest child, Charlie, is the inspiration for his books.

For more information, please visit **www.adventureswcharlie.com**

# WHAT'S HAPPENING

## 73-YEAR-OLD VIETNAM VET'S 'GIFT' TO SHOPPERS THIS HOLIDAY SEASON

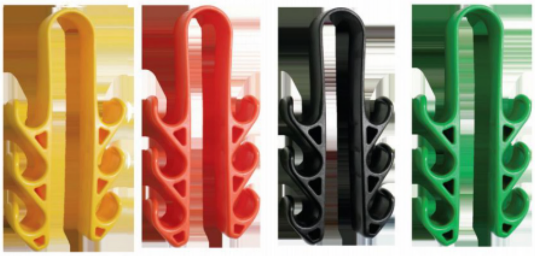
A former Marine and Vietnam Veteran from New York City, James MacDonald is no stranger to the concept of never giving up. But sometimes, even he's needed a little help on his daily walks, shopping trips, and travel excursions.

**TOTALLY USEFUL:** Designed to carry bags front to back, Tote-It does not block the sidewalk and allows others to pass by easily. Tote-It allows you to use your body strength rather than just your arm strength to carry bundles totaling up to 50 pounds. Rather than awkwardly struggling with multiple bags, simply load them on this bag-carrying device.

“As a New Yorker, and one that walks daily for long distances, I can say that I invented the Tote-It for myself, my family, and friends,” said Inventor James MacDonald. “But it took off with people asking about it, and we're helping to alleviate a lot of physical pain out on the streets.”

Tis' the season to be merry and it's certainly the season for shopping. Lots of shopping. And that means plenty of bags to carry. For many with disabilities, along with older folks, this part of the holiday experience can cause severe physical pain and stress. Some individuals' shopping experience is more than just pain, such as muscle loss, and weakness, to name a few. MacDonald, founder of Tote-It (https://tote-it.net) wants to help.

This product was created to allow you to have hands free or otherwise available to answer your phone, grab something off the rack, pull out your wallet, take out your keys, carry an umbrella, hold a child or friends hand, wave to someone, and generally make life easier for you while you carry two or more bags or other items.



Tote-It, a sturdy carrier, opens into a 15 inch long carrying device with notches at each end that hangs tightly onto bag handles. The shoulder rest area fits comfortably onto any shoulder. Friction holds it in place. Designed to carry bags front to back, it does not block the sidewalk and allows others to pass by easily. Tote-It will enable you to use your body strength rather than just your arm strength to carry bundles totaling up to 50 pounds. Most twice-weekly shopping trips weigh in at a great deal less.

For thousands of years, people have been using a stick to help carry bundles. As a result, the classic image of a peasant carrying agricultural products or a milkmaid carrying buckets on either end of a yoke has become ingrained into the universal psyche. It's perfect for a walk home from the grocery store in any urban environment or anywhere you have to carry bags or other items. In addition, new mothers and fathers can use Tote-It to help carry all the diapers and other accouterments necessary for even a short trip outside.

Find more information or order a Tote-It in one of four vibrant colors at https://tote-it.net

# Help Is Here

## Monthly payments for families with kids

Raising kids can be expensive, and the Child Tax Credit is here to help. President Biden's American Rescue Plan increased the amount of the 2021 Child Tax Credit to support families with children.

The full benefit of the Child Tax Credit is now $300 per month per child under age 6 and $250 for each child age 6 to 17.

**Did you file taxes in the last 2 years? Then you don't have to do anything to get the money you're already owed!**

If you filed your 2020 taxes this year or filed your 2019 taxes last year, or used the IRS "Non-Filer Portal" to get a stimulus check last year, you don't need to do anything. The IRS will automatically send you a monthly payment by direct deposit or check starting on July 15, 2021.

**The Child Tax Credit is $3,000 to $3,600 per child with advanced monthly payments.**

In order to get money to families quickly, the IRS will pay half of the credit as monthly payments now and the other half when you file your taxes next year. In total, you'll receive a total of $3,600 for each child under 6 and $3,000 for each child between 6 and 17.

**Didn't file taxes in the last 2 years? There's 1 easy step to start getting your Child Tax Credit payments.**

Just fill out a simple form to begin receiving your monthly Child Tax Credit payments. You can access it by going to childtaxcredit.gov

**All you'll need to apply are:**

- A reliable mailing address
- E-mail address
- Your children's Social Security Numbers
- Your Social Security Number (or ITIN)
- Your bank account information (if you want to receive your payment by direct deposit)

**Eligibility:** Most families, even those with little to no income, can receive the full amount. If you are a single parent making less than $112,500 or a married couple making less than $150,000—and have children under age 18 who will live with you for more than half of 2021—you are likely eligible for the full benefit. These benefits do not affect your eligibility for other federal benefits like SNAP.

Learn more and check out resources to help you fill out your form at **ChildTaxCredit.gov**

# WHAT'S HAPPENING

## AAPD STATEMENT ON THE PASSING OF SENATOR BOB DOLE

The American Association of People with Disabilities (AAPD) mourns the loss of great public servant and disability rights champion Senator Bob Dole. Senator Dole was instrumental not only in establishing the legislative foundation of the modern disability rights movement, but also in launching our organization.

“The world as we know it today is more accessible and inclusive for people with disabilities because of Senator Bob Dole. Senator Dole worked to elevate the voices and perspectives of people with disabilities, encouraging greater leadership opportunities for disabled people, and sharing his experience of disability with his colleagues to build bipartisan consensus for disability policy issues,” said Maria Town, President and CEO of AAPD. “His passing represents an enormous loss for AAPD, the disability community at-large, and the nation.”

**A PASSION FOR ADVOCACY:** Senator Dole was instrumental in the passage of the ADA in 1990. As a World War II service-disabled veteran, his leadership is one of the primary reasons the transformational bill garnered such significant bipartisan support.

From his first speech as a Senator in 1969 to his presence on the Senate floor in 2012, Senator Dole was a steadfast advocate for people with disabilities throughout his decades-long career in public service.

Senator Dole’s passion for disability rights came as a result of his personal experiences with disability – first becoming a service-disabled veteran during World War II, and then developing further disabilities as he aged. Senator Dole was instrumental in the passage of the Americans with Disabilities Act (ADA) in 1990, and his leadership is one of the primary reasons the transformational bill garnered such significant bipartisan support.

While Senator Dole regarded the passage of the ADA as one of the proudest moments of his career, he was keenly aware that the ADA was only one of the tools necessary to foster greater independence and dignity for people with disabilities in the United States and worldwide. In 1994, Senator Dole wrote to the Secretary of State to ask that the United States include the status of people with disabilities in its annual report on human rights. This became the launching point for Dole’s advocacy for what would become the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD).

From Senator Dole’s perspective, the United States led globally in its development of disability public policy, and it was his vision that the U.S. would continue to advance equality, justice, and dignity for people with disabilities. Although the Senate voted not to ratify the treaty, during the later years of his life, Senator Dole was stalwart in his commitment to getting the UNCRPD ratified, not only for the benefit of people with disabilities in other nations but also for the benefit of disabled Americans who traveled abroad, particularly disabled veterans.

In addition to his work on disability policy, Senator Dole was also deeply engaged in the further development of the disability community itself. In 1984, he created the Dole Foundation for the employment of people with disabilities, which provided grants to organizations to provide job placements, training, and other employment support. In recognition of the need to build the collective power of the disability community, Senator Dole was among those who founded AAPD in 1995. Our first offices were located in the Dole Foundation’s building, and his support was instrumental in helping our organization generate the support we needed to get our initial programming up and running. Senator Dole’s service to AAPD continues to inform our work to this day. In 2020, AAPD bestowed Senator Dole with our Lifetime Achievement Award at our annual Leadership Awards Gala.

AAPD sends the family and loved ones of Senator Bob Dole peace and comfort during this difficult time. His legacy will forever live on through the disability rights movement, as we build upon his hard-won progress. •

### ABOUT THE AAPD

AAPD

The American Association of People with Disabilities (AAPD) is a convener, connector, and catalyst for change, increasing the political and economic power of people with disabilities. As a national cross-disability rights organization, AAPD advocates for full civil rights for the over 61 million Americans with disabilities by promoting equal opportunity, economic power, independent living, and political participation. To learn more, visit the AAPD website: www.aapd.com.

# LJS Fac/X

## WE CAN HANDLE YOUR PROJECT


## HOME ELEVATORS • STAIR ELEVATORS • AUTOMATED SYSTEMS

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

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

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

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**AMERICAN ACADEMY OF DEVELOPMENTAL MEDICINE & DENTISTRY**

# Disability vs. Handicapped and Other Terms

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

*Since 1964, two of the authors (HBW & SPP) of this presentation have written more than 400 articles and book chapters for local, national and international publications regarding the special circumstances and needs of children and adults with disabilities. We used the word "disability" or "disabilities" 30 times in the titles of our writings and untold numbers of times in the body of the material.*

The reality, however, is that we never bothered to describe the differences with such words as "disability," "handicapped," "special needs." "disabled person," "people with determination" and any number of governmental agency legal definitions. We just thought that almost everyone understood the interchangeability of these terms.

We found out that we were wrong. It all began with the effort to eliminate the negativity associated with use of the **"R" word,** i.e. "retarded," in the vernacular of the general population in such phrases as **"that's a retarded idea,"** or **"you're a retard."** The wording **"a person with an intellectual disability"** would be much more appropriate and descriptive.

Next came the effort to introduce the **"people first"** identification of **people with a disability,** rather than the past wording approach of **"a disabled person."** This traditional wording presents an individual as though all that mattered about the person was his/her disability. It is like referring to someone as a **broken arm person** rather than a **person with a broken arm.**

## MORE EXAMPLES

***Difference between disability & handicap:*** These terms often are used interchangeably; however, they have distinctly different meanings. Disability describes the mental or physical limitation that a person has. Handicap refers to the disadvantage he/she experiences because of it.[1]

***Americans With Disabilities Act of 1990 (ADA):*** One of the most comprehensive laws addressing disabilities is the ADA. According to this legislation, a person with a disability is so defined if he/she:

- *Has either a physical or mental impairment that substantially limits one or more of his major life activities, such as walking, hearing or seeing,*
- *Has a record of such impairment or has been discriminated against because others perceived him as having a mental or physical impairment, regardless of whether the impairment actually exists or limits a major life activity.*
- *The ADA protects people with mental and physical disabilities from discrimination in various aspects of everyday life, includ-*

**AMERICAN ACADEMY OF DEVELOPMENTAL MEDICINE AND DENTISTRY**

AADMD

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

**HAPPY ENDING:** The Spread the Word to End the Word campaign was founded in 2009 and has collected millions of digital and physical pledges to end a particularly powerful form of exclusion: the word 'retard(ed)'.

> *ing employment, education, public accommodations and transportation. The ADA does not use the term handicap.* [1]

**It is important to remember that in the context of the ADA, disability is a legal term rather than a medical one.** [2,3]

***Children with special needs:*** Special needs are commonly defined by what a child ***can't* do** – milestones unmet, foods banned, activities avoided, or experiences denied. These hindrances can be devastating to families and may make special needs seem like a tragic designation. Other families may find that their child's challenges make milestones sweeter and that weaknesses are often accompanied by amazing strengths. [4]

> "Traditional wording is like referring to someone as a broken arm person rather than a person with a broken arm."

***Social Security and Disability:*** When it comes to being eligible for Social Security benefits as a result of a disability, the definition of disability changes again. The definition of disability under Social Security is different than other definitions because it determines who qualifies for Social Security Disability benefits.

> "Social Security is 85 years old. Receiving these benefits is often the difference between extreme poverty and low-income living. Yet **eligibility hinges on an arcane definition of disability** (sic) that equates disability with an inability to work. Eligibility also requires people have extremely limited assets. We discourage people with disabilities from saving for emergencies, never mind a brighter future. It's easy to see why many refer to Social Security as a poverty trap." [5]

To meet the definition of disability, you must not be able to engage in any substantial gainful activity because of a medically-determinable physical or mental impairment(s):

- *That is expected to result in death, or*
- *That has lasted or is expected to last for a continuous period of at least 12 months.*

The Social Security Administration uses the term "substantial gainful activity" to describe a level of work activity and earnings. Work is "substantial" if it involves doing significant physical or mental activities or a combination of both. For work activity to be substantial, it does not need to be performed on a full-time basis. Work activity performed on a part-time basis may also be substantial gainful activity.

Gainful work activity is:

- *Work performed for pay or profit; or*
- *Work of a nature generally performed for pay or profit; or*
- *Work intended for profit, whether or not a profit is realized.* [1,2]

## WHY IS A UNIFORM DEFINITION OF DISABILITY SO IMPORTANT?

The need for the recognition of **the totality** of the difficulties is critical.

- *Enormity of the increasing numbers (both the young and not so young) of individuals with disabilities.*
- *Seemingly infinite need for healthcare, education, social services and employment.*
- *Educational opportunities.*
- *Living arrangement facilities.*
- *Endless array of needed supported services for the increasing life spans of this population, has (and will continue to have) a profound impact on legislative support.*

Dividing the number of individuals with disabilities into a patchwork of defining categories only diminishes an appreciation and adds confusion to the total extent of the problems.

The reality of the increasing problems is worldwide. The World Health Organization (WHO) recently reported that:

- *Over a billion people, or about 15% of the world's population, have some form of disability.*
- *Between 110 million and 190 million adults have significant difficulties in carrying out necessary functioning.*
- *Rates of disability are increasing due to population ageing and increases in chronic health conditions, among other causes.*
- *People with a disability have less access to healthcare services and therefore experience more unmet healthcare needs.*
- *People with a disability continue to encounter a range of barriers when they attempt to access health care.* [6]

## POST SCRIPT

***Actual phone conversation with Social Security Administration:***

*"Hello, I'm calling to request proof of disability that I filed when I was on Social Security."*

*"What do you mean when you WERE on Social Security?"*

*"I'm no longer receiving benefits because I'm working full time."*

*"Then why do you need proof of disability? If you're working, you are no longer disabled."* [2]

***Definition of disability by people with disabilities:*** "I am vocal about having a disability because I don't want other people defining what having a disability means for me. Whether you're active most days, or spend most of your time in bed, you have the right to define that for yourself." [2]

*"Disability is articulated as a struggle, an unnecessary burden that one must overcome to the soundtrack of a string crescendo. But disabled lives are multi-faceted—brimming with personality, pride, ambition, love, empathy, and wit."* [7]

– Sinead Burke •

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Steven P. Perlman, DDS, MScD, DHL (Hon) is the Global Clinical Director and founder, Special Olympics, Special Smiles; and Clinical Professor of Pediatric Dentistry, The Boston University Goldman School of Dental Medicine.

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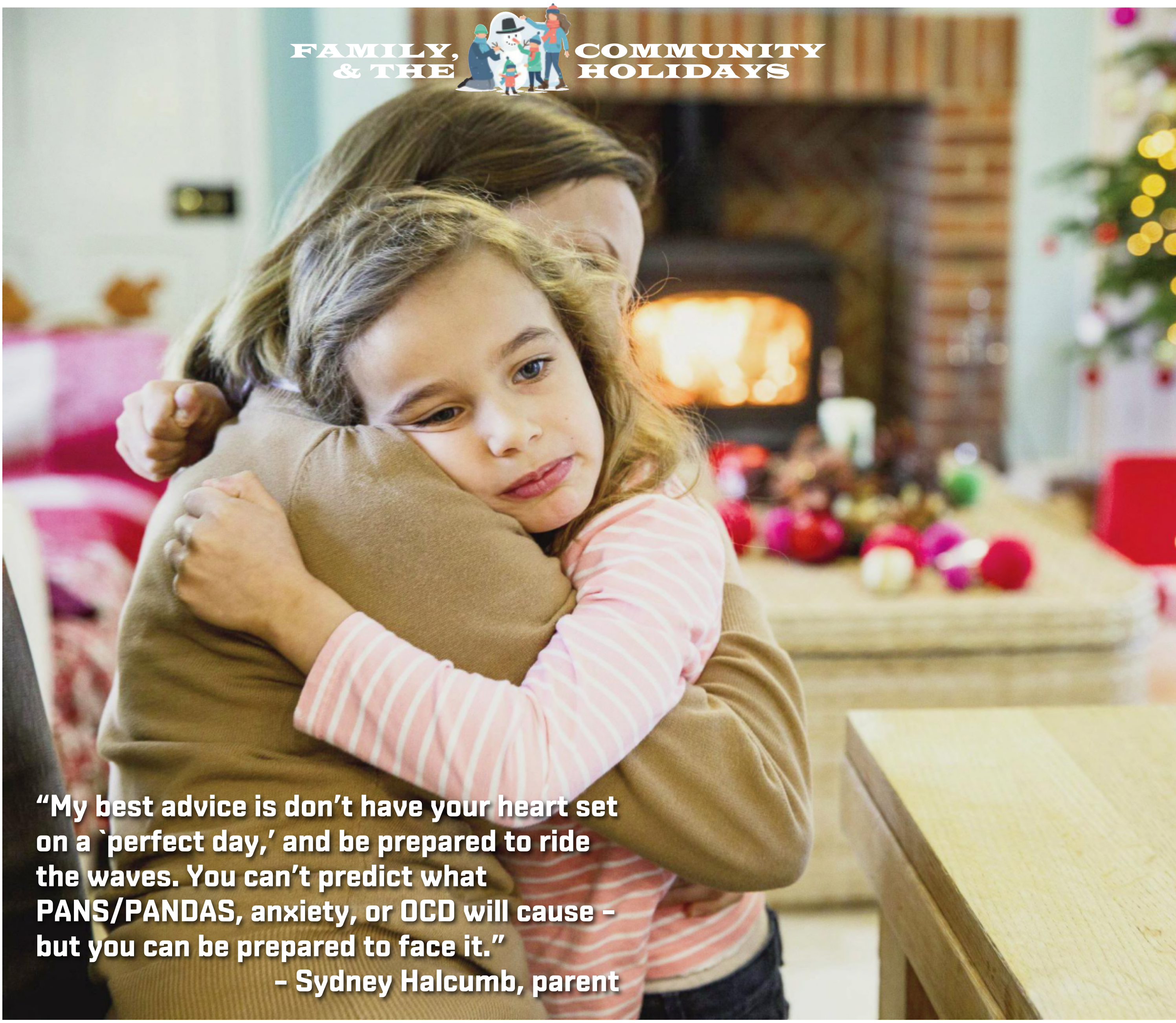

"My best advice is don't have your heart set on a `perfect day,' and be prepared to ride the waves. You can't predict what PANS/PANDAS, anxiety, or OCD will cause – but you can be prepared to face it."
– Sydney Halcumb, parent

# ANXIETY AND THE HOLIDAYS: HOW TO HELP KIDS COPE

BY KARA JOLLIFF GOULD, PH.D.

*The holiday season is here, along with the colorful decorations, gifts, foods, and activities that most kids find exciting. However, children with anxiety, OCD, PANS/PANDAS or sensory processing issues may find the holidays challenging. They may look forward to the season, only to be disappointed when they find themselves overwhelmed with the rush of the holidays. How can parents help children cope, so that everyone in the family can enjoy the celebration?*

**MAKING SPIRITS BRIGHT:** Parents of kids with anxiety need to carefully manage holiday activities and gatherings. Holidays this year have the potential to be even more stressful than in previous years, since some children may be less accustomed to social interactions due to the COVID-19 pandemic.

First, it is helpful to remember that many children need a daily routine to feel safe and secure. Holiday activities can disrupt the daily routine and can evoke feelings of anxiety and lack of control. Letting kids know what to expect in advance can help. Parent Marcy Stoner Nelson suggests keeping the child’s regular bedtime consistent whenever possible.

Next, to cope with potential sensory overload during holiday gatherings, Nelson also suggests preparing an “escape route” for your child, such as headphones and a table in a quiet room, to provide the option to take a break from noisy gatherings. After a few minutes, the child may feel ready to join the group again. Even if that’s not the case, such a retreat can prevent the “meltdowns” that sensory overload can cause.

For parent Ashley Collins, the biggest challenge as a parent of an anxious child during the holidays is the food. “We always bring what we know she will eat, and her go-to snacks. She often feels pressured to try something her relatives make, which causes her more stress, so we offer her reassurance by letting her know it’s okay if she doesn’t eat what is offered.”

Collins also has a tip for maximizing fun when taking a child to visit relatives and interact with cousins: careful planning. “Having games she can play successfully with very little to no help from my husband and [me], or her brother, allows her to interact with her cousins without feeling babied. It truly boils down to planning and prepping. We can’t foresee every issue, but we plan ahead. We prep her before we leave, while en route, when we get there, and check on her throughout the visit.”

Telling relatives and friends in advance about your child’s anxieties surrounding new foods, noisy gatherings and/or new situations is important to Sydney Halcumb: “I suggest making sure your relatives are aware of triggers and behaviors that could occur. You don’t want someone getting onto your child for something they can’t help! My daughter always finds that very embarrassing and stressful.”

Parents of children who don’t have sensory issues or anxiety may need an explanation as to why pressuring your child to eat certain things or play certain games will not help. Friends and relatives need to be prepared not to be offended if your child isn’t able to try every food offered, for example, or participate in every activity.

Halcumb agrees that “a private places to regulate and decompress” is helpful. “My daughter also likes to pack an ‘emergency bag’ with coping tools, such as fidget toys, essential oils, etc.,” she explained.

Most important, be flexible, and manage your own expectations for the holiday. With family support, ample preparation, and options for taking breaks, children with anxiety can enjoy holiday festivities more. As Halcumb recalled her family’s recent Thanksgiving experience with her daughter, she noted, “My best advice is don’t have your heart set on a `perfect day,’ and be prepared to ride the waves. You can’t predict what PANS/PANDAS, anxiety, or OCD will cause – but you can be prepared to face it. For us, that looked like being prepared to stay home if we needed to, being prepared to leave early if the crowd got overwhelming. Her mental stability comes before the holiday festivities.” •

### ABOUT THE AUTHOR:

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## GOOD CHEER : WAYS TO HELP ANXIOUS CHILDREN ENJOY THE HOLIDAYS

1. Let kids know in advance what will be happening and explain ways they can opt out or take a break if necessary.
2. Listen to kids’ concerns in advance and offer choices when possible.
3. Provide familiar foods, even when traveling or visiting others for dinner or treats.
4. Make friends and family aware of possible triggers and reactions that could occur. Other adults may try to treat triggered behaviors as discipline problems if they are unaware of the child’s anxiety.
5. Maintain routines as consistently as possible, especially at bedtime. Be prepared to leave gatherings early when needed.

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- 2 each spray bottles triggers
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- 1 pack of 12 machine washable microfiber cloths
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# HOW PEOPLE WITH DISABILITIES CAN STAY SAFER FROM COVID-19 DURING THE HOLIDAYS

BY MARIA DOCHERTY AND LAUREN AGORATUS, M.A.

*People who are immunocompromised and individuals with disabilities, particularly those with intellectual/developmental disabilities, are more at risk for complications of COVID-19.*

Research shows that people with I/DD (intellectual/developmental disabilities) have had worse outcomes during the pandemic.[1] The latest data shows that those with compromised immune systems are equally at risk and some don't develop antibodies after vaccination.[2] There are steps that vulnerable individuals and their families can take to reduce the risk, especially during holiday season.

## MASKING/SOCIAL DISTANCING SUPPORTS

Even after vaccination, the Centers for Disease Control and Prevention (CDC) suggests continued masking and physical distancing. Getting individuals with I/DD to wear a mask can be challenging. Some ways to address this are:

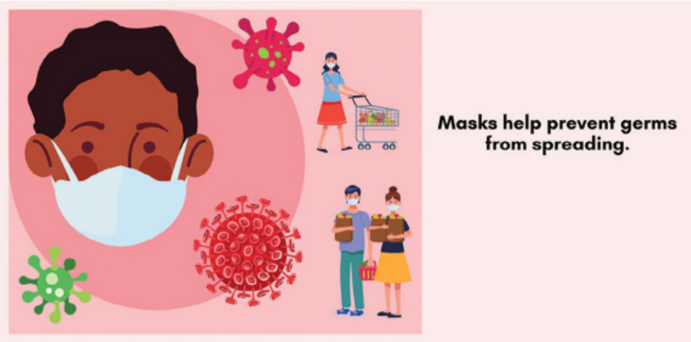
- *Addressing sensory issues such as mask material*
- *Having school specialists work with children on mask wearing*
- *Using plain language materials*
- *Social stories/videos on wearing a mask, handwashing, and physical distancing*

There is also information available on getting the vaccine, getting tested, and information for caregivers and families. Resources are available in English/Spanish and American Sign Language (ASL).

Those with weakened immune systems may need to get an "extra dose" vaccine which is different from a booster. It just gets their antibodies to the same level as everyone else. After that they may also need a booster. Immunocompromised individuals should discuss their options with their medical team. The CDC has information on how immune suppressed people can stay safer as well as important information on vaccines.

Here are some examples *(see Resources for links)*.

**Wearing a Mask:** Here is a page from a social story to help people with disabilities wear a mask.



Masks help prevent germs from spreading.

**Physical Distancing:** An example poster from the CDC about staying 6 feet apart:

Poster

Stay safe from COVID-19

Keep a safe distance until a few weeks after your last COVID-19 shot

CDC

This poster reminds people to social distance and stay safe from COVID-19.

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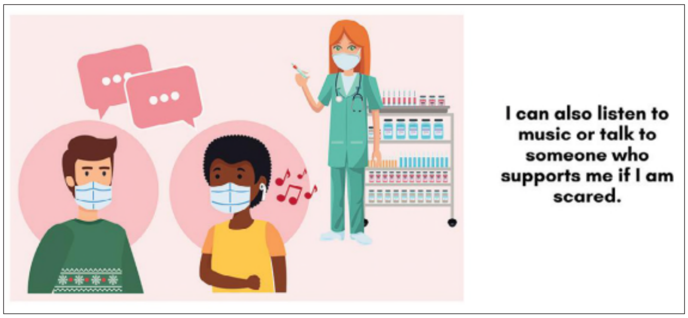
[1] https://catalyst.nejm.org/doi/full/10.1056/CAT.21.0051

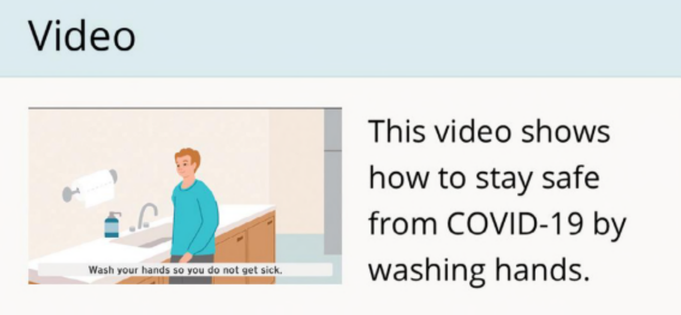
[2] https://www.cdc.gov/coronavirus/2019-ncov/vaccines/recommendations/immuno.html

**Getting a Shot:** This social story for people with disabilities walks through all the stages of getting a shot, including rolling up a sleeve, wiping with alcohol, and how to cope with anxiety.



I can also listen to music or talk to someone who supports me if I am scared.

**Handwashing:** This step-by-step video for people with disabilities shows safe handwashing techniques

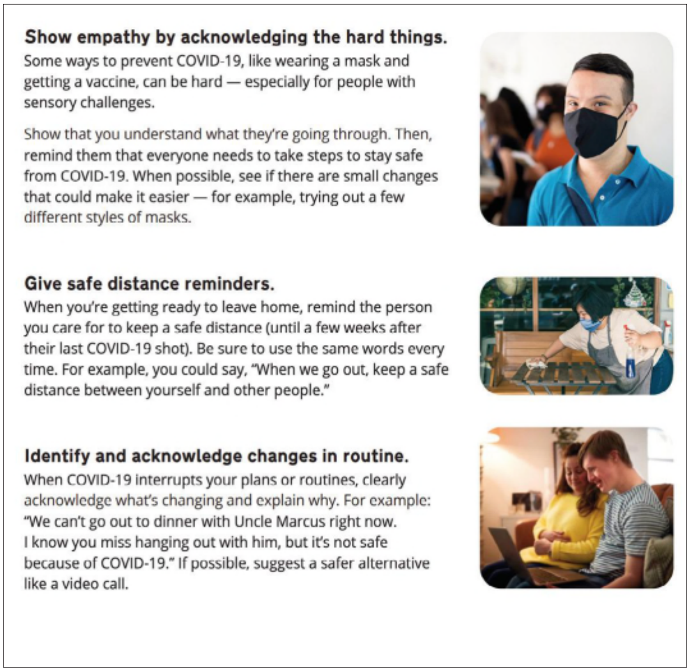


Video

Wash your hands so you do not get sick.

This video shows how to stay safe from COVID-19 by washing hands.

Here is part of a family/caregiver factsheet on assisting people with disabilities to deal with the difficulties associated with the pandemic, safety reminders, and changes in routine like virtual learning.



**Show empathy by acknowledging the hard things.**

Some ways to prevent COVID-19, like wearing a mask and getting a vaccine, can be hard — especially for people with sensory challenges.

Show that you understand what they're going through. Then, remind them that everyone needs to take steps to stay safe from COVID-19. When possible, see if there are small changes that could make it easier — for example, trying out a few different styles of masks.

**Give safe distance reminders.**

When you're getting ready to leave home, remind the person you care for to keep a safe distance (until a few weeks after their last COVID-19 shot). Be sure to use the same words every time. For example, you could say, "When we go out, keep a safe distance between yourself and other people."

**Identify and acknowledge changes in routine.**

When COVID-19 interrupts your plans or routines, clearly acknowledge what's changing and explain why. For example: "We can't go out to dinner with Uncle Marcus right now. I know you miss hanging out with him, but it's not safe because of COVID-19." If possible, suggest a safer alternative like a video call.

## PLAYING IT SAFE : STAYING HEALTHY DURING THE HOLIDAYS

**PARENT CENTER**

Information on COVID-19 Resources for Families of Children and Youth with Disabilities, (including resources to stay safe)

www.parentcenterhub.org/coronavirus-resources

**FAMILY VOICES' VACCINE OUTREACH PROJECT**

Information on COVID-19 Vaccines

https://familyvoices.org/vaccineoutreachproject

NFFCMH

*National Federation of Families for Children's Mental Health*

**NATIONAL FEDERATION OF FAMILIES**

Information on Vaccines:

COVID resources

www.ffcmh.org/covid-19-resources-for-parents

COVID vaccine resources

www.ffcmh.org/time-to-return

**CDC**

COVID-19 Materials for People with Intellectual and Developmental Disabilities and Care Providers

www.cdc.gov/ncbddd/humandevelopment/COVID-19-Materials-for-People-with-IDD.html

Easy-to-Read COVID-19 Materials

www.cdc.gov/coronavirus/2019-ncov/easy-to-read/index.html

Stay Safer While You Wait for COVID-19 Vaccines

www.cdc.gov/coronavirus/2019-ncov/easy-to-read/fully-vaccinated.html

COVID-19 Vaccines for Moderately to Severely Immunocompromised People

www.cdc.gov/coronavirus/2019-ncov/vaccines/recommendations/immuno.html

The Boggs Center on Developmental Disabilities

**THE BOGGS CENTER LIST OF COMPILED RESOURCES FROM MULTIPLE SOURCES**

COVID-19 Information By and For People with Disabilities

https://selfadvocacyinfo.org/wp-content/uploads/2020/03/Plain-Language-Information-on-Coronavirus.pdf

**Deaf and Hard of Hearing/American Sign Language (ASL):** Below are examples of ASL communication cards in English and Spanish and COVID information in ASL.

NJ HUMAN SERVICES CORONAVIRUS INFORMATION

**I AM DEAF OR HARD OF HEARING**

I am using this card to communicate. I may need a certified sign language interpreter or captioning to communicate.

**Symptoms:**

FEVER
COUGHING
SHORTNESS OF BREATH
CHILLS/REPEATED SHAKING WITH CHILLS
MUSCLE PAIN
HEADACHE
SORE THROAT
NEW LOSS OF TASTE OR SMELL

**Was near a person who has COVID-19?**

**How long sick?**
(number of days)

1 2 3 4 5 6 7 8 9 10+

INFORMACIÓN SOBRE EL CORONAVIRUS DE LOS SERVICIOS HUMANOS DE NJ

**SOY SORDO O CON DIFICULTADES DE AUDICIÓN**

Estoy usando esta tarjeta para comunicarme. Voy a necesitar un intérprete certificado de lenguaje de señas o subtitulados para comunicarme.

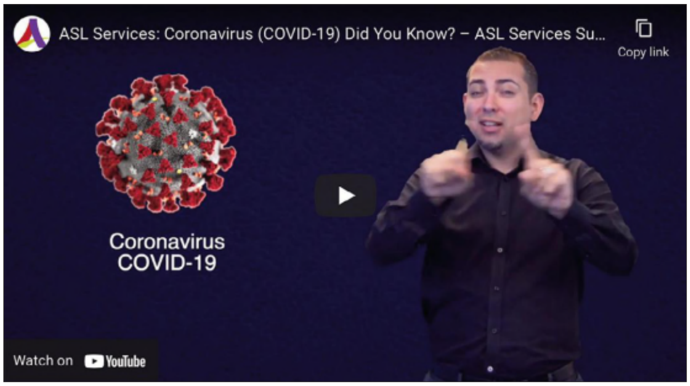
**Síntomas:**

FIEBRE
TOS
DIFICULTAD PARA RESPIRAR
ESCALOFRÍO/TEMBLAR REPETIDAMENTE CON ESCALOFRÍOS
DOLOR MUSCULAR
DOLOR DE CABEZA
DOLOR DE GARGANTA
NUEVA PÉRDIDA DE SABOR U OLOR

**¿Ha estado cerca de una persona que tenga COVID-19?**

**¿Cuánto tiempo enfermo?**
(número de días enfermo)

1 2 3 4 5 6 7 8 9 10+



There are many ways that individuals with disabilities and people with suppressed immune systems can stay safer during the upcoming holidays. These social stories, videos, and ASL/Spanish interpretation and translation materials make it easier for people with special needs to protect themselves and address the life changes brought on by the pandemic.•

## ABOUT THE AUTHORS:

Maria Docherty is the PTI (Parent Training and Information Center Director) of SPAN Parent Advocacy Network.
Lauren Agoratus, M.A. is a parent of a medically-complex young adult and serves as the Coordinator for Family Voices-NJ and as the regional coordinator in her state's Family-to-Family Health Information Center, both housed at the SPAN Parent Advocacy Network at www.spanadvocacy.org.

COVID-19 Explanation: Plain Language Video
**www.youtube.com/embed/MJ8eeC-tVD4?rel=0**

Getting a COVID-19 Vaccine: A Social Story for People with Intellectual and Developmental Disabilities
**https://rwjms.rutgers.edu/boggscenter/publications/documents/GettingACOVID19VaccineSocialStoryIDD-F.pdf**
In Spanish
**https://rwjms.rutgers.edu/boggscenter/publications/documents/GettingACOVID19VaccineSocialStoryIDD-SP-F.pdf**

Considerations for People with Disabilities at COVID-19 Vaccination Sites
**www.youtube.com/watch?v=9sd6QRzTV1g**

Resources for the Deaf and Hard-of-hearing Community
**https://publichealthinsider.com/2020/03/21/resources-for-the-deaf-and-hard-of-hearing-community**

Wearing a Face Mask:
A COVID-19 Social Story for Adults with Intellectual and Developmental Disabilities
**https://rwjms.rutgers.edu/boggscenter/links/documents/FaceMaskSocialStoryAdultswIDD-F.pdf**
In Spanish
**https://rwjms.rutgers.edu/boggscenter/links/documents/FaceMaskSocialStoryAdultswIDD-SP-F.pdf**

A Parent's Guide:
Helping Your Child Wear a Face Mask
**https://rwjms.rutgers.edu/boggscenter/Links/documents/ParentGuide-HelpingYourChildWearaFaceMask-F.pdf**
In Spanish
**https://rwjms.rutgers.edu/boggscenter/links/documents/ParentGuide-HelpingYourChildWearaFaceMask-SPA-F.pdf**

I Can Stay Healthy by Wearing a Face Mask
**https://rwjms.rutgers.edu/boggscenter/Links/documents/ICanStayHealthybyWearingaFaceMask-F.PDF**
In Spanish
**https://rwjms.rutgers.edu/boggscenter/links/documents/ICanStayHealthybyWearingaFaceMask-SPA-F.PDF**

Autism™ NEW JERSEY

**AUTISM NEW JERSEY**
Helping Individuals with Autism Wear Face Masks
(Visual Supports/Chaining)
**www.autismnj.org/article/helping-individuals-with-autism-wear-face-masks**

# PLANNING A SENSORY-FRIENDLY AND NEURODIVERSITY-HONORING HOLIDAY CELEBRATION

BY JANICE RYAN, OTR/L, HSDP

*Patterns were a key factor in the Christian Nativity Story and remain an important contributor to everyone's learning. When the Wisemen noticed there was a different star in the sky and discovered that it led them to Bethlehem, they were using a learning process that is now called pattern logic. We all see and understand patterns through comparison and contrast, and this process can tell us a lot about our own and our children's sensory preferences.*

Pattern logic can also tell us, how to support our children as we build trust, and they avoid developing the emotional challenges that commonly plague adults who grew up with sensory processing differences. Winnie Dunn has developed several versions of a strengths-based approach to assessing and planning healthier life experiences for people with sensory processing differences. She is an occupational therapy pioneer in promoting neurodiversity.

As Jenara Nerenberg, the founder of The Neurodiversity Project says, "we are all different flavors of human." Research has shown over and over that trust builds the feeling of "psychological safety." The feeling of psychological safety gives us the freedom to show the world our true self rather than putting a mask over our differences.

**RECOGNIZING PATTERNS:** Whatever your collective family Sensory Profile, broadening the neurodiversity conversation will spread the word that we are all just different flavors of human.

First, we will look at the four Sensory Profiles you might spot during your holiday celebration. Then, we will look at some of the behavior patterns that each of those Sensory Profiles can cause. We will end with some take-aways that you can use to create a sensory-friendly and neurodiversity-honoring celebration this holiday season.

## SENSORY SEEKER AND SENSORY BYSTANDER PROFILES

Both Sensory Seekers and Sensory Bystanders require more intensity than most people to process sensory information from their outside environment. Sensory Seekers have an active response to the feelings of boredom and disengagement that come from not having enough intensity to activate sensory processing. This causes them to have behaviors that might be called sensory intensity enhancers. Sensory Bystanders have a passive response to the feelings of boredom and disengagement that come from not having enough intensity to activate sensory processing. This causes them to have behaviors that might be called delayed meltdowns.

## SENSORY AVOIDER AND SENSOR PROFILES

Both Sensory Avoiders and Sensors feel sensory information from their outside environment with greater intensity than most people. Sensory Avoiders have an active response to experiencing too much intensity to activate sensory processing. This causes them to have behaviors that might be called sensory intensity dampeners. Sensors have a passive response to the feelings of discomfort that come from having too much intensity to activate sensory processing. This causes them to have behaviors that might be called delayed meltdowns.

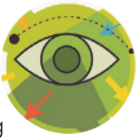
## HOLIDAY SENSORY SEEKER AND SENSORY BYSTANDER BEHAVIORS

A Sensory Seeker at a holiday celebration may experience sensory input as pleasurable that others consider annoying. They might make loud noises or fidget at the holiday dinner table. They may explore their food with their fingers or chew on nonedible objects like their napkin or eating utensil. They might have a hard time staying in their chair and annoy those they are seated beside by touching or pressing up against them.

Sensory Seekers are doing this because they are unconsciously trying to enhance the intensity of sensory information coming from their outside environment. This explains why a Sensory Seeker's occupational therapist may have made recommendations that add sensory value to everyday activities. Examples of these are playing music and providing fidget toys to promote attention for work or sitting on an inflatable seat cushion to intensify the rewarding feelings of squirming to promote better posture.

## BE AWARE : SENSORY-FRIENDLY TAKE-AWAYS

1. **Help everyone look beneath the behavior.** Holidays are sometimes stressful for the families of children with extreme Sensory Profiles. Some of you may have experienced a holiday gift exchange when your Sensory Avoider child wouldn't wear a single piece of clothing a grandparent gave them. Some of you may have experienced a holiday meal that you hoped could feel relaxed and instead, your Sensory Seeker child kept everyone else on the edge of their seats. By teaching everyone at your holiday gathering how to use pattern logic to understand Sensory Profiles, you just might teach someone about the beauty of neurodiversity.



2. **Read your environment for clues.** Lighting, color, sound, textures, unfamiliar touch, and unusual smells are all possible discomforts for Sensory Avoiders. Is there a way to use softer lighting or a favorite aroma that will increase his or her tolerance to unfamiliar events and therefore avoid a meltdown? Having to sit and stay quiet for long periods of time may be more than your Sensory Seeker can handle. Is there a way to provide opportunities for movement and heavy work that will increase his or her tolerance to quiet events and therefore avoid a meltdown? It is important for us to show others how the power of well-designed multisensory environments can change the stress response equation for people with extreme Sensory Profiles.

3. **Practice self-care.** Mindfulness practices and relaxation breathing have become commonplace in classrooms of students who have sensory processing differences. These are healthy self-care routines for everyone to know and can be especially useful for the families, caregivers, and teachers of children with extreme Sensory Profiles. Research showing the positive benefits of mindfulness and the relaxation response have been around for about 50 years now so, it's time for us to use these practices to help our kids and others with extreme Sensory Profiles.

4. **Avoid sensory sensitivities and emotional triggers.** Remembering that everyone has sensory preferences will do much to help your family circle, set conditions for building trust with more empathy and compassion for Sensory Profile differences. We are all pattern spotters and when everyone in your family learns to spot the sensory reason for behaviors, trust grows by becoming less about "how you make me feel" and more about "how we can all feel together." This is a great way to start creating future generations that value and enjoy neurodiversity.
5. **Build trust over time.** Creating a better future for your child with an extreme Sensory Profile will be a lifetime journey… but it can be a fun one. Research on the strengths-based approach to assessing and planning healthier life experiences for people with sensory processing differences have only been completed during recent decades. This is one reason that educating everyone on the importance of trust-building across our differences is so important. Whatever your collective family Sensory Profile, broadening the neurodiversity conversation will spread the word that we are all just different flavors of human.

A Sensory Bystander at a holiday celebration may need as much sensory input as a Sensory Seeker but, they are passively accepting the boredom and disengagement that they are experiencing. You want to understand and ideally help your child understand their own sensory needs because this is the way you build enough trust to help them keep their "I'm different" mask off. This is the way to help them develop the feeling called psychological safety.

## HOLIDAY SENSORY AVOIDER AND SENSOR BEHAVIORS

A Sensory Avoider at a holiday celebration may want nothing to do with activities that may be pleasurable for others. They might feel overwhelmed with holiday music that others enjoy. They may be uncomfortable with having holiday guests at the family dinner table and come across to others as being stubborn or controlling.

Sensory Avoiders are doing this because they are unconsciously trying to dampen the intensity of sensory information coming from their outside environment. This explains why a Sensory Avoider's occupational therapist may have made recommendations to maintain daily rituals that are easy to manage and that limit sensory input during a holiday celebration. Examples of these are getting dressed in everyday rather than special clothes, taking frequent breaks in a comfortable part of the house with low stimulation or having time to socialize more with familiar rather than unfamiliar people.

A Sensor at a holiday celebration may be as sensory sensitive as a Sensory Avoider but, they are passively accepting the discomfort that they are experiencing. You want to understand and ideally help your child understand their own sensory needs because this is the way you build enough trust to help them keep their "I'm different" mask off. This is the way to help them develop the feeling called psychological safety.

Here's wishing you and your family a sensory-friendly holiday and a peace-filled new year! •

### ABOUT THE AUTHOR:

Janice Ryan, OTD, OTR/L is a Doctor of Occupational Therapy and is the owner of Attunement Solutions, LLC, Chattanooga, TN. She is Director of Research for Sensory Health and a certified trainer for American Association of Multi-Sensory Environments, and has completed evidence-based practice research on the therapeutic benefits of multi-sensory environments and multi-sensory activities as an adjunct professor in the Department of Occupational Therapy, University of Tennessee Health Science Center, Memphis, TN. Janice continues to mentor interns and complete evidence-based practice research at Orange Grove Center, Chattanooga, TN.

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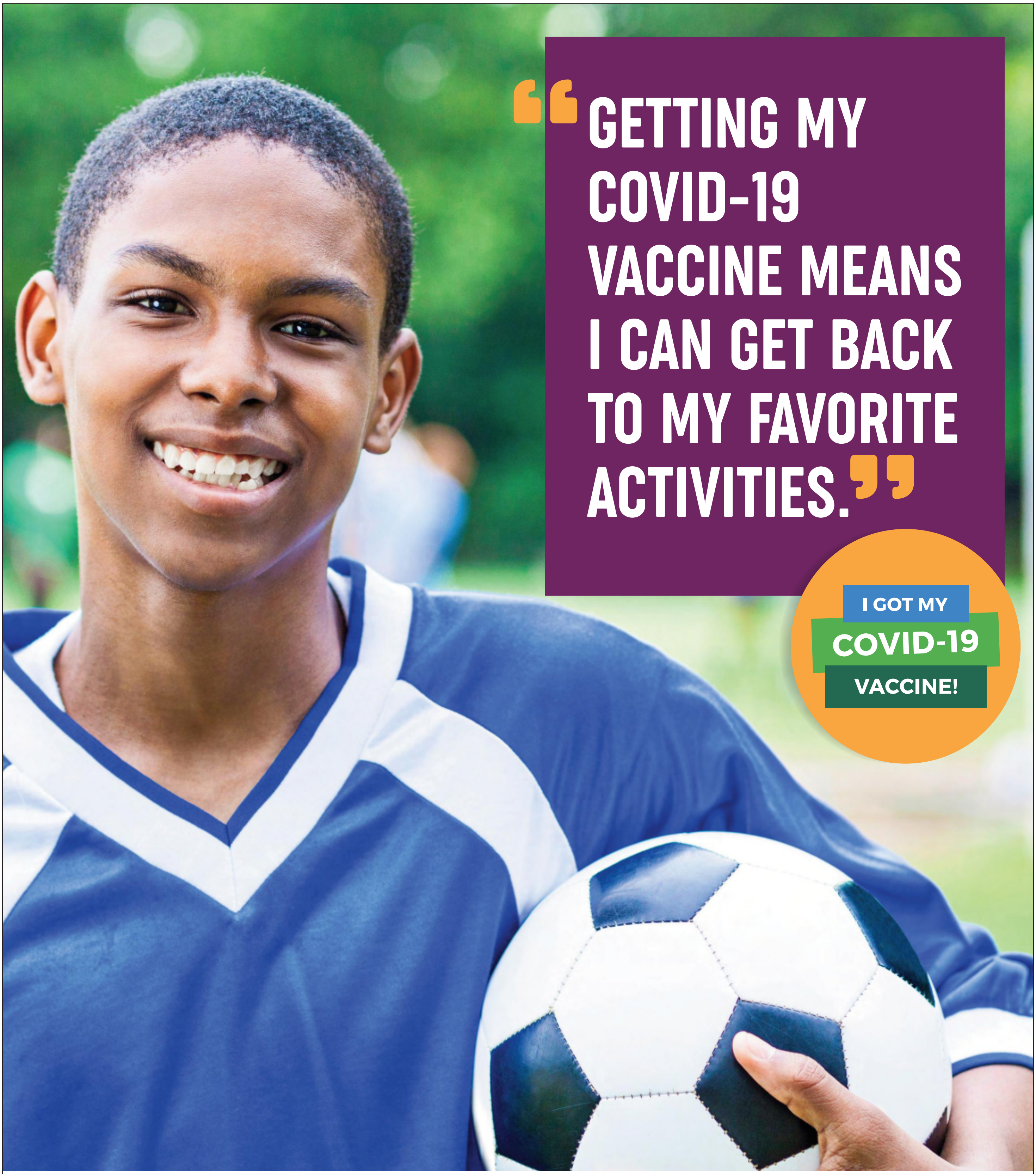

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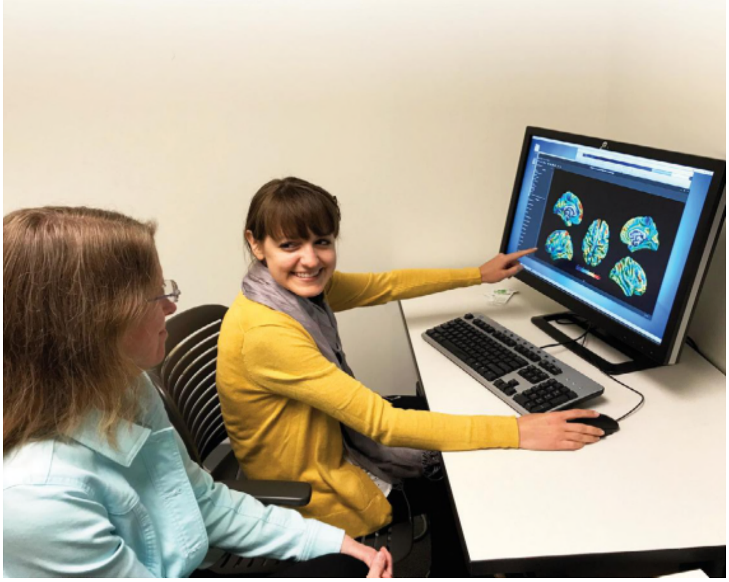

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Family & Community

# Home for the Holidays

## Self Regulation Strategies for Parents and Kids

By Carolyn Cantu, OTR

Parents, Brace yourselves! The third week of December marks the release of school children across the nation for the winter holidays. Caught up in the holiday spirit, youngsters celebrate their liberty from classes. Reinforcement of self-regulation for you and the children will help calm the overstimulation of the season-replacing tension with enjoyment throughout the break.

As a general rule, school calendars allow a substantial break between fall and spring semesters. Most school districts allow about two weeks during the holidays. Consequently, potential exists for agitation to increase and learned independent skills to decrease during this period.

A natural reaction occurs: the more self-regulation and independent skills slide, the more parents tend to pick up the slack that becomes burdensome while juggling holiday demands and expectations. Unless families use reinforcement strategies, two circumstances are likely to occur-parents become overwhelmed and children lose skills practiced in daily routines. To prevent this situation, families (in collaboration with teachers, therapists, and psychologists) can provide special environmental adaptations and therapeutic techniques at home. Acceptable behaviors and independent life skills are thereby reinforced while maintaining therapeutic and performance gains.

> Behaviors such as impulsivity, lack of initiative, memory difficulties, distractibility, disorganization, stress and anxiety may escalate.

Due to this season's festivities, common therapeutic strategies (i.e. daily routines, high structure, organization, visual and auditory prompts) relax in the atypical events of the holidays. Consequently, behaviors such as impulsivity, lack of initiative, memory difficulties, distractibility, disorganization, stress, and anxiety may escalate. This conduct interferes with learned regulatory behaviors and independent skills in family activities. Tensions and stress levels rise for both parents and youngsters. A review of calming and organizational strategies with school personnel or private therapists may prove beneficial through this year's holiday activities,

We know that children experiencing self-regulatory problems frequently exhibit sensory defensiveness to external stimuli. This season is particularly stressful. Sights, sounds, and smells are all unusual and often overstimulating, especially when sensory input is multiple and simultaneous. A review of self-regulatory techniques such as the sensory alert system, behavior modification, cognitive/ emotional/ social techniques, and adult modeling may certainly be welcomed by parents and caregivers before chil-

dren are released for the holiday break. For example, a review of self-regulation with parents whose children are involved in the "How Does Your Engine Run" program developed by Williams and Shellenberger offers a variety of strategies that can be adapted for home and community holiday activity. Activities and projects modified within this program may include: religious community activities, local celebrations, neighborhood caroling, library holiday programs, and of course, family gatherings. If people, routines, and community establishments are kept as familiar as possible, stress-causing disruptive behavior would most likely be kept to a minimum.

Suggestions and reminders focusing on independent skills may include: lowering expectations, engaging children with special needs in simple craft projects for gifts or decorations; breaking down activities into small components, reducing the complexity of an activity and length of time it takes to complete; providing a sense of external order using picture labels on holiday decorations; developing simple, uncluttered pictures, lists, and charts, and the use of verbal prompts which may be needed for such activities as gift wrapping, cookie baking or tree trimming; the use of simple, concrete instructions and emphasis on the concept that children vith memory difficulties succeed with repetition. Therapists may present creative strategies for transitions in home or community activities or suggestions of how to balance high energy activity like sleigh riding with sedentary activity like reading or computer games.

> Therapists may present creative strategies for transitions in home or community activities or suggestions of how to balance high energy activity like sleigh riding with sedentary activity like reading or computer games.

Balancing purposeful activities with holiday fun and relaxation during this season is a challenge for parents. Request support from your child's therapists and teachers by providing hints, tips and strategies that promote and reinforce independent life skills while reducing holiday stress. Backsliding will be minimized and children may actually gain new skills to bring into their class for the upcoming semester or to the clinic for the New Year!

Parent support groups from mid-November to mid-December may focus on suggestions, tips, and strategies that relieve stress caused by the break in daily routine while reinforcing positive behaviors and independent skills. Local meetings may be available on the Internet or through the school system. If a parent group is not currently meeting in school or community, this season is an opportunity for parents in the respective communities to gather together, and invite a speaker (parent, therapist, or teacher) to share ideas.

Parents and caregivers benefit from self-regulatory strategies as well. Internet sites with "Holiday Tips for Parents" are plentiful this time of year. To avoid falling into a "tension trap" during the holidays, log onto some of the numerous articles written on line suggesting parental strategies that relieve seasonal stress. Sites such as Smart Start at **www.nesmartstart.org** or Ann Vernon's Holiday Stress Busters at **www.familyeducation.com** offer valuable suggestions. Examples include participation in at least one physical activity daily, acceptance of offers from family, friends, or respite agencies to stay with the children for short durations including an overnight retreat, practice deep breathing or yoga daily, get adequate nutrition and sleep, and maintenance of a family schedule. These suggestions are a sampling of many more that promote self regulation and stress reduction benefiting the entire family.

Remember this is a vacation for all of us! Occasional down time with visions of sugarplums is therapeutic for children and parents as well.

Happy Holidays! •

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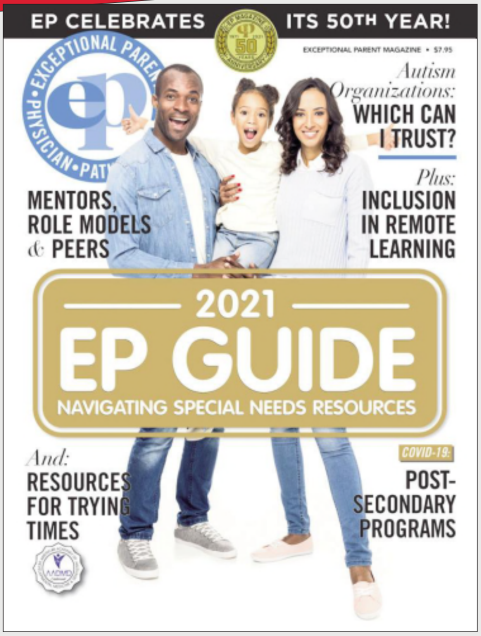

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*"As our kids grow, they may forget what you said, but they won't forget how you made them feel."*
**– Kevin Heath**

# LOVING AKHILESH

## REFLECTIONS OF PARENTING A CHILD WITH SEVERE LEARNING DISABILITIES

BY DHANALAKSHMI KADARI

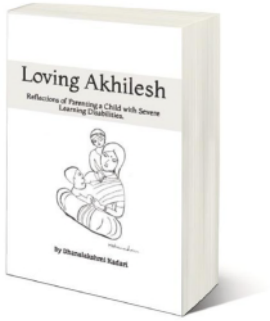
PHOTO PROVIDED BY DHANALAKSHMI KADARI

*A learning disability can be diagnosed at birth or later in life, and is lifelong. A person might have a mild, moderate or severe learning disability, which depends on how much it affects their daily activities and the amount of support they need in activities like eating, sleeping, going out, washing and dressing.*

A child with a learning disability may find it harder than a child without it. This includes the capacity to learn, understand and communicate. Although they may find it hard to express things, they are still aware of their surroundings.

The National Health Service (NHS) states that learning disabilities affect around 1.5 million people in the United Kingdom, and that this figure is rising every minute. It can be distressing to a parent to discover their child has a learning disability, but there has been an increase in resources available to help care for the child – support services like outreach, short breaks and residential support. Disability does not stop a child from having a full and enjoyable life and the aim of all the specialist services is to help children with a general learning disability and their families to have lives that are as enjoyable and fulfilling as those of other people.

All of these factors mentioned above and the resources available are covered in *Loving Akhilesh – Reflections of Parenting a Child with Severe Learning Disabilities,* a new book publication based on my parenting experience with my son, Akhilesh, who was diagnosed with learning disabilities soon after birth. Being my son's main carer for his personal care these past 25 years and for the future, I have always wanted to share my parenting experience in the hope that it would be helpful for others from all walks of life, including families with a child with or without a learning disability. However, I never managed to find the time to do so before. I was inspired to finally complete this book after reading many questions from parents caring for a child with a learning disability on social media, especially those who had recently moved into the UK who were seeking help for resources available to help care for their children.



Title: **Loving Akhilesh - Reflections of Parenting a Child with Severe Learning Disabilities**

Author: **Dhanalakshmi Kadari**

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www.kobo.com/us/en/ebook/loving-akhilesh

During the COVID-19 lockdown, my daughter, Srilekhini, was interested in getting to know my parenting journey better, having just become a mother herself. Our journey together writing this book started there and my daughter helped me write a few sentences for the book here and there, whenever we had time. Finally, by God's grace, I managed to complete this book and also create a podcast from this book with her support.

The book is composed of concepts such as health and social care plans taking Akhilesh's care plan as an example and is described in detail, including feeding, sleeping, mental wellbeing and social plans. I discuss the different healthcare professionals involved in the care, including the occupational therapist, physiotherapist, speech and language therapist and more, all of which provide a holistic and multi-disciplinary approach in managing Akhilesh's care. Other concepts like Deprivation of Liberty (DoLs), Power of Attorney, Disabled Parking, and more, are also mentioned in this book to help give readers an insight into all of these which may rise when taking care of child with a learning disability. I talk about Akhilesh's birth history, his current condition during the COVID pandemic, and my parenting experience when we relocated to the UK, including the resources available to help care for Akhilesh. I also mention certain medical conditions such as cerebral palsy, epilepsy and lissencephaly, which Akhilesh had been diagnosed with, and speak about the clinical signs and symptoms, treatment and prognosis.

I thought it would be nice to share my parenting experience to help raise awareness about learning disabilities, to provide insight into the advancements made in the resources available when caring for a child with learning disabilities these past 10 years – and to provide hints, tips and ideas for parenting.

One of my favourite affirmations that I would like to mention that is connected to writing this book is from Kevin Heath who stated that "as our kids grow, they may forget what you said, but they won't forget how you made them feel." I hope that my book will highlight that a parent's job is to not cure the disability but to create the best physical, mental, spiritual and social environment for the child to help them work through their challenges. I believe that we should try our best to take care of our child despite their learning disabilities.

Some people often feel that they are closer to God given their innocence, and so we are blessed with this parental duty in this lifetime as a way of devotional worship to Him as we care for our child. I hope that you enjoy reading this book and listening to the podcast as much as we did creating them.•

## ABOUT THE AUTHOR:

Dhanalakshmi Kadari was born in Visakhapatnam, Andhra Pradesh, on the Bay of Bengal, India, before coming to the UK where she studies at University of Essex. Married to Ravi, the family lives in Ipswich, Suffolk.

PHOTO BY SHARON BRANVOLD PHOTOGRAPHY

# WORKING FOR PURPOSE AND MEANING THROUGH ENTREPRENEURSHIP

### BY JENNIFER BERTRAND

*I am a parent of a young adult daughter who experiences a significant intellectual and developmental disability (I/DD). I have learned she wants many of the same things in life as people without disabilities, including work opportunities. Working provides a sense of purpose and is a critical part of living a meaningful life.*

A job and career through gainful employment also provides increased financial security, independence, and is an important part of one's pride and identity. Too many working-age people with I/DD in the U.S. are still unemployed or underemployed. "Low societal expectations of individuals with I/DD" persist today and contribute to large employment gaps between people with and without disabilities (Optum, Inc., 2018, p.1). Parents can and do play a pivotal role in fostering and supporting the development of a vision and work skills, so every young adult has the opportunity to pursue employment.

Our daughter Chloe discovered work through entrepreneurship was a powerful way for her to earn an income while offering a valuable service in the community. Individuals with I/DD can be entrepreneurs! While entrepreneurship may not be of interest to everyone, for Chloe it provides a customized job experience that allows her to contribute with a sense of pride and purpose. If your family is like ours, you may not know exactly where to begin and/or how to start a business, but there many resources out there to help. Our family used the websites on the next page to support Chloe and get more information and ideas.

**SHREDDING OBSTACLES:** Chloe Bertrand in front of her Shred Shed. Entrepreneurship provides Chloe a customized job experience that allows her to contribute with a sense of pride and purpose.

If you or your family member with a disability is approaching transition to adulthood (ages 14-22) and/or has struggled to identify a job or career path they are interested in, you may want to consider entrepreneurship. Self-employment is another name for entrepreneurship, which is a flexible option and is considered a type of customized employment (CE). Customized employment is defined as a "…universal employment strategy that is especially useful for employment seekers with significant life complexities and barriers to employment…based on a determination of the strengths, needs, and interests of the employment seeker" (Marc Gold & Associates, n.d.).

Customized employment is one approach of achieving competitive integrated employment (CIE). CIE means a person with a disability working full or part time, earning a salary at or above the minimum wage, receiving comparable pay and benefits offered to someone without a disability for doing the same type of job, and working with people without disabilities (U.S. Department of Labor, n.d.). These are terms that can be complicated, but highlight the importance of individualized approaches for employment and raised expectations for all. If you or your family member with a disability is planning for adult life and approaching transition, start planning early, even years before graduation, to explore and develop interests and skills. We used the transition planning tips listed on the next page to support Chloe to develop a vision of employment and a plan for her business.

> **Parents can and do play a pivotal role in fostering and supporting the development of a vision and work skills, so every young adult has the opportunity to pursue employment.**

## CHLOE'S STORY

Special Education transition planning in New Hampshire begins at age 14, two years earlier than the federal requirement. Given the significant nature of Chloe's disability and because she was unable to verbally articulate for herself what she felt passionate about and wanted to do in her future, our family and Chloe's Direct Support Professional had meaningful discussions to develop a picture what a future job/career path might look like for her. Around the

### GETTING TO WORK : ENTREPRENEURSHIP/SELF-EMPLOYMENT RESOURCES

**COUNSELORS TO AMERICA'S SMALL BUSINESS SCORE ASSOCIATION**
www.score.org

**JOB ACCOMMODATION NETWORK (JAN)**
https://askjan.org/topics/Entrepreneurship.cfm

**OFFICE OF DISABILITY EMPLOYMENT POLICY (ODEP)**
www.dol.gov/agencies/odep/program-areas/customized-employment

**SMALL BUSINESS ADMINISTRATION (SBA)**
www.sba.gov

**NATIONAL COLLABORATIVE ON WORKFORCE AND DISABILITY**
Road to Self-Sufficiency: A Guide to Entrepreneurship for Youth with Disabilities:
www.ncwd-youth.info/publications/road-to-self-sufficiency-a-guide-to-entrepreneurship-for-youth-with-disabilities

kitchen table, we talked about her skills and interests and the things we knew she enjoyed including the activities and places that made her eyes light up with excitement. From those discussions we created a person-centered vision for a meaningful adult life. We also identified the supports and services needed to help Chloe realize it. We then met with the members of Chloe's Individualized Education Plan (IEP) Team at school to share the vision and together we worked to create a robust transition plan based on high expectations and informative vocational assessments.

## MAKING YOUR WAY : TRANSITION PLANNING TIPS

- Set high expectations at home and school.
- Encourage participation in decision making for big and small things.
- Support identity development and independence through self-determination

- Focus on your family member's strengths.

- Use person-centered strategies to keep activities focused on what the individuals needs.
- Identify and use the individual's interests and passions .
- Believe and they will achieve – parents' attitudes are a strong predictor of adult employment.

- Stop asking "Can s/he?" and start asking "What will it take (supports/services/resources) for him/her to be successful?"
- Family involvement/support is key to success.
- Utilize a variety of effective vocational assessment strategies especially for students with complex communication challenges to further identify skills and interests.

- Identify multiple community work-based activities/internships to build and expand work skills.
- Identify needed long-term supports and services for adulthood.

Each year we had measurable goals and specific learning activities aimed at building and expanding her work skills. The process required much trial and error over time to allow us to get to know Chloe as a worker. We explored a variety of hands-on work tasks in different settings to evaluate her skills and determine what she liked and did not like. Throughout her high school years, Chloe worked at the high school store and administration office and tried a variety of internship opportunities at local businesses. It was through these opportunities we discovered Chloe had many employable skills as well as her ultimate passion, shredding paper. With the robust support she needed, Chloe completed her senior project. She researched the data destruction industry, interviewed and surveyed local businesses regarding their data destruction needs, and created a simple small business plan.

All of Chloe's school services were based in the community during the two years leading up to her transition from school. She also had a paid job that was fully inclusive. Using a customized employment approach, she was able to achieve competitive integrated employment (CIE) while in high school. Chloe worked at Whole Foods Market store where she completed a variety of work tasks and felt truly valued by her coworkers for her contributions. Being around people and working on a team was invigorating to Chloe. When the pandemic hit, everything came to a grinding halt and she had to leave her job to shelter-in-place due her medical vulnerabilities.

**Chloe tried a variety of internship opportunities at local businesses. It was through these opportunities we discovered Chloe had many employable skills as well as her ultimate passion, shredding paper.**

In the spring and early summer of 2020 leading up to her 21st birthday, our family used the business plan she created in high school as a road map to launch her small business project – Chloe's Shred Shed. My husband Shawn connected with local business experts from the Service Corps of Retired Executives (SCORE), a nonprofit organization that helps entrepreneurs get a new business off the ground. We were paired with a mentor who provided guidance, answered questions, helped us avoid pitfalls, and walked us through the process of starting a small business. Opening Chloe's Shred Shed and registering the business with the state was more straightforward and easier than we had imagined. As a family, we combined creative efforts to create a logo and tagline using free available technology. With our community and professional connections and by leveraging social media, Chloe quickly started getting local shredding jobs. She now even has a human service agency as a client and handles all their data destruction needs.

As her customer base started to grow, it became clear Chloe needed her own dedicated workshop because it was too cramped to work out of her Dad's home office. Consequently, I wrote a letter to a local family-owned company, Reeds Ferry Sheds, and told them about Chloe and her Shred Shed business. They were excited to learn about Chloe's plan and very generously donated a shed. With the help of a few other local community businesses, we finished the interior and also outfitted the space with electrical and an HVAC system. Additional funds to furnish the shed and cover the cost of materials were raised via a GoFundMe initiative. We were so touched by the outpouring of community support and belief in Chloe as she embarked on building her business.

As a family, we rolled up our sleeves, did much of the finish work as we could, including the insulation, floor installation, painting, etc. By December 2020, Chloe's Shred Shed was complete! She loves going to work each day and having a purpose. She also takes pride in doing her work. Our family and Chloe's dedicated Direct Support Professionals (DSPs) continue to support and teach her different aspects of her business and she has gained increased independence and self-direction. Her Dad set up QuickBooks and helps with preparing and emailing invoices and other financial duties. We also use picture-based symbols so Chloe can learn the filing system. In addition to doing the actual shredding, Chloe also helps wipe down the work stations and machines, dump and recycle the shreds, vacuum the floors, and restock the shredding trays. Customers can call to schedule a drop-off or we drive Chloe to do a pick-up. Despite the unique challenges brought by the pandemic and barriers working-aged people face to attaining employment, Chloe was able to transition seamlessly into her adult life, launch a small business, and create real work through entrepreneurship!

## OTHER CONSIDERATIONS

As Chloe and her family developed her business, there were several other things we had to consider. Being able to identify other resources was a key to the success of Chloe's Shred Shed.

- *Business exploration -What passion and skills does the individual have to offer as valuable service/product in your community?*
- *Impact on disability benefits - Meet with a certified employment benefits specialist to discuss SSI limits & essential Medicaid benefits!*
- *Financial Planning for your business*
- *State and federal programs for small businesses* •

### ABOUT THE AUTHOR:

Jennifer Bertrand is the Director of Community Partnerships at Community Crossroads and coordinates the agency's public policy, marketing, and development activities. She provides information and training to further the dignity, inclusion, and civil rights of people who experience developmental and other disabilities. Her professional career began in the field of education and she holds a Bachelor of Science in Education from Plymouth University and a Master of Arts in Public Policy from New England College.

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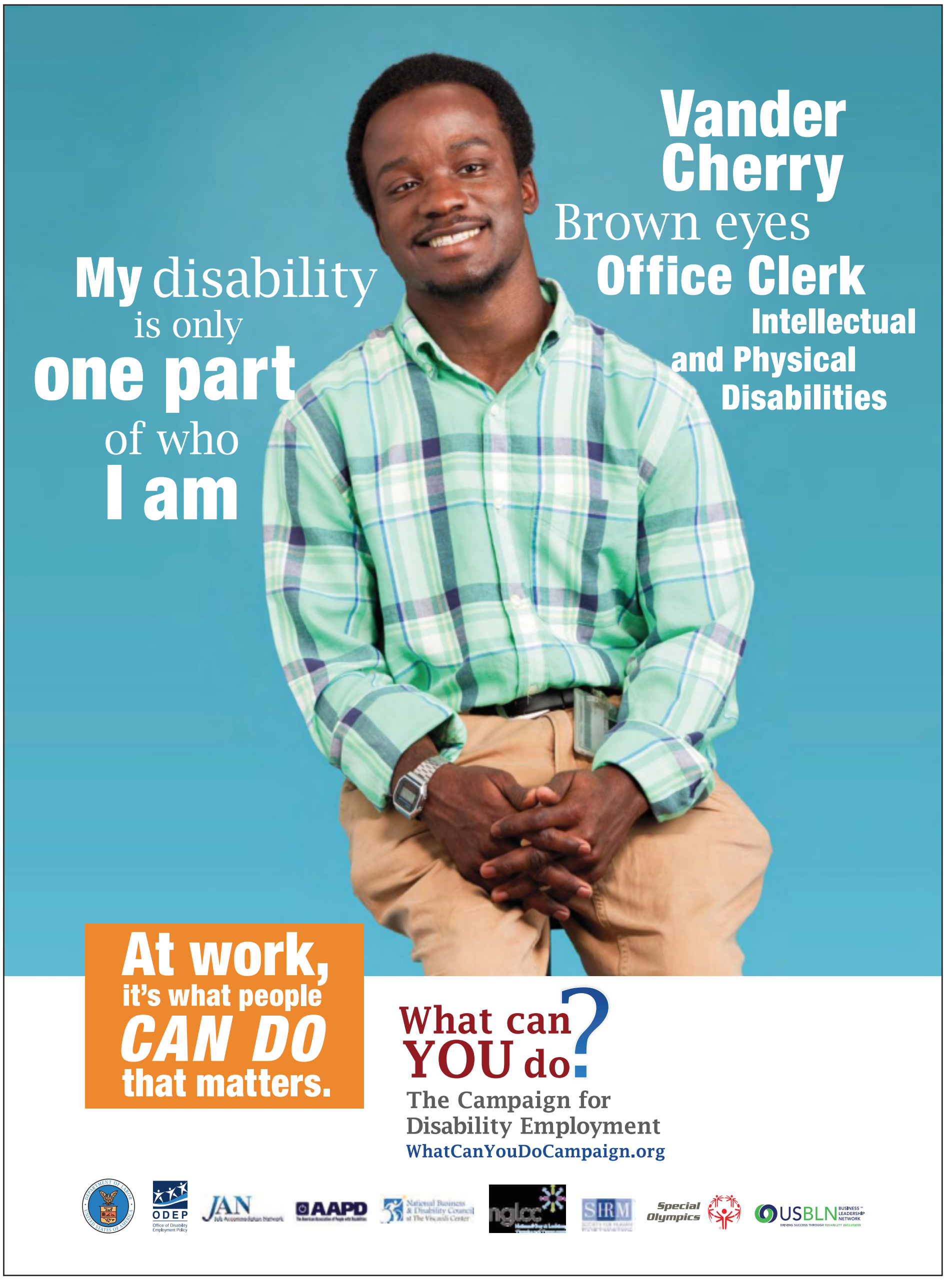
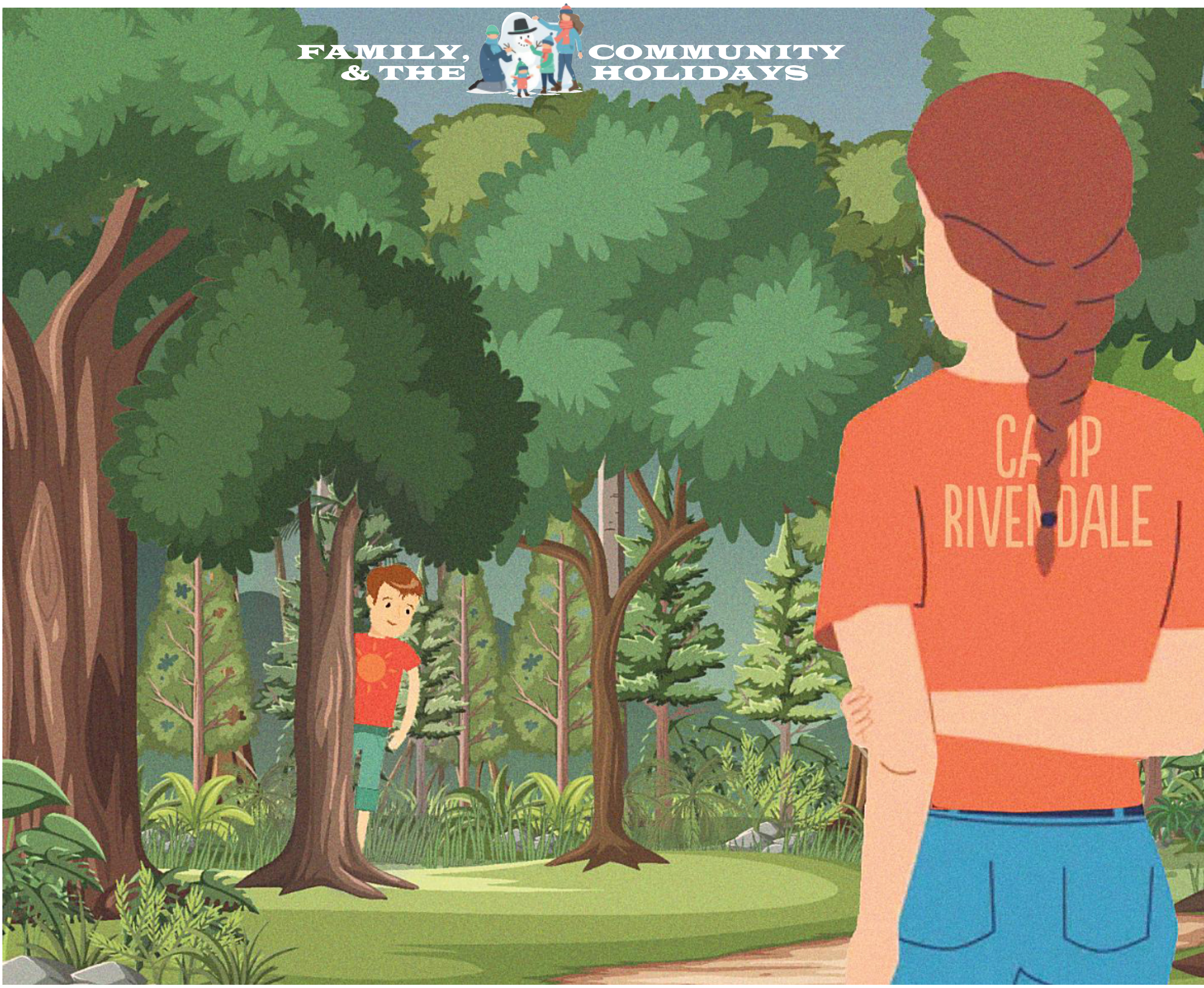




# WHAT I LEARNED AS A SPECIAL NEEDS CAMP COUNSELOR

BY ABBY PHILLIPS

*Tilting my chin to the sky, I feel the warmth of the sun on my face. “Give another big push,” Rachael chants, “Underdog!” She squeals with delight as I pull her back as far as I can, and then shove her forward, racing quickly out from under her swing. I roll beside Hayden, who is currently trolling his heart out to the* iCarly *theme song. The only other sounds I can hear right now are the laughter of kids running through the sprinklers on the field above as it trickles down to where I am on the playground.*

**QUICK THINKING:** "Eli stops laughing and looks back up at me. I take his hand and I lead him out of the trees and back towards the playground. While we are trotting up the hill, I realize something: the importance of acting fast."

These memories were the highlights, the positive moments at Camp Rivendale. However, although much of the time was full of fun and laughter, not every moment was as easy.

I learned a lot from my time working at Camp Rivendale. Working with children experiencing disabilities requires specific skills and talents. Three important things to remember are to have flexibility, act on instinct, and show dedication.

In the summer of 2021, I decided to quit my job at a frozen yogurt shop in search of something new. I had several friends who worked for the park district in the area, so I decided to try my luck there. I loved working with kids and had run several kids camps myself in the past, so I thought a camp counselor would be a good fit for me.

EXCITED TO HAVE NEW EXPERIENCES AND STRETCH MYSELF IN NEW WAYS, I ENTERED THE POSITION WITH A POSITIVE MINDSET. BUT I QUICKLY REALIZED THAT I, COMPARED TO THE OTHER COUNSELORS, WAS FAR FROM EXPERIENCED.

I wanted to push myself in ways I hadn't before, so I applied to Camp Rivendale - a summer camp specifically designed for individuals with disabilities. Excited to have new experiences and stretch myself in new ways, I entered the position with a positive mindset. But I quickly realized that I, compared to the other counselors, was far from experienced.

## HAVING FLEXIBILITY

It's my first week of camp, and I am focused on the importance of following the rules and sticking to the schedule. I am sitting with two girls under the slide as they tell me a story. I glance down at my watch. My lunch break is coming up. I redirect them to another counselor, concerned about getting on my break late and throwing off the schedule. Waving goodbye, I think to myself "I did the right thing by sticking to the schedule." However, on returning, I realize that they have bonded with the other counselor. They end up spending most of their time with the other counselor the rest of the week. I realize that the break schedule was very flexible, and I should've just waited a few more minutes to let them finish their story. This experience taught me that being flexible is important, otherwise I risk missing out on experiences or relationships that I would've enjoyed.

A coworker of mine, Jack Henry, shared an experience he had while working at Camp Riverdale. The sun is beating down on him while he runs the slip 'n' slide activity of the day. Water sprays out of the hose, soaking squealing children. Kids tumble down the slide like raindrops racing down a window. Jack has an idea. There's no reason he should miss out on the fun. Ten minutes later, both campers and counselors are speeding down the slip 'n' slide like hot wheels racing on a track. Suddenly, the end of the slip 'n' slide rips like a piece of wet paper. The water begins to gush onto the grassy slope. The grass slowly turns into a sloppy mess. With mud running down the slope, kids and counselors alike begin to play. By the end, we're all drenched in muddy water, but still had one of the best days at camp.

As Jack said, "it is okay to get your hands dirty or in this case your whole body because life is short." It is important to be flexible to make good memories. Working with children with disabilities requires flexibility in order to not miss out on relationships, experiences, or fun.

## ACTING ON INSTINCT

Another lesson I learned was to act fast. The assistant director, Meghan Gorman, shared a time when she was monitoring the playground. A camper named Lincoln is playing Legos by himself. Tony is swinging on the swings. Meghan said she "kind of saw a flip switch in Tony." Suddenly, Tony makes a bee line for Lincoln and the Legos. He snatches Lincoln's creation straight out of his hands and smashes it on the ground. Lincoln and Tony are both aggressive kids, so it quickly escalates into a fight. Meghan is holding Tony back as he spews threats in Lincoln's direction. Physically restraining Tony, he thrashes left and right. She has a bad feeling and wonders if she should call over another counselor but hesitates. Suddenly, Tony bites down with the power of a crocodile's jaw. Instantly regretting not asking for help, Meghan quickly radios for backup.

Meghan, being a Special Education major, said "you start to think you've seen everything, but kids always prove to you that you haven't." When she saw Tony's flip, she said her gut told her to immediately remove him from the playground to get some space. But, since he was a new camper, she let him be. What if she was wrong? If she would have acted sooner, she would have saved Lincoln and Tony both from a traumatic altercation and she could've avoided injury. She learned the importance of trusting your instincts and acting fast.

A time where I acted on instinct was during an experience with another child I worked with, a boy named Eli. Eli is what we counselors like to call a "runner." He thinks it's hilarious to run away from camp. Luckily, Camp Rivendale is slightly secluded, not close to any busy roads and parking lots. But even then, it is stressful when Eli decides to bolt. On one of these occasions, I just happen to be at the right place at the right time. I see him slip into the trees as quickly as a rabbit out of the corner of my eye. I carefully follow him into the trees, quiet as a fox. I chase him down, weaving in between the trees. Catching up to him, I approach him carefully. "Eli! Don't you want to come back to the park?" I plead with him. I try to be stern. "The Park is this way, it's time to go back. Now, Eli." He isn't listening to me. He erupts into laughter. This is all a game to him. I realize that trying to talk to him logically isn't going to work. I have a hunch, so I will try a different approach. "Eli, when you run off like that it makes me feel very scared. I don't know where you are, and it makes me feel sad. Please don't do that again because it worries me." I look him right in the eyes. Suddenly, like changing a TV channel, his face changes. He stops laughing and looks back up at me. I take his hand and I lead him out of the trees and back towards the playground. While we are trotting up the hill, I realize something: the importance of acting fast.

CREATING A RELATIONSHIP WITH THE CHILDREN I WAS WORKING WITH WAS VERY IMPORTANT. SHOWING DEDICATION IS A GREAT WAY TO HELP WHEN WORKING WITH CHILDREN EXPERIENCING DISABILITIES.

It is important to act on your instincts while working with children with disabilities. You never know what to expect. That was one of my first experiences where I was able to handle a situation purely on my own. I didn't know that I had that kind of self-composition and quick control in me.

## SHOWING DEDICATION

The final lesson that is important to learn when supporting children with disabilities is the power of dedication. Being committed and having patience is a very important skill to develop when supporting any individual. It was the first day of camp when I met Avery. She's rocking on the ground and I can't understand a word she's saying. All I can hear are incoherent sounds; sometimes it seems like she's speaking another language. This is my first time trying to communicate with someone who is nonverbal. It is more difficult for me than I realized. I can't understand her needs. I can't understand what she is saying. But most important, I can't understand how to help her. The first breakdown she had at camp is on that very first day. All the campers are down in the lower pavilion after drop-off. I walk down to go meet the new campers and there she is, sitting on the ground, rocking back and forth, examining puzzle pieces. Suddenly, she begins to cry. Arms flailing, she throws her head back and screams. It is out of nowhere, like a surprising streak of lightning in a quiet rainstorm. Puzzle pieces fly. Punches are thrown. She never intentionally hurts anyone, of course. I watch, dumbfounded, as another counselor begins trying to calm her down. Doubtful thoughts echo in my head "I will never be that good. How does she do it?" I am simultaneously unsure of myself and in awe at how patient and composed my coworker is.

On that first day, I had no idea how to help Avery. But by the end of camp, I can understand both her needs and the way she communicates. I learned that she pouts with her hands when she is bored, she stomps her feet when she is having fun, and she chews on water orbeez when she is hungry. But this knowledge came only after spending time and energy to get to know her and her needs. Being dedicated to the children you are working with is so important. I learned how to show my dedication throughout camp.

The last week of camp was when I demonstrated this dedication. I face the biggest meltdown yet. A boy named Hayden has just built something out of Legos. As the end of the day draws closer, Hayden leaves the Lego station. Another camper, assuming he is done, begins to build her own creation, taking pieces from Hayden's periodically. On Hayden's return, he realizes what has happened and has a full meltdown. He takes it personally, switching into fight mode, writhing his whole body, and channeling threats at the other camper. No one can calm him. At any other camp, behaviors like this are reason enough to send the child home. But not at Camp Rivendale. I approach Hayden with the intent to help; I have gotten through to him before during a few other minor incidents. I sit across from him and take his hands in mine. "Hayden, look at me. Squeeze my hands." Hayden does as I say, then crawls into my lap. I scratch his back and rock him back and forth like a boat on the sea. I help him work on his breathing. "Deep breath in. And out. Deep breath in. And out. Good job Hayden, you're doing awesome." I help him talk through the situation. "Hayden, I promise you, it was not personal. She had no idea that it belonged to you. She was just trying to have fun. She didn't know." I hold him in my lap as everyone packs up. I stay with him as everyone leaves the playground and walks back to check out. We sit there on that turf for at least 20 minutes, until his pitch, volume, and breathing are as even as a drumbeat. Those 20 minutes with him made me realize how much I had learned. I was the only one who could get through to this child.

As everyone else left, I was the one he needed to stay and help him. Creating a relationship with the children I was working with was very important. This was achieved by showing that they can trust you and that you care for them. Showing dedication is a great way to help when working with children experiencing disabilities.

All these experiences put me in uncomfortable situations. At times, I didn't know how to react. I was lost and didn't know what to do. Over time, I got to know many of the individuals personally. I began to understand what worked, and what didn't. I realized that I have a lot to learn, but I also learned that I know a lot.

Working at Camp Rivendale made me realize just his important it is to push yourself out of your comfort zone. It's the only way to truly grow. I knew that it would be different, and I knew that it would be difficult. But the first day I had no idea how much I was about to learn, or how much fun I would have. •

*(Note: the names used in this essay have been changed for privacy purposes.)*

### ABOUT THE AUTHOR:

Abigail Phillips is currently studying at Brigham Young University in Idaho. For the past four years, Abby has been involved in the special needs community, both working locally and traveling.

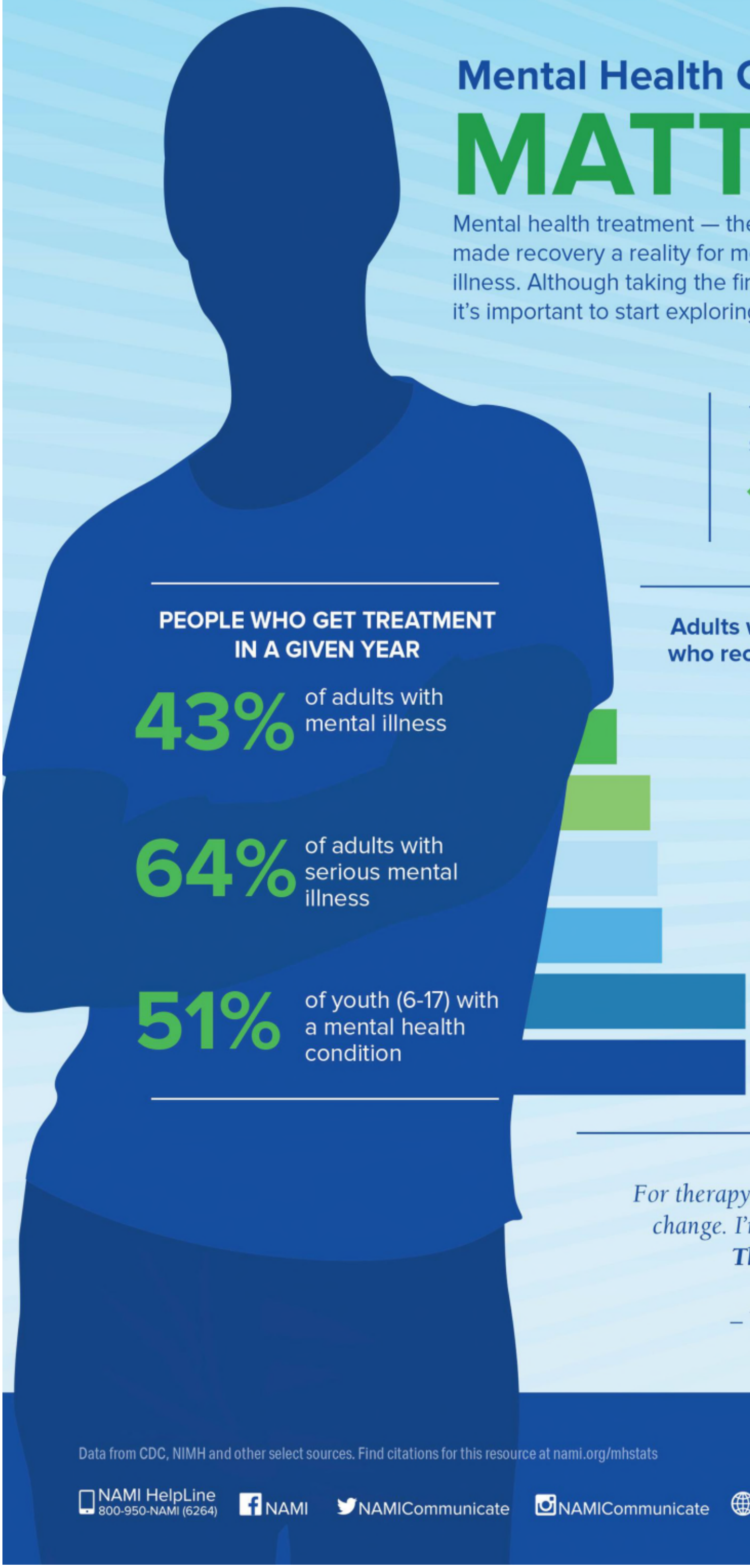
## Mental Health Care

# MATTERS

Mental health treatment — therapy, medication, self-care — have made recovery a reality for most people experiencing mental illness. Although taking the first steps can be confusing or difficult, it's important to start exploring options.

The average delay between symptom onset and treatment is

**11 YEARS**



### PEOPLE WHO GET TREATMENT IN A GIVEN YEAR

**43%** of adults with mental illness

**64%** of adults with serious mental illness

**51%** of youth (6-17) with a mental health condition

### Adults with a mental health diagnosis who received treatment or counseling in the past year

**25%** of Asian adults

**31%** of black adults

**32%** of adults who report mixed/multiracial

**33%** of Hispanic or Latinx adults

**49%** of white adults

**49%** of lesbian, gay and bisexual adults

> *For therapy to work, you have to be open to change. I'm proud to say that I changed.* ***Therapy saved my life.***
>
> – NAMI Program Leader

Data from CDC, NIMH and other select sources. Find citations for this resource at nami.org/mhstats

NAMI HelpLine 800-950-NAMI (6264) NAMI NAMICommunicate NAMICommunicate www.nami.org

NAMI
National Alliance on Mental Illness

# YOU GOT THAT RIGHT, DOC!

BY DAVID A. ERVIN, BSC, MA, FAAIDD

In his November Ancora Imparo, Editor in Chief Dr. Rick Rader penned “On Walking into a Bar with a Guy Named Dunbar” (https://reader.mediawiremobile.com/epmagazine/issues/207527/viewer?page=5) Sparing all the gory details (you gotta read it yourself!), it speaks to the profundity of friendships. This sentence gripped me:

“Of all the things that people with disabilities come up short with are the number of friends they have.”

Dr. Rader went on to observe that we “do a poor job of providing opportunities for [people with intellectual and developmental disabilities] to make friends, not to mention opportunities for them to walk into bars. The richness of life has its roots in relationships, friendships and hanging out with folks who know us, forgive us, tease us, support us, and root for us.”

***You got that right, Doc!***

Forgetting about everything else about which we worry in this field, arguably the greatest obstacle to full engagement in and as part of community for people with intellectual and/or developmental disabilities (IDD) is they rarely have friends – never mind acquaintances, colleagues, co-workers, fellow students, the list is endless – with whom to contemplate going anywhere and doing anything.

Oh, and a bar? A bar??! Please!

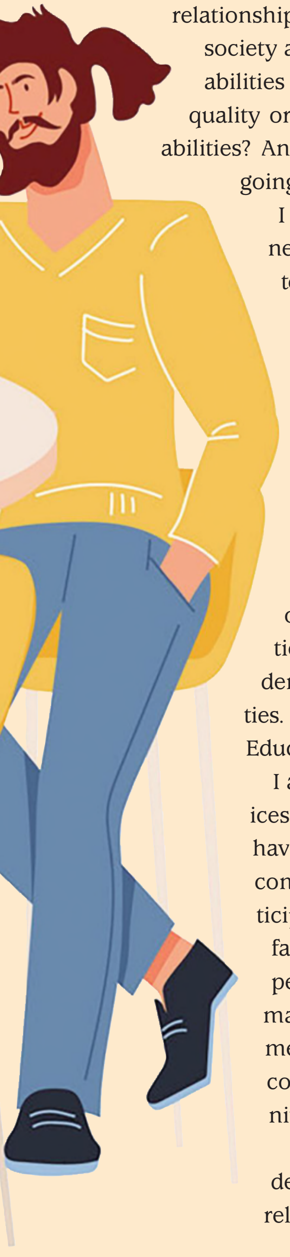
Whether it was the moralistic, “eternal child” arguments of our not-terribly-distant past (which resulted in people with IDD being considered asexual teetotalers), or our clinical “contraindication” arguments of our more recent past (gosh, Jimmy can’t possibly have a beer, lest it mix with the elephant drugs we have him on), or the persistent attitudinal barriers that would have the whole of the bar stop dead, turn and stare at the dude with Down syndrome who’s turned up to play pool (“Is he allowed in here??!”) and have a brew.

Where to begin to unwind this terrible dilemma? I have thoughts, of course – we all do. But what is the epidemiology of loneliness among people with IDD? Why, more than 45 years after passage of what we know today as the Individuals with Disabilities Act, which brought kids with disabilities into public schools to be among their peers with and without IDD, are life-

**A SEAT AT THE TABLE:** Why, after hundreds of thousands of people with IDD have been discharged from far-away, out-of-sight-out-of-mind institutions and into their home communities, do so few people with IDD enjoy the richness of friendship? What are we gonna do about it?

long friendships so lacking? Why, after hundreds of thousands of people with IDD have been discharged from far-away, out-of-sight-out-of-mind institutions and into their home communities, do so few people with IDD enjoy the richness of friendship? In the USA, where hundreds of billions of dollars have been spent in supporting Americans with IDD over decades, finding people with IDD who have meaningful friendships – not with people paid to support them – is persistently like finding a needle in a haystack.

"On Walking into a Bar with a Guy Named Dunbar" got me thinking about Robert Putnam's *Bowling Alone*, an admittedly dated (I highly recommend it nevertheless) but provocative examination of social capital. Putnam argues that fewer and fewer Americans are joining things like PTA or synagogues, mosques and churches, or bowling leagues. We are, in essence, disengaging from the ecosystems that connect us, through which we make and sustain friendships. This is not a review of *Bowling Alone.* But, its premise is worth considering: our relationships, our friendships, are building blocks of social capital, which in turn enables society to function optimally.



How do we contemplate the centrality of friendships and relationships as essential to an optimally functioning society against the stark realities that people with disabilities tend not to enjoy friendships of the same quality or in the same number of people without disabilities? And maybe way more important, what are we going to do about it?

I met my wife, my substantially better half of nearly 25 years, at work. Did you know that 70% to 80% of people with intellectual and developmental disabilities in the United States are unemployed? For 2020, the US Bureau of Labor Statistics reported that only 17.9% of people with disabilities were employed. Yes, you read that right.

I met four of my best friends on the planet more than 30 years ago in college. Did you know that for the school year 2015-2016, only 19.4% of undergraduate students in post-secondary education were students with disabilities? Worse still, only 11.9% of graduate students that same year were students with disabilities. (Data are from the National Center for Education Statistics.)

I am Jewish, and regularly attend *Shabbat* services and participate in my synagogue's activities. I have friends from and who are part of the Jewish community. Did you know that while actual participation is hard to measure, studies suggest faith community participation is limited for people with disabilities? Did you also know that many congregations, even in 2021, haven't meaningfully addressed the need to deeply welcome people with disabilities into their communities?

Three places that are central to how I've developed virtually all of my most meaningful relationships. Three places from which people with disabilities continue to face stubborn, persistent barriers to full participation. So, what are we gonna do about it?

It's one-dimensional thinking, but let's try some easy things:

1. **Let's stop finding jobs *for* people with IDD.** Let's instead ask younger people with IDD, while they're still in secondary school, what they want to be when they grow up, and then walk alongside them in *their* pursuit of an actual career. The former is where a job is simply a box to be ticked, a transaction. And, it's not working. Since 2009, the aggregated growth in number of people with IDD in integrated employment is a not-so-whopping 6.6%.
2. **While the number of people with IDD who are formally enrolling in post-secondary college and university-based options is growing, the actual number barely registers.** Zhang and colleagues put it bluntly: "individuals with intellectual and developmental disabilities as a whole have not been fully included in the college and career readiness movement nationally."[1] It's not for lack of options – on Think College (great resource at https://thinkcollege.net), there are more than 200 post-secondary education options for people with intellectual disability and autism. Of those, more than 100 are four-year programs, more than 90 offer housing, and 99 offer financial aid.
3. **According to the Collaborative on Faith & Disabilities, 84% of people with disabilities say their faith is important to them.** Contrast this with only 10% of faith communities that do any congregation- or community-wide disability awareness. A big part of creating a warm, inviting and welcoming faith community is attitudinal. Yes, architectural accessibility matters and yes, it costs money. But, liturgy can be modified to facilitate active engagement of all people for free. Asking people with IDD how they'd like to be welcomed into faith communities, and then taking their responses seriously as calls to action takes only time and a commitment to change. And starting a dialogue with your temple, mosque, synagogue or church spiritual leaders and boards of directors is a first step that anyone can and should take.

One more thing. For those of you for whom a trip to the bar or local pub is not unusual, join me in hoping for the day when the guy with Down syndrome walks through the door and welcoming him to a game or two of pool. Maybe even buy him a pint. Have a laugh, make a friend. Not only will you add a friend to your world, you'll become one in his. •

## ABOUT THE AUTHOR:

David Ervin, BSc, MA, FAAIDD is CEO of Jewish Foundation for Group Homes, a nonprofit supporting people with intellectual and developmental disabilities (IDD) in Maryland and Virginia. With more than 30 years in the field, David has extensive professional experience working in and/or consulting to organizations and governments in the US and abroad. He is a published author and speaks internationally on health and wellness and healthcare for people with IDD and other areas of expertise.

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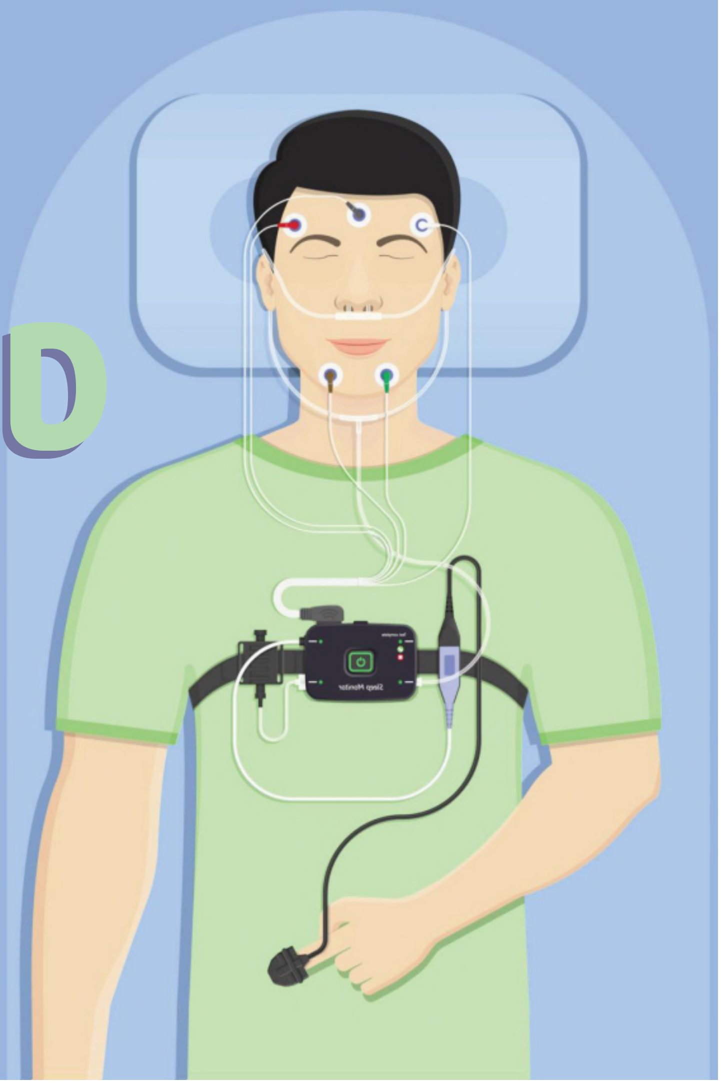
PART VII: EP MAGAZINE SLEEP SERIES

# WHAT IS INVOLVED IN A SLEEP STUDY?



BY DR. LANA JERADEH BOURSOULIAN

*In this article, we will talk about what is involved in a sleep study, and what we can do to improve the experience for patients with disabilities.*

## WHAT IS A SLEEP STUDY?

A lot goes in the brain while the body is asleep. A sleep study is usually done on an overnight stay, although some studies are performed during the day. Sleep studies tell us how much time is spent in each sleep stage, breathing patterns, and oxygen levels in the blood. Tracking these parameters during a sleep study can help doctors diagnose and treat a variety of sleep disorders.

## HOW IS THE DATA BEING COLLECTED?

A sleep technician applies several small sensors on the head and body with an adhesive. Elastic belts are wrapped around the chest and abdomen to measure breathing and a clip is placed on the finger or earlobe to monitor blood oxygen levels.

## WHY DO WE HAVE A SLEEP STUDY?

Healthcare providers may suggest a sleep study if they think there might be a sleep problem. Sleep studies help diagnose sleep disorders. An example of a sleep disorder is Obstructive, often seen with snoring, and night awakenings. Another example of a sleep disorder is narcolepsy, in which there may be episodes of sleep attacks and daytime sleepiness.

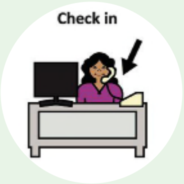
## ARE SLEEP PROBLEMS MORE COMMON IN INDIVIDUALS WITH DISABILITIES COMPARED TO TYPICALLY DEVELOPING PEOPLE?

Sleep problems are more common in individuals with disabilities. Rates of poor sleep reported to be as high as 86 %.[1] Sleep problems can lead to challenging daytime behaviors and worsen health issues.

## REST EASY : ADJUSTING SLEEP STUDIES TO MEET EACH PERSON'S NEEDS AND EXPECTATIONS

*What steps can be done to help individuals with IDD get comfortable with a sleep study? Here are some suggested tips to help:*

- Let your healthcare provider know of the accommodations that you need; examples can include wheelchair access, bed lift, extra parent/caregiver present, ext.



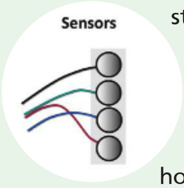
- Talk to your healthcare provider to arrange a visit to the sleep center to get familiar with the setting and equipment that will be used.

- Consider using visual supports to assist with an understanding of what to expect during a sleep study. The visual would include the steps or the process, including checking in with the receptionist, going to the room, putting the "stickers" in, and going to sleep. Here is a brochure that provides examples of visual supports: https://vkc.vumc.org/assets/files/resources/sleepstudy.pdf Version for adults that is similar: https://vkc.vumc.org/assets/files/resources/sleepstudy-adults.pdf

- For individuals with limited language - a First-Then board is a basic way of communications that could help breaking down the steps of the sleep study. "First" can include going to the elevator and checking in. "Then" would be bubble time, TV time or a piece of candy.

- Consider bringing a bag of preferred items or "rewards" to the sleep study.

- Consider taking objects from home to make the new sleep environment more comfortable. Examples can include a blanket, or a stuffed animal.



- Think about making a social story to help understand a new social situation. An example of a social story can include "My name is xxx, I sometimes need to see the doctor who needs to do a test. When the doctor wants to see how I am sleeping, they may order a sleep test. During the sleep test, I will have stickers on my head just like an 'alien' or a 'superhero'. In the morning I will go home."

- In individuals with sensory issues, having sensors placed on their skin can cause unpleasant sensory experience. Consider preparing them by applying band-aids at home while watching TV to assist with getting used to the sleep study.

## WHAT ARE EXAMPLES OF DISABILITIES THAT OCCUR WITH SLEEP PROBLEMS?

People with disabilities can have a variety of sleep problems, depending on the underlying condition. Insomnia, which includes difficulty falling asleep or staying sleep is common in autism.

Down syndrome is a genetic disorder that is associated with increased risk of medical sleep problems, including OSA.

## WHAT ARE SOME OF THE COMMON SLEEP COMPLAINTS?

**Difficulty falling or staying asleep** - Potential reasons can include:

- *Behavioral issues: including trouble sticking to a bedtime routine and difficulty with self-regulation*
- *Medical conditions, such as constipation*
- *Anxiety or depression*
- *Medications: for example, those to treat depression or attention deficit-hyperactivity disorder (ADHD)*
- *Sensory difficulties: for example, room temperature (too hot or too cold), tactile sensitivities (to fabrics, bedsheets)—noises or light while the person is falling asleep or is sleeping*
- *Pain: Individuals with disabilities may have limited language; therefore, may not be able to communicate when they have pain*
- *Obstructive Sleep Apnea (OSA)*
- *Periodic limb movements of sleep*
- *Seizures or epilepsy*

**Excessive daytime sleepiness** - this may be associated with:

- *Short amount of time in bed*
- *Irregular bedtime routine*
- *Medications*
- *Excessive daytime sleepiness: for example, narcolepsy*

## WHY IS A SLEEP STUDY HARDER FOR A PERSON WITH IDD?

New situations can trigger anxiety for anyone, this is particularly true in individuals with IDD. Speech and other problems with communication can make it difficult for the person to let their parent/caregiver or the sleep study technicians know that they are frightened or upset. They may not be able to understand the steps of a sleep study or to know what to expect or what might happen to them.

In summary, while sleep studies are important to help assist clinician diagnose sleep problems, they can be more challenging for individuals with disabilities. Expectations of a sleep study should be adjusted to meet each person's needs and expectations.•

### ABOUT THE AUTHOR:

Dr Lana Jeradeh Boursoulian is a neurologist and sleep medicine specialist. Her clinical and research interest is treatment of medical conditions associated with autism, including sleep and epilepsy.

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# WHY PARTICIPATE IN HEALTHY ATHLETES SCREENINGS?

BY CHAD EASON

*Did you know that Special Olympics not only offers sports programs for children and adults with intellectual disabilities, but has become the largest global health organization dedicated to serving people with intellectual disabilities through the Healthy Athletes program?*

**A LEG UP:** Special Olympics Texas Athlete Shaun Linsey during an online virtual soccer skills event

Through this free program, athletes are offered screenings in eight health disciplines to ensure the athletes can compete at the top of their game. Healthy Athletes health disciplines include Fit Feet, FUN Fitness, Health Promotion, Healthy Hearing, MedFest, Special Olympics Lions Clubs International Opening Eyes, Special Smiles, and Strong Minds, all of which are offered at Special Olympics competitions.

The Mission of Special Olympics is to provide year-round sports training and athletic competition in a variety of Olympic-type sports for children and adults with intellectual disabilities, giving them continuing opportunities to develop physical fitness, demonstrate courage, experience joy, and participate in the sharing of gifts, skills and friendship with their families, other Special Olympic athletes, and the community. However, the movement is shifting the focus to not only sport, but health and fitness as the opportunities for individuals with disabilities are increasing every day.

The Healthy Athletes program certifies licensed professionals in each of their respective fields to lead these screenings. Medical professionals volunteer their time and expertise, come from different disciplines, and are provided pertinent training to help them communicate and care for this vulnerable population, who may not otherwise be getting the care they need. Through training and hands-on experience at screenings, Healthy Athletes is a program for healthcare students and professionals to increase knowledge of best practices in caring for people with intellectual disabilities. Special Olympics is always looking for more willing volunteers to serve in these roles to increase access to quality health care and improve the health status of people with ID.

To participate in Special Olympics competition, each athlete needs an athlete medical to compete. This athlete medical includes a medical history as well as a physical exam to ensure athletes are fit to compete. Athletes are encouraged to go through the MedFest screening where they can receive their athlete medical and screening at no charge thanks to partnerships within

PHOTOS PROVIDED BY CHAD EASON

the communities. Special Olympics has delivered over two-million free health screenings since the start of the program in 1997.

Growing up, I was next door neighbors to a family with five children, the youngest, Shea, having Down syndrome. We were always active in sports and playing outside, with Shea right by our side. Down syndrome has led to his vision impairment where he must wear glasses and while playing sports, sports goggles. I can’t tell you how many pairs of sports goggles Shea went through before I finally heard the cost of over 400 dollars for the price of one pair. Through the Opening Eyes screening, athletes and individuals with disabilities who go through the screening and are diagnosed as needing these glasses, are offered them at no charge to that individual. This is a huge help to many of the families who are looking for opportunities not only to help financially but, more important, improve their child’s quality of life. Not only are the screenings offered, but resources and connections to follow up care are provided to any athlete who may need a more in-depth visit.

**UPLIFTING:** Liam O’Reilly *(left)* with brother and Special Olympic Athlete Shea O'Reilly with his favorite sports goggles received through Opening Eyes.

Expanded opportunities for children and adults with intellectual disabilities are happening through the health messenger program where athletes are becoming leaders in the health and wellness field. Individuals with intellectual disabilities (ID) must have a leadership role in order to build more effective public health initiatives, enhance health systems, and have community participation that supports the health of people with ID. Special Olympics Texas offers the Health Messenger program to give athletes the tools they need to develop healthy lifestyles, influence other athletes to live healthier lives, advocate for inclusion in health and wellness services, education, and resources in their communities, and develop leaders to advocate for the health needs of people with ID.

Special Olympics Texas recognizes that athletes have a variety of skills, abilities, experiences and passions. Athletes who have completed the Health Messenger program determine how they wish to serve as a leader. They may feel qualified to serve in one or more leadership roles. The typical leadership roles Health Messengers take on include: Spokesperson, Healthy Athletes Coordinator, Healthy Habits Leader and Health & Fitness Leader. Athletes who act as spokespersons can speak on behalf of individuals with intellectual disabilities about their health and wellness needs, as well as the challenges they encounter. Additionally, Health Messengers can lead and be present throughout Healthy Athletes screenings to guide athletes through the screenings, recruit athletes to attend the screenings, act as a peer educator at health education stations, and assist with screening logistics.

Now in Special Olympics, not only are volunteers in the healthcare industry leading the charge in making sure our athletes are fit to compete, but the athletes themselves are empowered to serve as a health and wellness leaders in their communities. Says Special Olympics athlete Shaun Linsey. “As a Health Messenger, it is important to me to have the opportunity to help other athletes to follow a healthier lifestyle. I have made exercise videos to stress the need to stay active with good physical fitness, including proper warmup and cool down exercises and exercises in which I have shown modifications to those athletes who are not able to stand while exercising. I always promote the need for proper nutrition and making healthy decisions in the athletes’ food choices as well as maintaining a good level in the portions of the food they eat at each meal and snack time. Keeping up good mental health is another health aspect that I support through having a positive mental attitude and deep breathing techniques. I encourage the athletes to partake in the SO Connected Live activities since these activities provide a good way to connect to friends while having fun.”

“I hold virtual bingo games throughout the year for athletes to say hi to their athlete friends and meet new athlete friends. I also have promoted ways to stay safe with a poster showing proper hygiene at practices, competitions, and during everyday life. I make sure that the athletes stay hydrated during their exercising, practices, and competitions. I have created a video presentation on the importance of sunscreen and sunglasses for protection against the damaging ultraviolet rays to the skin and eyes when we are outside in the sun. Thus, being trained as a Health Messenger has allowed me to pass my knowledge of fitness, safety, and well-being to other athletes for a healthier athlete community.”

As a friend, family member and employee who works alongside individuals with intellectual disabilities, it brings me comfort to know that the children and adults who participate in our events and competitions, have the opportunity to receive care and support from individuals who truly understand what our athletes go through. Each state program offers varying Healthy Athletes screenings in regard to needs, access to healthcare providers, facilities. The best way to find out when and where these Healthy Athletes screenings will take place is to contact your local Special Olympics program and ask for the staff member.•

### ABOUT THE AUTHOR:

Chad Eason is the Sr. Director of Competition and Games for Special Olympics Texas whose mission is to provide year-round sports training and competition for individuals of all ages with intellectual disabilities. In this role, Chad plans and implements the statewide competitions for Special Olympics Texas and includes the Healthy Athletes screenings at each of these events. Special Olympics Texas looks forward to returning to action with Winter Games including Healthy Athletes, February 18-20 in Bee Cave and Lakeway, TX.

# THE PROFESSIONAL ROAD LESS TRAVELED

BY ROBERT SAUL, MD

*It began in college. Not knowing what career path to follow (I thought psychology was where I was headed), things changed dramatically when my first wife and I became foster parents for a child with congenital rubella. Teaching our nine-year-old foster son (with congenital heart disease and impairments of both vision and hearing) to be toilet-trained was quite the task.*

We eventually triumphed, but I was quickly thrust into a world I had no previous concept of. Several years and several foster children with disabilities later, we were no longer foster parents, but my path was set. I needed to go to medical school. In medical school I was tempted by most every specialty. Yet, my experience as a foster parent for children needing special care was always in the back of mind. And I guess, the back of my mind won.

After medical school in Colorado, I did a pediatrics residency at Duke University Medical Center and then pursued a fellowship in medical genetics at the Greenwood Genetic Center in Greenwood SC. Medical genetics was at its infancy in 1979 so I had to convince my pediatric chair at Duke (a wonderful mentor and friend, Dr. Sam Katz) that pursuing a career as a general pediatrician and a medical geneticist was not the dead end that he anticipated.

> “IN MEDICAL SCHOOL I WAS TEMPTED BY MOST EVERY SPECIALTY. YET, MY EXPERIENCE AS A FOSTER PARENT FOR CHILDREN NEEDING SPECIAL CARE WAS ALWAYS IN THE BACK OF MIND. AND I GUESS, THE BACK OF MY MIND WON.”

For 24 years, I was both a general pediatrician and medical geneticist. I found that wearing one hat or the other was a challenge but at the same time quite exhilarating. Sometimes I felt like the Certs breath mint commercial – I was two, two, two docs in one! It was this dual role that allowed me to expand my horizons. I could be a general pediatrician, making newborn rounds at 7 AM, see children and families with possible genetic disorders during the day and then be on call again at night. I think it was these opportunities that hopefully made me a better doctor – that I could understand complex processes and issues faced by families with children with multiple problems and at that the same time I could engage in discussions about some of the more routine issues that all children and families face. For example, all children can get croup. I was able to recognize, treat and counsel families understanding the standard of care and understanding how a complex disorder might complicate a “routine” pediatric disease. I’d like to believe that my listening ears became hypersensitive because of this hybrid model.

Yet, after 24 years, change was afoot. Medical genetics began to occupy more of my time, and I realized that I could no longer burn the candle at both ends with 12-plus hour days. I was fortunate enough to get involved in multiple projects and serve on the board of the American College of Medical Genetics and Genomics and serve in leadership roles for several genetic initiatives of the American Academy of Pediatrics. The next 10 years went by quickly, but I missed the opportunity to do more teaching and practice general pediatrics.

So, at the possible retirement age of 63, I chose to work harder and became the Medical Director of General Pediatrics at a medical center (Prisma Health Upstate) and children’s hospital (Prisma Health Children’s Hospital – Upstate) in Greenville, South Carolina. I was afforded the opportunity and the privilege to work with an incredible, dedicated group of pediatricians providing care to a large underserved population and teaching the doctors of tomorrow (medical students and residents). Being an administrator certainly has its challenges, but being able to actively guide policy decisions that profoundly impact others was both humbling and empowering. And I’d like to think that all of my experience as a pediatrician, medical geneticist, and educator could help guide some of those decisions.

Retirement was put off until the end of 2020. I stepped down as the Medical Director in 2019 and was able to finish my clinical career in the most delightful way possible. I was a staff physician in the Ferlauto Center for Complex Pediatric Care. I was pulling together my decades of experience as both a pediatrician and medical geneticist. For over three years, I had the pure pleasure of working with a team of physicians, nurses, dieticians, case managers, and front office folks that saw it as their singular purpose to provide the best holistic care to children and families dealing with various disabling conditions. Truly their passion and, by extension, mine was to leave no stone unturned providing care and support for these families. The exciting part of this was to see how much I learned from these folks. It would be an understatement to say that I also learned so much from the families. Their trials and tribulations became mine, and the resiliency that they displayed taught me so much. I still internalize to this day so many of the stories that they shared with me. I continue to be amazed at how they shared their humanity with me, making me a better doctor but, more important, a better person.

I retired clinically at the end of 2020. I do not miss having to wear PPE (personal protective equipment) for many patient visits. I might have retired, but I certainly am not withdrawing from my role as a children’s advocate. I continue to pursue my writing (www.mychildrenschildren.com) and am currently serving as the President of the South Carolina Chapter of the American Academy of Pediatrics. In the latter role, I am very busy but find this engagement to be a continuation of my lifelong work. I might be retired but I refuse to withdraw from role as a children’s advocate.

To conclude, one might ask what I have learned in my close to 50 years since college and foster parenthood being a pediatrician, medical geneticist, educator, administrator and author. I could create a long list, but I will choose just a few:

- *Trust the intuition of parents. Let that guide your evaluation and decision-making.*
- *Listen intently. That sounds so simple but so hard to do at times.*
- *Leave your biases at the door. Preconceived notions based on supplied information or past experience can taint your ability to provide the best care possible.*
- *Smile and engage. It’s amazing how comforting a smile can be.*
- *Remember our shared humanity. You could just as easily be on the other end of this medical encounter.* •

### ABOUT THE AUTHOR:

Robert A. Saul, MD is Professor (Emeritus), Prisma Health Children’s Hospital – Upstate; University of South Carolina School of Medicine, Greenville (Greenville, SC).


I AM A VETERAN
AND THIS
IS MY VICTORY.

FROM OUR FAMILIES… TO YOUR FAMILIES

# MILITARY SECTION

## FAMILY, COMMUNITY & THE HOLIDAYS

## MILITARY LIFE

## PUZZLES AND CAMO

# SPARKING HOLIDAY JOY & CHEER WHILE CREATING NEW TRADITIONS FOR MILITARY FAMILIES

BY ANGELA SHAW

*Holidays and family gatherings are in full swing. For many people during the holidays, spending time connecting with family while enjoying the glittering sights, joyful sounds and scrumptious smells of the holiday season is the hallmark of the season. As treasured remembrances swirl in the air, thoughts easily turn to cookie baking parties, and rich and gooey seasonal foods.*

For military families, due to deployment (or being stationed stateside hundreds or thousands of miles from extended family and lifelong friends), navigating the event-filled season may bring challenges. Still, the inevitable struggle of bringing together extended family and connection to life for our military-connected kids can be attained through emotional resiliency and inspired action.

When the going gets tough, success can be gained throughout the year through creative and flexible mindsets that many military families possess. It might mean celebrating Thanksgiving a bit early – or late – to accommodate military leave. Or maybe "face-timing" in matching PJs at Christmas Eve with cousins and grandparents. Engaging with our children during this exhilarating time of year inspires lasting memories for everyone, no matter that the activities and surroundings may be a little different than what we have enjoyed in the past. Customizing positive moments and encouraging optimism leading up to seasonal gatherings can help provide families with that glittering holiday finale.

Opportunities to share special times with family and friends in our life can sometimes cause a bit of whirlwind for kids and adults. The hustle and bustle of the holidays can play havoc with family, work and school-time routines. Dazzling lights can overstimulate visual senses. Holiday music or increased laughter and voices raised in celebration can overwhelm the auditory pathways for some people with special needs. Seasonal smells from fragrant Christmas trees or mouthwatering treats simmering on the stove may trigger anything from allergies to appetites. Crowds at the mall and special events, family and school parties, or unfamiliar visitors, can heighten anxiety or stir up a mild meltdown in plenty of folks. The high-energy season can also intensify panic and sensory overload, when one or more children in the family have an executive function disorder such as autism or attention deficit/hyperactivity disorder, sensory processing or learning disorder, or physical or behavioral challenges. Fortunately, we often know our children's triggers and how best to adapt to their needs. Through a proactive and flexible mindset, we can still achieve a merry and bright holiday season!

## COMMUNICATE : SPARKING JOY AND CHEER TIP 1

Talk early and talk often with your spouse about one another's expectations and vision for the holiday season. Dig deep. Discuss what is important to each of you, what you feel you can keep or need to discontinue, and consider modifying or creating new family traditions. Fuel meaningful conversations through an open mind and heart, rather than an approach spiced with judgement or negativity. Open yourselves up to adjusting expectations during the holidays. Discuss and plan exit strategies for those moments that may arise. Embark upon difficult conversations, such as the very real fact that you may need to decline some invitations that have the potential to cause too great a disruption to your child. Discuss plans with extended family or friends to pave the way toward smooth experiences that include your child. Engage in a manner that children and adults feel heard and acknowledged. Sidestep miscommunication traps:

**Speak to be understood.** Remember that communication is a two-way street; therefore, it's okay to check in to see if you are being understood, or ask questions if you are unclear about something.

**Ensure understanding.** Clarify where your thinking is coming from, or the meaning of your intent. Often, the perception of shared knowledge is not as apparent as we believe.

**Relate direct messages.** Avoid the subtle conversational conveyances of sarcasm, vagueness, or overly-emotional expression.

## PLAN : SPARKING JOY AND CHEER TIP 2

Hope for the best and plan for other possibilities. You know your child better than anyone. The daily structures used successfully at home and within the community are just as viable and beneficial during the holiday season. Adapting supports and preparing proactively for rocky moments are key factors to increase success during this busy seasonal. Parental flexibility, however, will be an important commodity as plans may still go awry. A range of ideas to ignite choices and opportunities include:

**Consider reviewing your child's IEP accommodations and modifications as a springboard for added ideas.** Oftentimes, the accommodations set forth in the IEP can be readily adapted for home and community life. If noise cancelling headphones are something that your child uses at loud school assemblies or in the noisy cafeteria, this tool will be useful for crowded shopping malls or noisy celebrations.

**Practicing cool down protocols at home through breathing, or stop and think strategies,** before venturing out into the maze of holiday fun. All will go a long way toward reducing conflict with a relative, friend or even a stranger.

**Role-playing a scenario** is an excellent strategy in supporting your child.

**Social narratives** customized to support changes in routine, and responses to unfamiliar events or people, can be read together and even shared in preparation with family.

Visual schedules adapted to support activities or transitions are familiar and welcoming.

**Cool-down activities** that appeal to your child, or calming spaces, can be planned for and woven into an occasion.

**Packing a preferred child-size meal** and some favored snacks may go a long way in support of a calmer dinner. Your hosting family will appreciate knowing ahead that you plan to bring some of your child's familiar eats, in case of challenges with sensory aspects of food texture or food allergies.

**Modifications to greetings** can be practiced and arranged ahead of time. For instance, perhaps a high-five, gentle elbow bump or a smile paired with a nod to unfamiliar relatives, or Santa Claus, may serve to regulate and calm the senses. It is okay to join the Santa picture with your child or even guide him or her to stand next to Santa and wave, rather than have your child sit on his lap and experience a meltdown. Better yet, if a real-time Santa visit is just too overwhelming at the moment, how about a virtual visit?

**Preserve your family's collaborative vision.** Consider crafting a vision poster in support of your shared holiday journey.

## BE PRESENT : SPARKING JOY AND CHEER TIP 3

This time of year, it is easy to be overwhelmed by the trimmings and accoutrements of the season. When life gets busier, it is essential that we take extra care of ourselves. Feeling calmer and more focused equips us to positively engage in our family's care. In turn, this empowers us to nourish our souls and bring care and joy to others. Connecting to self-care and enjoying the holiday season can be accomplished through mindfully approaching the realities in life.

**Stay organized.** Make a list and check it twice. Choosing a different color ink or pencil for holiday events when updating calendars provides a visual reminder of what is out of the ordinary and also lets us know at a glance if we are starting to get too jam-packed with holiday events.

**Keep a routine.** Fold in special activities to your child's visual schedule in the manner that they are accustomed to. If your child uses pictures to support understanding or anxiety, gather some meaningful clip art or photos. If you or your child checks off each item on the calendar with a crayon or a sticker, keep the routine going. Once the holiday whirlwind winds down, kids with planning or social issues, routines and rules may take twice the time to reconnect. Including some everyday playtime moments are recommended until the seasonal activities come to a close.

**Decrease the stress.** Your child will pick up on your stress levels. By being vigilant about our mental and physical limits, we can lessen stress. Eat and drink healthfully. Get plenty of exercise and fresh air. Take a walk after lunch. Dance, sing, create. Share some kids' yoga stories and activities with your child. Read some beloved seasonal books together. Be flexible. Let go of expectations. Folding in the expectations of others in relation to what holiday time should look, smell, taste and feel like creates extra burden in an already full life.

**Practice gratitude.** Studies show that creating positive change through the mindset of gratitude has the potential to lower blood pressure, decrease depression and boost energy. Try keeping a gratitude journal or regularly sharing your gratitude with family and friends.

**Start a new family tradition.** Talk about the traditions that you or your spouse enjoyed growing up. Consider blending or modifying those into something that meets your child's needs. A launchpad of ideas include:

### HOLIDAY BAKING

If you loved family baking days when you were growing up, but your child is not quite ready for a full-blown baking session, try modifying the process. Include pre-made cookie dough, boxed muffin mixes and seasonal cupcake papers during a family bake session. Enjoy creating festive holiday mixes by blending a couple of cereals, some nuts and a bit of chocolate or peanut butter chips and serving in a fun holiday bowl. Your budding chef will enjoy the cooking and eating experience while working toward improving executive function through following directions and planning. They will increase motor skills while mixing and measuring their favorite recipe. Kids will also enhance mathematics concepts and skill through measurement and counting, as well as social connection, and even empathy through creating favored family treats and adjusting ingredients to needs or desires of others.

### BLENDING TRADITIONS

Shared experiences and adventures are a perfect way to create memories that will be talked about for years to come. Joining forces and combining traditions to support the needs of your child provides a great opportunity for compromise and respect. Play to your child's strengths and be ever vigilant about your child's needs and sensitivities. For example, if your child enjoys visual stimulation, ring in the holiday by taking a driving tour of the dazzling and twinkling Christmas lights. Encourage chats about the sights during the journey and, afterwards, around the tree at home, perhaps while sipping a warm beverage and enjoying a holiday treat. Your child will experience visual joy while building language and social skills. Is your child sensitive to sound? Bring along a set of noise-canceling headphones when shopping in crowded malls, attending parades, parties or caroling events.

### CRAFTING

Perhaps you grew up in a family with the tradition of creating handmade gifts and treats for one another, but these days, your time is limited. Try crafting together. Create ornaments or other keepsakes at your child's developmental level. Kids will love creating and sharing. In addition to family bonding through problem solving, laughing and creating together, increased executive function, language development, fine motor and spatial development are advanced.

As you journey mindfully through this holiday season, explore innovative pathways and scaffolds of support toward parental and child learning. These unique experiences and opportunities may create discoveries leading to resolutions for amazing possibilities into the New Year and beyond. •

### ABOUT THE AUTHOR:

Angela Shaw is a writer and retired special educator. Her son-in-law is active-duty military. Angela and her husband spend their time enjoying their military family and exploring the scenery along the way. With a writing focus on special education topics, Angela synthesizes her teaching experiences and education to support and encourage families and educators navigate the diverse learning needs of the children in their care across a changing educational landscape.

**MILITARY LIFE**

# EXPEDITE AIRLINE BOARDING WITH TSA PRECHECK

*The next time you get to the airport and see a long line at security, keep your shoes on and your laptop packed.*

Active-duty service members are eligible for expedited screening through the TSA PreCheck. You can board your flight quicker with TSA PreCheck at more than 180 airports nationwide – and you don't even have to be in uniform.

## WHAT ARE THE BENEFITS OF THE TSA PRECHECK PROGRAM?

When passing through airport security, program members don't have to remove the following:

- *Shoes*
- *A 3-1-1 compliant bag from carry-on baggage*
- *Laptop from its bag*
- *Light outerwear*
- *Belt*

## HOW CAN I USE MY TSA PRECHECK BENEFITS?

- *Use the Defense Travel System* (www.defensetravel.dod.mil/site/dts.cfm) *to book your flights when on official travel. Vacation flights can be booked through any airline or travel site.*
- *Enter your Department of Defense ID number (the 10-digit number on the back of your common access card) when asked for your "known traveler number."*
- *Save your Department of Defense ID number* (www.defensetravel.dod.mil/Docs/How_to_Enter_Your_DoD_ID.pdf) *in your Defense Travel System profile to make sure you're always signed up for the program when on official travel.*
- *Keep in mind if you're booking your flight through a commercial travel office that they are not required to ask for your known traveler number. Be ready to provide it on your own.*

Your TSA PreCheck eligibility information will be embedded in the barcode on your boarding pass. Some airlines print a PreCheck-approved indicator on your pass.

The bottom line: You can check your eligibility at a dedicated security lane as long as you enter your Department of Defense ID number as your known traveler number when you make your reservation.

## WHAT ELSE DO I NEED TO KNOW?

- Family members younger than age 12 can also pass through expedited screening if they're flying with you.
- Expedited boarding isn't a guarantee — TSA always reserves the right to incorporate random security measures to ensure passenger safety.

Get more information about TSA PreCheck by visiting www.tsa.gov/travel/frequently-asked-questions

*– Military OneSource*

# CYBERBULLYING: RECOGNIZING THE SIGNS AND HELPING YOUR CHILD

*Online communication offers a convenient way for military families to keep in touch with friends and family during deployments and throughout frequent moves. But with the amount of online communication taking place in today's world, there are some things to watch out for when it comes to keeping your children safe.*

According to cyberbullying statistics from i-SAFE Inc., a nonprofit leader in internet safety education, more than half of adolescents and teens have been bullied online, and about the same number have engaged in cyberbullying.

Given the prominent role technology plays in children's lives, it's important for parents to understand cyberbullying, be aware of where it can leak into a child's environment and explore resources and tools to help create a plan to prevent and address cyberbullying, whether their child is a target, a participant or both.

## WHAT IS CYBERBULLYING?

Cyberbullying is unwanted and repeated aggressive behavior that takes place through digital or electronic devices.

Stopbullying.gov adds that cyberbullying includes "sending, posting or sharing negative, harmful, false or mean content about someone else" and "sharing personal or private information about someone else" that brings them embarrassment and/or humiliation.

These virtual exchanges can be hurtful, and their effects can carry over to face-to-face interactions.

Cyberbullying can leak into your child's world through avenues such as:

- *Instagram, Snapchat, TikTok, YouTube, Facebook and other social media platforms*
- *Text messaging, email and messaging apps on phones, tablets and computers*
- *Online gaming communities, via voice or through messaging inside the game app*
- *Instant messaging, direct messaging, online chatrooms and various websites*

## BREAK IT UP : TIPS FOR ADDRESSING YOUR CHILD'S CYBERBULLYING BEHAVIORS

If you think your child may be engaging in cyberbullying, it is best to approach the situation with an open mind. As mentioned above, the roles played in virtual communication spaces can shift quickly. The goal is to explore, understand and correct cyberbullying behavior and prevent your child or teen from engaging in the behavior in the future.

- If you think your child may be engaging in cyberbullying, it is best to approach the situation with an open mind. As mentioned above, the roles played in virtual communication spaces can shift quickly. The goal is to explore, understand and correct cyberbullying behavior and prevent your child or teen from engaging in the behavior in the future.
- Maintain open communications with teens. Make sure they know they can come to you to discuss issues they're having with peers — online or offline.
- Ask questions so you can better understand specific situations. How did the interactions begin? Did they feel attacked or victimized? Is their behavior a form of retaliation?
- Be clear about what is acceptable and unacceptable behavior and the importance of demonstrating respect for others, in person and in virtual spaces.
- Help your child understand how it would feel to be the target of cyberbullying.
- Set up parental controls, if necessary, to monitor your child's online activities.
- Connect with other parents or seek counseling services for you or your child.

## STRATEGIES TO PROTECT YOUR CHILD AGAINST CYBERBULLYING BEHAVIORS

If your child is the target of cyberbullying, they will likely need your guidance in navigating the maze of securing cybersafety.

The first thing to do is find out what happened:

- *Talk with them to better understand the situation.*
- *Ensure that your children are (and feel) safe.*
- *Ask them calmly about the details of the situation — it's important to understand how it began, who said what and how the interactions escalated.*
- *Listen to how they feel and express empathy.*
- *Offer assurance that you will help them address the content and the bullying behavior.*

Together, you can take these and other steps to deal with the issue:

- *Do not respond to or forward messages.*
- *Block the person who is cyberbullying.*
- *Report the cyberbullying to the website, app or cellphone service provider* www.stopbullying.gov/cyberbullying/how-to-report
- *Keep a record of the messages that include dates and times as well as screenshots of bullying texts and comments.*
- *Change email addresses, screen names, phone numbers and passwords, as necessary.*
- *Consult with your school's administration if the bullying takes place during school hours or on school-issued devices. All 50 states have laws pertaining to cyberbullying, and those laws guide schools in dealing with these aggressions.*
- *Contact local law enforcement to report threats of violence, sexually explicit content, unauthorized videos and stalking.*

## SIGNS THAT A CHILD MAY BE CYBERBULLYING OTHERS

The roles all of us play in virtual space are fluid – it is easy to cross over from being the target of cyberbullying to being a cyberbully.

Be aware that this can happen easily, and it's important to get a handle on it quickly. Detecting whether a child or teen is engaging in cyberbullying is a little trickier than with traditional bullying, but youth may demonstrate similar behaviors to face-to-face bullying. Check out this article on how to identify and address bullying behaviors: www.militaryonesource.mil/family-relationships/parenting-and-children/parenting-youth-and-teens/how-to-identify-and-address-bullying-behavior/

Teens may be engaging in cyberbullying activities if they:

- *Switch off their screens quickly or try to hide their devices when you are close by*
- *Use or want to use their devices at all hours of the night*
- *Avoid discussions about what they're doing online, won't disclose with whom they're engaging or won't share what they're laughing about*
- *Show increases in behavioral issues at home or at school*

*Tips for addressing your child's cyberbullying behaviors*

Talk openly with your children about cyberbullying, keep a pulse on their online interactions and share strategies for dealing with the issue. By doing so, you can teach them to be aware of their behaviors and help them navigate difficult situations. For additional help, contact Military OneSource to speak with a child and youth counselor. Call 800-342-9646 to start a live chat.

*– Military OneSource*

U.S. MILITARY ★

# FOR MILITARY YOUTH & TEENS: THE ESSENTIALS

*As a parent, your job is to find activities for your youth and teens that will teach them life skills and build community without boring them or turning them away.*

It's especially important to engage military youth and teens in wholesome interests in which they feel safe and grounded. Military OneSource offers several ways youth and teens can build a sense of community, helping you keep your family strong. Here are some ideas:

## DISCOVER MILITARY KIDS CONNECT

Service families have access to an engaging website that helps youth and teens connect to an online community of other military kids, prepare for upcoming moves and have fun with interactive tools. The site offers forums for kids to share their own ideas, experiences and suggestions with other military children, resources for helping youth and teens appreciate military life, tours of your next installation and more. Military Kids Connect also has great information to help adults understand what it takes to support military youth and teens at home and at school.

**Relevant Articles:**

- *Getting the Most From Military Kids Connect:* www.militaryonesource.mil/family-relationships/parenting-and-children/parenting-youth-and-teens/getting-the-most-from-military-kids-connect
- *Helping Your Child Find a Mentor:* www.militaryonesource.mil/family-relationships/parenting-and-children/parenting-youth-and-teens/helping-your-child-find-a-mentor

**Relevant Resources:**

- *Military Kids Connect:* https://militarykidsconnect.health.mil/Caring-for-Our-Youth
- *Top Military OneSource Resources for Busy Parents:* www.militaryonesource.mil/family-relationships/parenting-and-children/parenting-youth-and-teens/top-military-onesource-parenting-resources
- *12 Can't Miss Parenting Resources for Military Parents:* www.militaryonesource.mil/family-relationships/parenting-and-children/parenting-infants-and-toddlers/12-can-t-miss-parenting-resources-for-military-parents

## EXPLORE THE BOYS & GIRLS CLUBS OF AMERICA

Your child may have countless friends on social media, but nothing beats that face-to-face interaction in a new environment. The military services work with the Boys & Girls Clubs of America to provide access to youth centers and clubs around the country. The program offers children between the ages of 6 and 18 a solid support network that provides a sense of belonging, ongoing relationships with caring adults and a safe and healthy environment to develop lifelong skills.

**Relevant Articles:**

- *Top Military OneSource Resources for Busy Parents:* www.militaryonesource.mil/family-relationships/parenting-and-children/parenting-youth-and-teens/top-military-onesource-parenting-resources
- *Military Youth and Teen Programs:* www.militaryonesource.mil/family-relationships/family-life/for-military-youth-and-teens/military-youth-and-teen-programs

**Relevant Resources:**

- *Boys & Girls Club of America:* https://bgca.org/about-us/military
- *4-H Military Partnerships:* https://4-hmilitarypartnerships.org

## TAKE ADVANTAGE OF OTHER YOUTH AND TEEN PROGRAMS

Check out programs exclusive to military families that keep your youth and teen engaged in inspiring activities. This includes installation youth centers, which offer access to everything from computer labs and music rooms to gyms and game rooms and more, to teen adventure camps – available for teens ages 14 to 18. These teen adventure camps partner with universities around the country and include wilderness excursions like sailing, kayaking and survival camps. Also, deployment support camps provide a safe space where your youth or teen can build a supportive network of other military youth who may have similar experiences.

**Relevant Articles:**

- *Military Youth and Teen Programs:* www.militaryonesource.mil/family-relationships/family-life/for-military-youth-and-teens/military-youth-and-teen-programs
- *Department of Defense Summer Camps:* www.militaryonesource.mil/family-relationships/family-life/for-military-youth-and-teens/department-of-defense-summer-camps

**Relevant Resources:**

- *4-H Military Partnerships:* https://4-hmilitarypartnerships.org
- *MilitaryINSTALLATIONS:* https://installations.militaryonesource.mil
- *Boys & Girls Club of America:* https://bgca.org/about-us/military

## HELP YOUR CHILD MOVE

Even though your military youth or teen is used to moving, he or she may still experience some apprehension. Military OneSource provides information for youth and teens to make the moving process smoother.

**Relevant Articles:**

- *Making the Move Easier for Military Kids:* www.militaryonesource.mil/family-relationships/parenting-and-children/parenting-youth-and-teens/making-the-move-easier-for-military-kids
- *Moving Overseas With Children:* www.militaryonesource.mil/moving-housing/oconus-moves/life-overseas/moving-overseas-with-children

**Relevant Resources:**

- *Focus on the Go:* https://focusproject.org

*– Military OneSource*

# Chores.

## A perfect moment to talk about alcohol.

Alarming numbers of pre-teens are drinking alcohol — which makes it urgent to find every opportunity to talk to your kids about the dangers of underage drinking. For tips on how — and when — to begin the conversation, visit:

**www.underagedrinking.samhsa.gov**

talk
they hear you

**PUZZLES & CAMO** SHELLY HUHTANEN

# Loss Through Transition

As I process this transition in our life as Hayden prepares to embark a new journey on his own, I try to remind myself that typical or not, a new journey is just that—a new path to take as we meander through life.

Last night, my oldest son, Hayden, and I worked on filling out college applications for next year. As we sat on the couch talking through his college essay and I listened to what he wanted to talk about when describing himself, I took the time to pause in order to stay in the moment. I've heard parents with kids in college say, "Blink and then you'll miss their senior year." They weren't kidding. I feel like I'm driving a car going 60 miles an hour. I am putting my foot on the brake, but the car won't slow down. I remind myself that I am not the only one who is feeling this way. I'm convinced the older my children are, the faster life goes by year after year.

A friend of mine shared a story the other day about filling out ISS (Individual Support Services) paperwork for her son who would be a senior in high school if he did not have his diagnosis. She expressed a sense of heaviness that came over her as she went through paperwork of his diagnosis when he was a toddler, "Throughout his life I've come to terms with his diagnosis and level of severity, but filling out ISS paperwork has weighed heavily on me. As I fill out his ISS paperwork, I should be helping him fill out his college applications."

It seems that each milestone of our children's lives, typical or not, we experience the pains of transition. The similarity between my experience filling out the college application with Hayden, and the experience my friend faced with the ISS application, is loss. I sense a loss when I come to the realization that I will not see Hayden's car in the driveway every afternoon when I come home from picking up Broden from clinic. I will miss Hayden's boisterous laugh through the thin walls of our home on post while he banters back and forth with his friends online. I think about Broden sitting on his bed not seeing his brother across the hall and eventually coming to the realization that his brother will not be there every day when he comes home from clinic. The days of Hayden surprising Broden in the parking lot to pick him up from clinic with Broden's favorite gummies in hand will dwindle. It will only be me seeing him in the afternoons, and I wonder if Broden will wish it was Hayden with a bag of gummies instead.

**MOVING THOUGHTS:** "I think about Broden sitting on his bed not seeing his brother across the hall and eventually coming to the realization that his brother will not be there every day when he comes home from clinic."

I can't imagine my friend's sense of loss who fills out the ISS paperwork for her son, instead of that college application, because when I feel loss with Hayden, I also experience excitement for his future and knowing that this is the time where his life begins a new chapter, a new chapter with less of me in it. He'll be on his own and truly have freedom to make his own choices. When filling out ISS paperwork, I can only imagine a sense of somberness with the realization that her child is also entering a new chapter, a new chapter that involves needed supports moving away from a path of a typical young adult.

As I process this transition in our life as Hayden prepares to embark a new journey on his own, I try to remind myself that typical or not, a new journey is just that – a new path to take as we meander through life. With Broden, I need to see his progress for truly what it is. It's progress. As Broden completes the first semester of his vocational rehabilitation program, he is now practicing on participating in an interview. The goal is for him to be on a team that prints t-shirts. Years ago, I would never have imagined him being placed on a team such as this one and I'm proud of how far he's come.

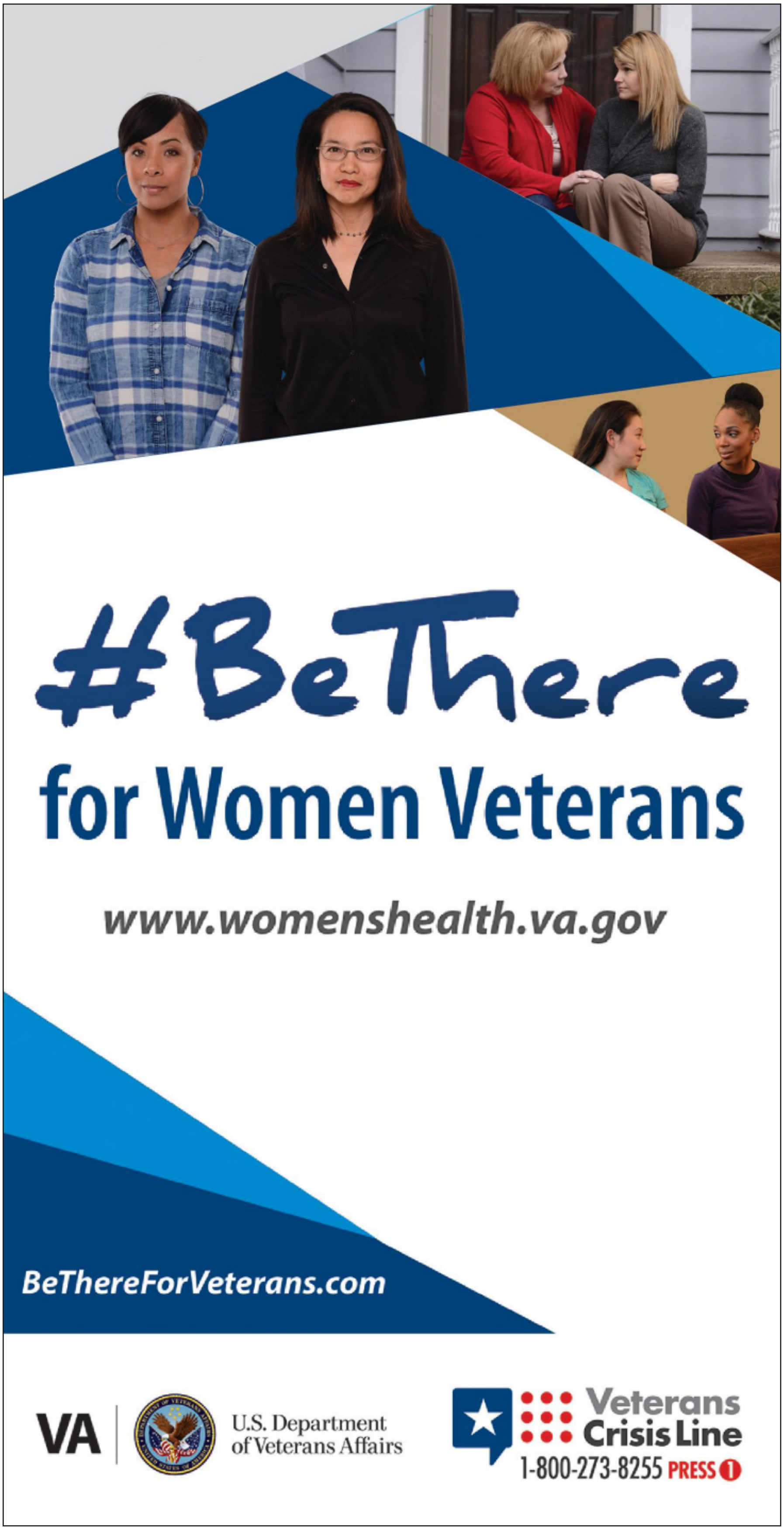
As I hear about Broden's progress and

participate in discussions about the work being done to encourage more expressive language and the training that will be involved so he can be an active participant on the printing press team, I look down the hall where the younger children with autism receive services. It feels like a lifetime ago when there were so many unknowns as to what the future was going to be for Broden or what it would look like. At fifteen years old, we soon will be possibly filling out ISS paperwork and experiencing a transition like my friend. Either way typical or not, there is a feeling of loss, but of a different kind. •

> "I sense a loss when I come to the realization that I will not see Hayden's car in the driveway every afternoon when I come home from picking up Broden from clinic. I will miss Hayden's boisterous laugh through the thin walls of our home on post while he banters back and forth with his friends online."

**PUZZLES & CAMO**

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



## ADAPTIVE/SPECIAL NEEDS BEDS

### KAYSERBETTEN

P: 800-574-7880
E: ruthann@kayserbettenus.com
W: www.kayserbettenus.com

*Designed to allow the child to be part of the surroundings while being safe and secure in their bed.*

## CLEANING/SANITIZING SOLUTIONS

### BANTEC SANITIZING

www.bantec.store.com

*Easy to use disinfecting products and safe, environmentally friendly hygiene strategies that are efficient and cost effective.*

## FINANCIAL PLANNING/ ESTATE PLANNING/ INSURANCE

### MASS MUTUAL SPECIALCARE

www.massmutual.com/specialcare

*Financial planning products and services by a company that cares.*

### THE AMERICAN COLLEGE OF FINANCIAL SERVICES

www.theamericancollege.edu

*A private college focused on professional training for financial practitioners*

## HOME ADAPTATION/DESIGN

### LJS ELECTRIC

www.ljselectric.com

*Home automation products and devices professionally installed.*

## NON-PROFIT

### IRENE AND ERIC SIMON BRAIN RESEARCH FOUNDATION

www.iesbrainresearch.org

*Helping to further research and find answers to addiction, pain and other brain diseases and disorders.*

## SCHOOLS/CAMPS/RESIDENCES

### THRESHOLD PROGRAM AT LESLEY UNIVERSITY

Cambridge, MD
W: www.Lesley.edu/threshold
P: 800-999-1959 ext. 8181; or 617-349-8181
E: threshold@lesley.edu

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