PLUS: **UNITED STATES MILITARY SECTION**

EXCEPTIONAL PARENT • PHYSICIAN • PATIENT • PEOPLE

EXCEPTIONAL PARENT
MAGAZINE
FEBRUARY 2022
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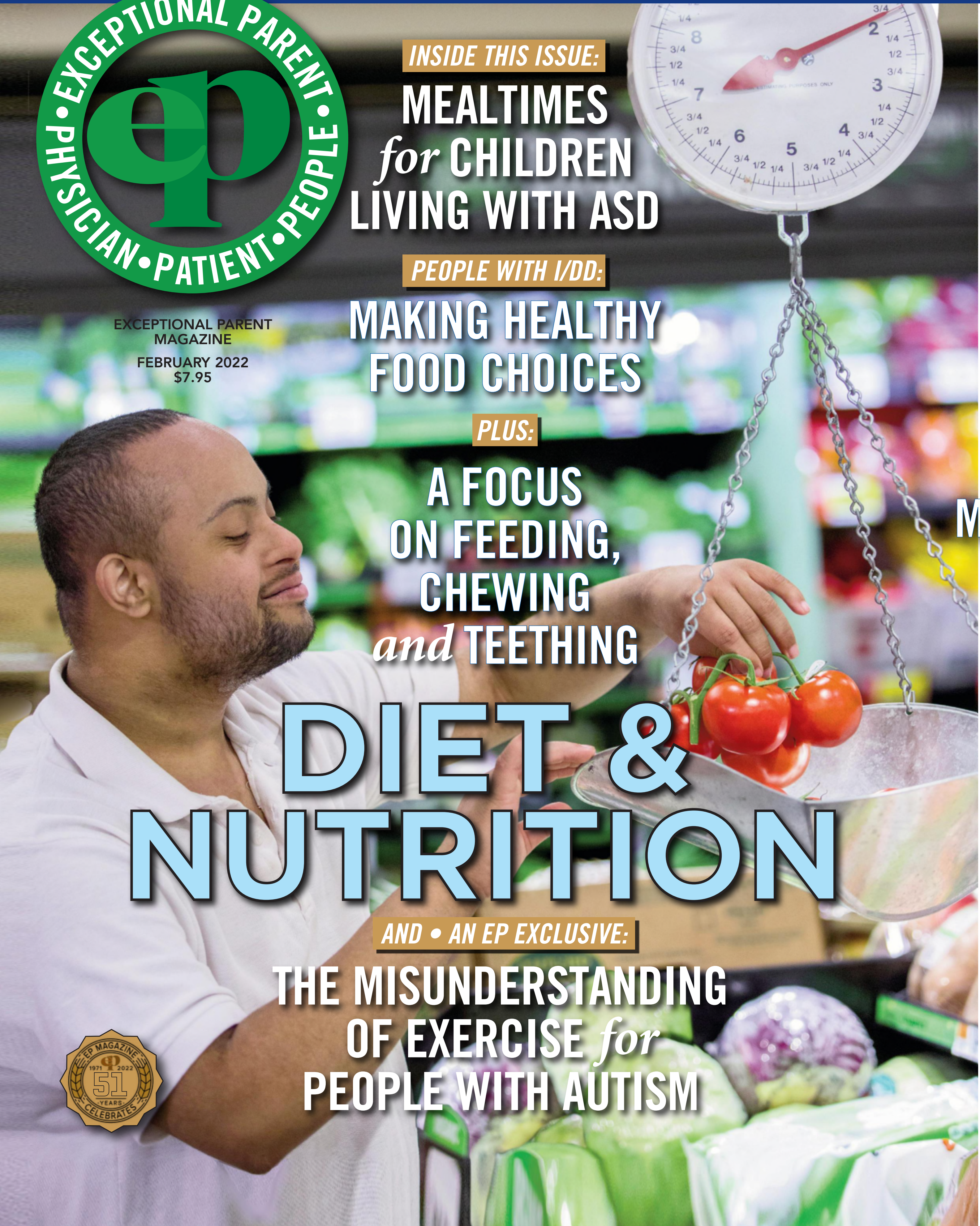

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PEOPLE WITH I/DD:

MAKING HEALTHY FOOD CHOICES

PLUS:

A FOCUS ON FEEDING, CHEWING *and* TEETHING

DIET & NUTRITION

AND • AN EP EXCLUSIVE:

THE MISUNDERSTANDING OF EXERCISE *for* PEOPLE WITH AUTISM

EP MAGAZINE
1971 2022
51
YEARS
CELEBRATES

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Information and Support for the Special Needs Community

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

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

"How lucky I am to have something that makes saying goodbye so hard."

~ Winnie the Pooh

Feel Free to Quote Me

After more than 20 years, several hundred editorials, articles, awards, and growth with *EP Magazine*, I will be retiring as the Editor-in-chief.

I love quotes.

When it comes to quotes, I can't help myself.

"I love quotations because it is a joy to find thoughts one might have, beautifully expressed with much authority by someone recognized wiser than oneself." (Marlene Dietrich)

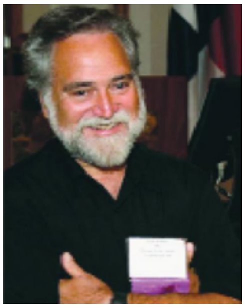
See what I mean?

For long-time readers of *EP*, that should come as no surprise. I have peppered (more like "oregano-ed") my monthly musings with insights from Hippocrates, Sir William Osler, Nelson Mandela, Florence Nightingale, Shakespeare, Plato, Martin Luther King, Helen Keller, Walt Disney, Mahatma Gandhi, Groucho Marx and Eleanor Roosevelt, among others.

So, it was a given that I wanted to find a suitable quote to oregano this month's editorial. My last one.

After more than 20 years, several hundred editorials, articles, awards, and growth with *EP Magazine,* I will be retiring as the Editor-in-chief.

"Life is full of goodbyes. People move, switch jobs, end relationships, retire, and ultimately leave this world." That, by the way, was a quote from the essay "Top 30 Farewell Quotes of All Time."



My departure is simply part of the formula that influences personal growth for all of us. I am not leaving the field of disabilities, or even reducing my time, energy and focus on the issues that face, challenge, plague and inspire the disability community. It's certainly not a decision (made popular by politicians leaving their posts) "to spend more time with my family" (a quote attributed to more public figures than we can count). While the disability community ***is*** "my family", there simply aren't enough hours in the day for me to spend more time with them. For 24/7 does have its stated constraints.

EP Magazine was among the first portals I encountered in the disability community. It was only after a few months of accepting

WINNIE-THE-POOH © THE WALT DISNEY CORPORATION

the position as the Director of the Morton J. Habilitation Center at Chattanooga's Orange Grove Center that I found myself at a national conference for intellectual and developmental disabilities in Wisconsin. I attended a lecture presented there by Exceptional Parent and was introduced to this resource, this forum for "information that counts from people who care" (*EP*'s tagline at the time). I knew I had to be a regular reader of this magazine to even have a hint as to the issues, power, goals and challenges of this growing movement. It was for me, and millions of readers over the decades, a place where things came together.

So back to the quote that I selected as my farewell quote. After reading scores of "farewell speeches" (including those by Shakespeare, Napoleon, Winston Churchill, M.L. King, Mother Teresa and Lou Gehrig), I found the one that best describes my current emotions.

> "I am leaving EP Magazine with contentment, appreciation, loyalty and allegiance. I have EP to thank for introducing me to thousands of dedicated and committed individuals who share both the burdens and opportunities to make a difference."

While not a poet, statesman, athlete or theologian, I found Winnie the Pooh expressed it best: "How lucky I am to have something that makes saying goodbye so hard."

That, in a nutshell says it all.

I am leaving *EP Magazine* with contentment, appreciation, loyalty and allegiance. I have *EP* to thank for introducing me to thousands of dedicated and committed individuals who share both the burdens and opportunities to make a difference. I have *EP* to thank for setting me straight, causing me to rethink and re-navigate my understanding of what really matters. And I have *EP* to thank for the opportunity to cry out, stand on a soap box and receive invitations to many inner circles.

I want to thank my colleague Vanessa Ira, our award-winning Managing Editor who continues to redefine "managing." For years, she has been primarily responsible for gathering the relevant, practical and indispensable content that readers craved, cried out for, and demanded. She is the personification of the quote, "The difference between involvement and commitment is like ham and eggs. The chicken is involved; the pig is committed." (Martina Navratilova; based on the business fable, The Chicken and the Pig, where "the chickens are the people who have something to say but usually have nothing to contribute." Whereas, "The pigs are those who are on the chopping block – the committed people who have stakes in the project and are essential to its success or failure.") I use this quote to describe Vanessa as the committed one; for sure she was, and I imagine, will continue to be committed to providing the disability community with what they deserve; access to information that they can use the very next day.

I have every assurance and confidence that I will find another soapbox and you will hear me continue to quote the great quotes. And while I personally want to thank Winnie the Pooh for providing a great farewell quote, it's probably also appropriate to quote another mentor of mine, Dr. Seuss.

"Don't cry because it's over, smile because it happened." •

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

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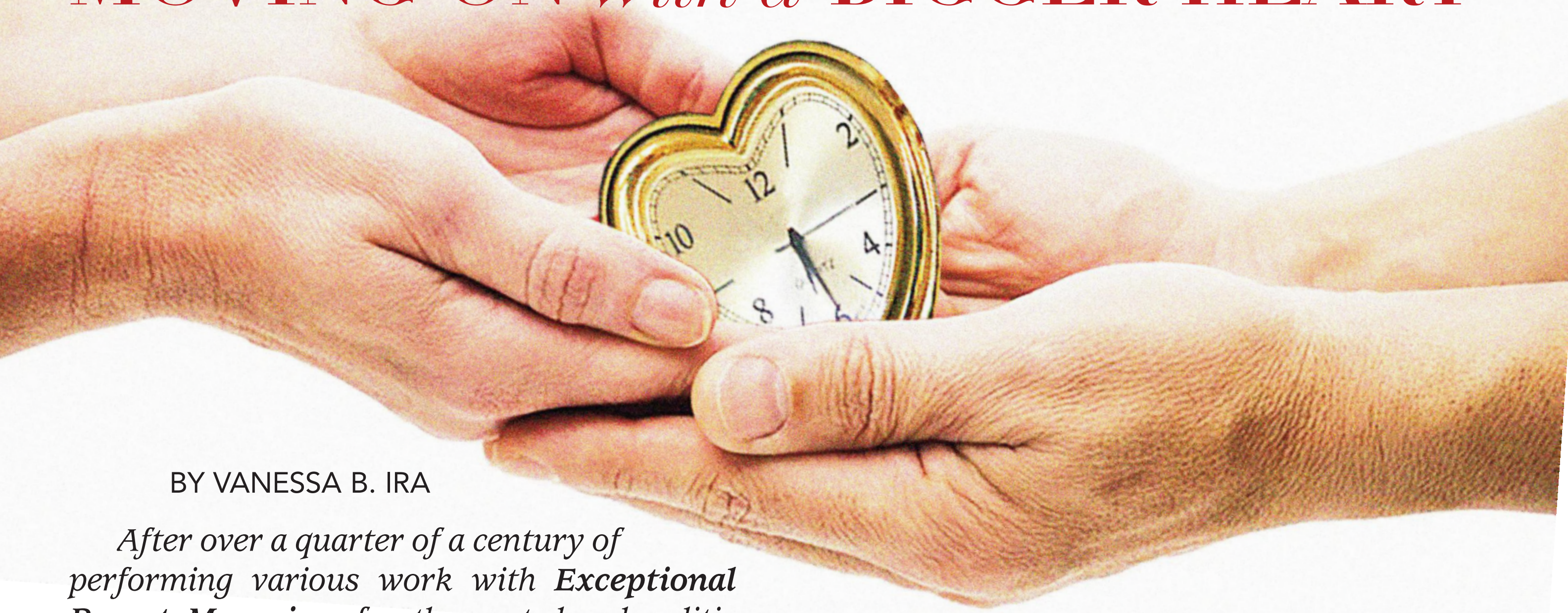

BY VANESSA B. IRA

*After over a quarter of a century of performing various work with **Exceptional Parent Magazine**, for the past decade editing and writing, I am moving on. The gold watch I take with me is the awesome blessing of having witnessed or read one story after another of individuals with special needs, their families, caregivers and advocates in the act of **giving**. They all **gave more** like no other people I've known in this world.*

Just recently, after I emailed one of my favorite regular *EP* writers, Shelly Huhtanen, about my plans to explore new adventures in life, she wrote back, "Here is my column for the month. I am so saddened by the fact that you are leaving. I have never met you in person, but I feel like I know you… Thank you for always allowing me to write and submit a column that reflected how I was feeling at the time. Writing is very therapeutic for me and I appreciate the opportunity of *sharing* my thoughts and lessons with others."

> "Remember that the happiest people are not those getting more, but those giving more."
>
> *~ H. Jackson Brown, Jr.*

Here is a mother of a teenage son with autism, Broden, who's had to deal with the constant change and stress that comes with being a Military spouse. Yet, she's never missed a deadline. She also never misses a day of giving the best life possible for her two sons and husband, as chronicled in her articles – articles that, she confessed, have given her the opportunity to *share* her thoughts and lessons with others. See what I mean by how people in this community *give* so much of themselves?

About four years ago, *EP Magazine* put Luke Rosen's daughter, Susannah, on the cover to help bring attention to the rare and degenerative pediatric disorder KIF1A (she was diagnosed in 2016). If you knew the story of Susannah and her crusader "Dadvocate", you'd know their story had to be told. For me, that was all the "reward" needed – I got to work with Luke and his family to help spread the word. Imagine my joy when I received this heartfelt message from him:

"It seems I owe you a bit more than a giant thank you for helping us raise awareness for Susannah's Disease. Yesterday we heard that Early Intervention rejected Susannah's application for expensive braces that the city is to pay for. We were floored, so were the doctors and therapists. I forwarded them the piece you so kindly did with the title 'safety for a child with severe movement disorder' and the caption under a picture of her braces. They amended their response immediately and she was approved without hesitation. They just needed to hear the story, or read it. Again, you have done so much for us."

"You have done so much for us." Really? No, it's the other way around! A former actor, Luke has been devoting most of his time, working tirelessly as founder and head of KIF1A.org, a nonprofit organization seeking to fund research for KIF1A. Recently, I read that Luke has stage 3 colon cancer. Yet again, there he was, relating his latest challenges with listeners of the podcast *Once Upon a Gene,* talking about his recent medical difficulties, down to his raw thoughts and feelings about what happens when a caregiver dies. *Giving*.

Through my work as managing editor for *EP Magazine*, I've been fortunate to follow the sage advice my father once gave me – "find something you like to do that will make you want to jump out of bed and eagerly face the world each morning."

My part through it all has been relatively easy, working with hundreds of authors of extraordinary lives. The ones who *gave*, at times, *even as they were hurting*. Because of them, I am moving on from *EP* with a bigger heart. Thank you. It's been the privilege of a lifetime knowing and working with all of you! •

ABOUT THE AUTHOR:

Vanessa B. Ira has been a member of the Exceptional Parent family for more than half of the magazine's 50 years of publication. She is currently EP's Managing Editor. Previously, she oversaw and managed EP's very first website, served as project manager for several successful healthcare webinars, and contributed to various business development efforts. She previously wrote a nostalgic piece, A Behind-the-Scenes Journey Through Half of EP's 50 Years, for EP's Anniversary edition: **https://reader.mediawiremobile.com/epmagazine/issues/207207/viewer?page=35**

CLARITY CHILD GUIDANCE CENTER FOR CHILDREN'S MENTAL HEALTH

TURNING LIVES AROUND: Clarity Child Guidance Center provides a continuum of mental health care to manage conditions ranging from ADHD and anxiety to suicidal ideation, bipolar disorder and/or schizophrenia. Clarity serves all children in need of care, regardless of their family's ability to pay.

Clarity Child Guidance Center is a nonprofit in South Texas providing a continuum of mental health care for children ages 3-17 and their families, to manage mental health conditions ranging from ADHD and anxiety to suicidal ideation, bipolar disorder and/or schizophrenia.

Clarity Child Guidance Center features:

- *Stand-alone mental health hospital on an eight-acre campus in San Antonio's South Texas Medical Center*
- *66-bed hospital and 6-bed Crisis Service unit offering specialized inpatient/outpatient treatment for children*
- *Serves all children in need of care, regardless of their family's ability to pay; more than 60% of patients are disproportionately low-income*
- *Offers the region's largest concentration of child and adolescent psychiatrists through a partnership with Southwest Psychiatric Physicians*
- *Serves as a teaching hospital for the University of Texas Health Science Center at San Antonio, Baylor College of Medicine, Incarnate Word Nursing College, and several other nursing schools*

Clarity CGC's continuum of treatment, intervention and prevention services include:

- *Psychiatric emergency care in 24/7 Crisis Services area;*
- *Inpatient treatment for children in crisis and/or children experiencing long-term complex problems;*
- *First Step appointments help caregivers recognize when a child's behavior escalates from age-appropriate challenges to mental health disturbances requiring professional help;*
- *Partial hospitalization (day treatment) during daytime; children return home in the evening to practice coping skills outside of the treatment setting;*
- *Outpatient therapies, including individual, group and family sessions;*
- *Wraparound services such as case management, medication management, education support and an innovative Play with Purpose™ therapeutic art and active play program;*
- *Next Step program helps families transition out of treatment by ensuring medications are filled; answering questions; helping with school re-entry; connecting families with resources food and clothing; and making follow-up care appointments;*
- *One in Five Minds online resource is free for parents, including articles, videos and handbooks;*
- *Collaborations with schools, churches, businesses and organizations.*

A December 2021 advisory from U.S. Surgeon General Dr. Vivek Murthy addresses the nation's youth mental health crisis "further exposed by COVID-19 pandemic," filled with alarming statistics that Clarity CGC is experiencing in real time:

- *Before COVID-19, mental health challenges were the leading cause of disability and poor life outcomes in young people, with up to 1 in 5 children ages 3 to 17 in the U.S. having a mental, emotional, developmental or behavioral disorder.*
- *From 2009 to 2019, the share of high school students reporting persistent feelings of sadness or hopelessness increased by 40%, to more than 1 in 3 students.*
- *Suicidal behaviors among high school students also increased during the decade preceding COVID, with 19% seriously considering attempting suicide, a 36% increase from 2009 to 2019, and about 16% having made a suicide plan in the prior year, a 44% increase from 2009 to 2019.*
- *Between 2007 and 2018, suicide rates among youth ages 10-24 in the U.S. increased by 57%, and early estimates show more than 6,600 suicide deaths among this age group in 2020.*

Besides Clarity's continuum of care cited above, CCGC develops many community partnerships and collaborations aimed at quality assurance, providing parent education, increasing children served, increasing children's mental health providers, and reducing duplication of services with partners and United Way partner agencies including:

- Reciprocate patient referrals with Center for Health Care Services, Hill Country MHDD Centers, Roy Maas Youth Alternatives, Stonebridge Alliance, San Marcos Treatment Center, St. PJ's Children's Home, The Cohen Clinic, Meridell Achievement Center and many others.
- "Food for the Soul" initiative allows volunteers to bring in and serve meals to the kids. Other volunteer opportunities (**www.claritycgc.org/get-involved**) include gardening, campus upkeep ("Caring for Clarity"), in-kind donation drives ("Bridge the Gap") to provide food and clothing, and an on-going Amazon wish list for clothing and educational supplies (**www.amazon.com/registries/custom/3O2VBGA8FTE8L**).

With the right treatment, the response rate for psychiatric disorders is high. Prevention programs and parental participation in treatment can reduce symptoms by as much as 60% in school age children; 81% of children with anxiety respond in as little as 12 weeks, and 86% of children experiencing depression improve within 36 weeks.

In FY20, Clarity CGC treated over 5,600 children with 18,497 inpatient nights, 6,860 day treatment days, and 27,255 outpatient visits. Children served resided predominantly in Bexar County with remaining from 48 other Texas counties and 7 states outside of Texas who could not find or afford services in their area. 60% were uninsured, under-insured, or low-income.

Clarity CGC accepts most insurance and accommodates families by billing them on a sliding scale based on their income. However, for uninsured patients, mental health treatment remains cost prohibitive, and insurance company reimbursements, especially for companies such as CHIP and Managed Medicaid, do not fully cover the cost of treatment. Day treatment is often completely excluded from coverage.

Clarity serves all children in need of care, regardless of their family's ability to pay.

Professional education and CEUs are offered at Claritycon, a children's mental health conferences sponsored by CCGC. Claritycon has three options for attendance: live in-person at studios of KLRN-PBS TV; live virtual; or digital on-demand. Registration is now open for the February 18 Claritycon from 8 a.m. to 1:30 p.m. featuring these experts in mental health and children; contact **events@claritycgc.org** or 210-593-2148, or visit **www.claritycgc.org/annual-conference-claritycon**:

- "Law Enforcement Working with Children and Adolescents: Perceptions, Strategies, and Future Development" - Brandi Burque-DeCarlo, PhD, a psychologist with the Bexar County Sheriff's Office, will explore the perceptions and perspectives of the importance of law enforcement interacting with children and adolescents in various environments, review potential future developments and how mental health providers can play a role in these interactions. She is responsible for providing psychological treatment for police officers and their families, teaching classes for the police academy, and on call with their Crisis Negotiation Unit.

In 2020, Clarity CGC treated over 5,600 children with 18,497 inpatient nights, 6,860 day treatment days, and 27,255 outpatient visits. 60% were uninsured, under-insured, or low-income.

- "Strong Families, Strong Forces: An Innovative Program to Support Family Systems" - Vanessa Jacoby, PhD, an Assistant Professor within the Department of Psychiatry and Behavioral Sciences at UT Health San Antonio and a Licensed Clinical Psychologist, provides clinical services to active-duty service members and their families for the STRONG STAR Consortium and the Consortium to Alleviate PTSD. She specializes in Cognitive Processing Therapy for PTSD and Prolonged Exposure.
- "Migrant Children" - Monica Faulkner, PhD, LMSW, is a Research Associate Professor at the Steve Hicks School of Social Work at The University of Texas at Austin and director/co-founder of the Texas Institute for Child & Family Wellbeing. She has worked as an advocate for survivors of domestic violence and sexual assault, and as a case manager for children in foster care. She worked in the Texas Legislature focusing on policy issues related to health and human services for two sessions. •

ABOUT THE CLARITY CHILD GUIDANCE CENTER

clarity child guidance center

Clarity Child Guidance Center's mission is to help children, adolescents, and families overcome the disabling effects of mental illness and improve their ability to function successfully at home, at school, and in the community. Those wanting more information can visit **www.claritycgc.org** or contact 210-616-0300 or **info@claritycgc.org**. Those wanting to donate can visit **www.claritycgc.org/give-now**

AMERICAN ACADEMY OF DEVELOPMENTAL MEDICINE & DENTISTRY

Different Perceptions of Individuals with Disabilities

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

> *"The degree to which persons with disabilities are accepted within a society is not directly proportionate to that society's financial resources and/or technical knowhow."* [1]

Historically, societal perceptions and treatment of persons with disabilities underwent dramatic changes. Among the ancient Greeks, the sick were considered inferior. In his *Republic*, Plato recommended that off-springs with deformities be put away in some "mysterious unknown places." Early Christian doctrine introduced the view that disease is neither a disgrace nor a punishment for sin but, on the contrary, a means of purification and a way of grace."[1] During the 16th century, however, Christians such as Luther and John Calvin indicated that individuals with intellectual disabilities and other persons with disabilities were possessed by evil spirits. These men and other religious leaders of the time often subjected people with disabilities to mental and/or physical pain as a means of exorcising the spirits.

In the 19th century, supporters of social Darwinism opposed state aid to the poor and individuals with disabilities. They reasoned that the preservation of the "unfit" would impede the process of natural selection and tamper with the selection of the "best" or "fittest" elements necessary for progeny.[1]

In some countries and regions, persons with disabilities are rejected or treated as economic liabilities and grudgingly kept alive by their families. In other settings, persons with disabilities are tolerated and treated in subsidiary ways. But in different cultures, they were given respected status and allowed to participate to the fullest extent of their capability.[1]

Variations in the treatment of persons with disabilities are evident in many nations and areas of the world and in other parts of the world.

AFRICA

Depending on the region, children with disabilities are seen either as a gift or punishment from God, or doing something evil during pregnancy. Epilepsy could be construed that the child is possessed or results as part of divine intervention.

- *Among the Chagga (Bantu speaking indigenous Africans and the third largest ethnic group in* ***Tanzania****) the physically handicapped are perceived as pacifiers of the evil spirits. Hence, care was taken not to harm the individuals with these disabilities.*
- *As to the citizens of* ***Benin*** *(formerly Dahomey in West Africa), constables are selected from those with obvious physical disabilities.*

In some communities, children born with disabilities are seen as protected by supernatural forces. As such, they are accepted because they are believed to bring good luck.

- *Among the Ga in* ***Ghana****, individuals with intellectual disabilities are treated with great kindness.*

AMERICAN ACADEMY OF DEVELOPMENTAL MEDICINE AND DENTISTRY

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

STATUS UPDATE: In certain cultures, persons with disabilities are given respected status and allowed to participate to the fullest extent of their capability. In the United Arab Emirates, they are referred to as "people with determination;" This describes the character of the individuals and the government to bolster the traditional image of the "handicapped."

- *Most **Ugandans** regard disabilities, and particularly mental illness, as a curse, and many are taken to the* abafumu *(traditional healers) for treatment. Uganda, in 2006, passed the "disabilities act" that gave rights to these persons; however, not much has been implemented.*[1]
- *"70 percent of people in **Nigeria** believe mental disabilities are caused by evil spirits. Many people believe that psychological disorders are like every other illness."* [2]
- *In countries where under-age-five-years mortality rates have decreased below 20 percent, the mortality proportion for children with disabilities could be as high as 80 percent. The United Kingdom's Department for International Development suggested that it seems as though kids with disabilities **are being "weeded out."*** [1]

SIGN OF THE TIMES: Updated symbolic images for individuals with a disability emphasize the person rather than the wheelchair.

ARABIC COUNTRIES

"To those familiar with Arab culture, it is no secret that the topic of disability remains a taboo. When speaking about disability in the Arab world, generally, the topic is either met with silence, ignorance, or able-bodied people expressing their sympathy. This does nothing short of continuing the stigma and perpetuating ignorance surrounding disability."[3]

> *"**(However,)** overarching institutional and legislative frameworks on disability have expanded significantly in the Arab region over recent years… their establishment…represents an important development in national efforts to protect and promote the rights of persons with disability."*[4]

UNITED ARABIC EMIRATES

Individuals with special needs are referred to as **"people with determination."** This describes the character of the individuals and the government to bolster the traditional image of the "handicapped." The increasing use of the new symbolic image for individuals with a disability emphasizes the person rather than the wheelchair *(See images, left)*.

MORE FACTS ABOUT INDIVIDUALS WITH DISABILITIES IN DEVELOPING COUNTRIES

- **80 percent** of people living with a disability reside in developing countries, and most of them have limited access to healthcare. The World Bank has estimated that **20 percent of the world's poorest people have some kind of disability.**
- When mothers **lack access to healthcare during their pregnancy,** the odds that their child will have a disability increases. Additionally, some permanent injuries are caused by civil conflict, dangerous working conditions, and environmental hazards.
- People with disabilities living in developing countries **have lower levels of educational experiences.** UNESCO reports that 90% of children with disabilities in developing countries do not attend school. [5,6]
- Women with a disability are considered multiply-disadvantaged because they are excluded on two counts: **their gender and their disability.** This population is especially vulnerable to

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abuse. A study in Orissa, India found that almost all women and girls who had a disability had been beaten at home, 25 percent of those with intellectual disabilities had been raped and 6 percent of those with a disability had been forcibly sterilized.

- **Only 45 countries** in the world have anti-discrimination and other disability-specific laws and far too few countries have programs and services that support this vulnerable group.[5]
- Children with disabilities **receive harsher punishment** across the developing world, based on interviews with nearly 46,000 caregivers in low-to-middle-income countries.

IT CAN GET COMPLICATED

"Vilma lives in the small town in the Patacancha Valley in Peru. At 25 years of age, Vilma suffers partial blindness, along with other cognitive ailments, stays home alone for hours at a time while her single mother works to provide for them. Vilma's problems are more than just superficial; an inaccurate birth certificate has prohibited her mother from receiving government assistance. Vilma's life would improve vastly with an amended birth certificate, but the cost and time associated with wading through an implacable bureaucracy has proved to be unaffordable to her mother… In addition to growing populations and the many countries' inability to properly care for their disabled, many families lack the resources to care for their family members or ***they are humiliated that they have a disabled child"*** (emphasis added). [7]

> "Only 45 countries in the world have anti-discrimination and other disability-specific laws and far too few countries have programs and services that support this vulnerable group."

HOW DO WE STACK UP TO THE REST OF THE WORLD?

France: There are housing benefits available, as well as support for parents caring for a child with a disability – including help with education and paying for a caregiver. Companies with more than 20 staff members are required to have at least 6 percent of their workforce comprised of people with disabilities.

Germany: Children with a disability are covered under Germany's health insurance. Other measures to assist people with disabilities include:

- *Incentives for companies to employ people with disabilities*
- *Offering housing benefits and home modification to accommodate a person's needs*
- *Free public transport*
- *Home care assistance*

Russia: Russians with disabilities have many obstacles to overcome. In addition to surviving the logistics of Russia's notorious winters and infrastructure, other difficulties include workplace discrimination, lack of access/accommodation, and low payouts for those out of work. Russia has laws protecting people with disabilities in place, but actually **enforcing them and taking action** is what really counts.

Italy: Individuals with disabilities can get tax breaks to buy things like disability-friendly vehicles and home accommodations. However, **Italians with disabilities have a high rate of poverty.**

> *"Compared to the United States, wealthy European nations (and Scandinavian countries like Norway, Sweden and Denmark) tend to have more generous disability benefits and larger social safety nets in general."* [8]

NEVERTHELESS

> *"Parents may believe that children with disabilities won't respond to less harsh forms of discipline. Or they may be frustrated, and may not know what else to do."* [9]

> *"People with disabilities in third world countries are left to beg or live off the kindness of others. People with disabilities in the USA are educated, trained to work, and protected from discrimination (thanks to tax-funded programs like Public Education, the Rehabilitation Act and Americans with Disability Act)."* [10] •

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ORGANIZATION SPOTLIGHT

THE ARC NORTHERN CHESAPEAKE REGION

Where Employees Get More Value from Their Jobs than Just a Paycheck

If the post-COVID world has taught us anything, it is the fact that "work" needs to be more than a way to collect a paycheck. Many workers have left their jobs searching for better opportunities that will enhance their personal life goals. As a result, many industries are facing a worker shortage. However, employees at The Arc Northern Chesapeake Region are quick to say WHY they love their jobs. The fact that they feel "valued' repeatedly tops the list.

BETTER TOGETHER: The Arc Northern Chesapeake Region has helped people with differing abilities build better lives one person at a time, empowering them to live, work and thrive in the community.

Kristen Schnell found that value very quickly at The Arc NCR. Schnell, a Case Manager, has been employed there for four years. She explained, "The Arc NCR is not just another workplace, it's a career in which I get to help others grow and succeed, and in turn, I succeed myself." Schnell plans to stay for a very long time, "this (is) a lifelong career that I could embrace to really help others."

The mission of The Arc NCR is clear; it helps people with differing abilities build better lives one person at a time. The Arc NCR supports individuals and their families over "The Arc of a Lifetime' by empowering people with differing abilities to live, work and thrive in the community.

Case Manager Leslie Kydd has also found job satisfaction and growth opportunities at The Arc NCR. Kydd explained, "The Arc NCR encourages and promotes personal development and serves as a model for it. Every day, I go to work knowing that I am valued and that I make a difference."

Many of The Arc NCR employees have also found value in watching the impact they can have on other people's lives. For example, Hillary McArthur, a Psych Support Specialist, has worked at The Arc NCR for eight years and is passionate about her role. McArthur explains, "Being part of the reason, someone thrives, communicates effectively, reaches a goal, or any other awesome thing that happens is the motivation that keeps me employed here."

Madicella Martinez also appreciates seeing progress in others as a value that can't carry a price tag. The Advocacy and Database Manager eagerly explained, "I work at The Arc NCR to see change happen in people's lives. We all have our own stories to share, and the people we support often share much more with the world than people realize."

The Arc NCR employees have the unique opportunity to work flexible schedules, gain crucial work experience, and even earn tuition reimbursement. Martinez encourages everyone to apply for jobs at The Arc NCR, "This community is not found everywhere, and I'm grateful to be part of it!"

The pandemic has created a greater need for services offered by The Arc NCR. Many valued employees, like Alice Mbugua, began their careers as Direct Support Professionals (DSP's). Mbugua explained, "I like working here so that I can make a positive impact on the individuals I support, it's my passion."

Another Direct Support employee, Celine Goins, echoes the same sentiment, "What drives me is putting myself in our clients' shoes and giving them new experiences. Seeing smiles is what is encouraging me to plan the next outing or project."

The Arc NCR offers qualified job applicants an opportunity to empower people with differing abilities to thrive at home and in the community. Benefits include:

- *Paid orientation and onboarding*
- *Professional certification opportunities*
- *Tuition Reimbursement (including CNA/GNA certification support)*
- *Insurance plans for health, dental and vision coverage*
- *Flexible spending accounts, 403b/Retirement, agency and supplemental life insurance and disability insurance, and a variety of banking options*
- *Employee Assistance Program with a 24/7 hotline, various wellness activities/initiatives, and educational opportunities on well-being*
- *Up to $6,000/year in educational and financial growth through our Direct Support Professional certification program*

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ABOUT THE ARC NORTHERN CHESAPEAKE REGION

The Arc
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For close to 70 years, The Arc Northern Chesapeake Region has empowered people with differing abilities to live, work and thrive in our community by providing support services and advocacy to adults and children and their families in Harford and Cecil Counties. For more information, call 410-836-7177 or visit **www@arcncr.org**

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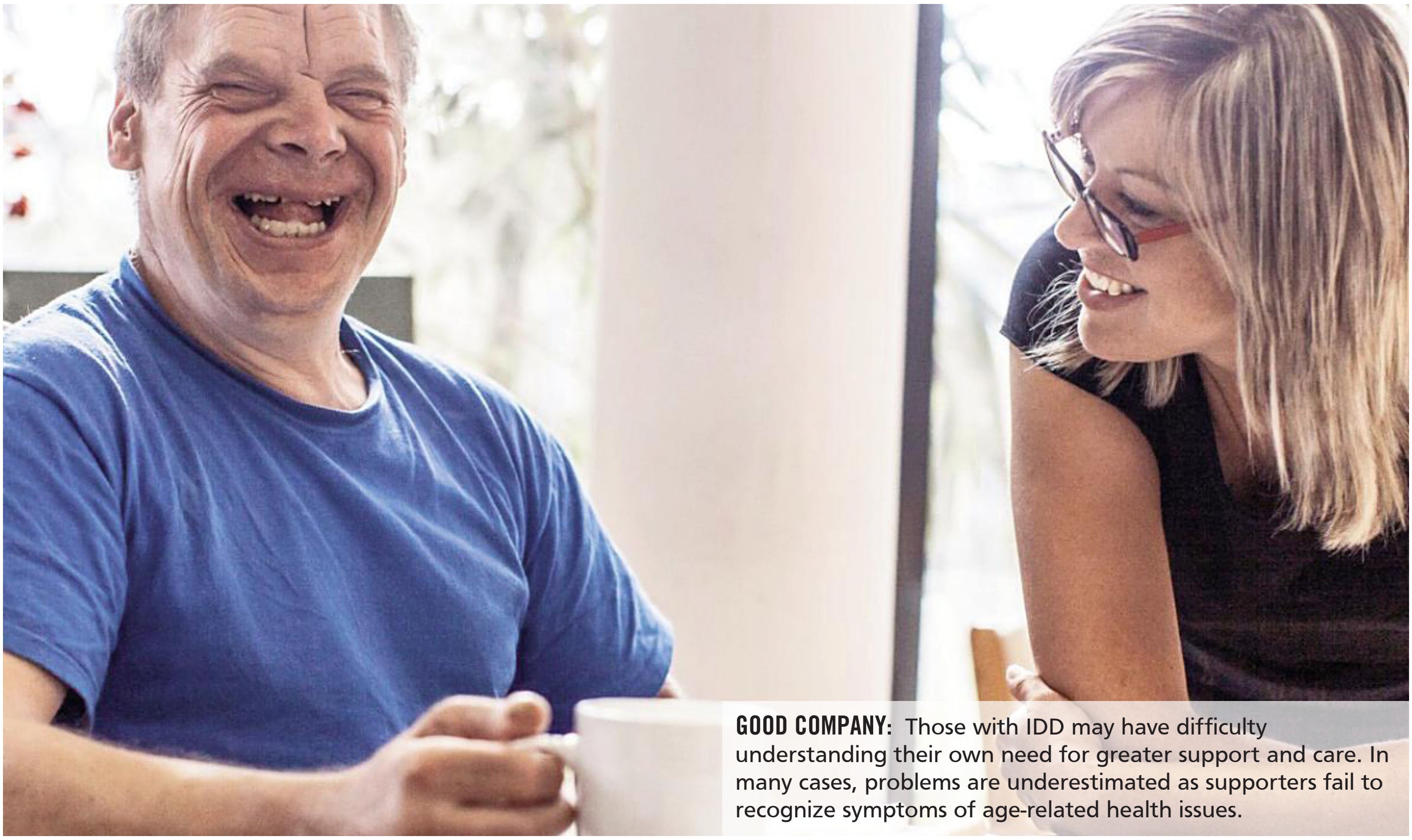

GOOD COMPANY: Those with IDD may have difficulty understanding their own need for greater support and care. In many cases, problems are underestimated as supporters fail to recognize symptoms of age-related health issues.

AGE-RELATED MEDICAL CONDITIONS GOING UNRECOGNIZED, UNTREATED IN PEOPLE WITH IDD

SUBMITTED BY INTELLECTABILITY

The population of the United States is getting older quickly. By 2050, it's projected that approximately 90 million adults will be over age 65.[1] *By 2030, it's anticipated that one in five Americans will be 65 years old or older.*[1] *These estimates include a large number of people with intellectual and developmental disabilities (IDD).*

EP FEATURES A LIFESPAN OF HEALTH

People with IDD are just as likely to suffer from the same age-related ailments as any other person. Dementia, Alzheimer's disease, arthritis, vision and hearing loss, and many other chronic health conditions affect large numbers of people with IDD, but signs of those problems often go unnoticed by supporters.

Dr. Craig Escudé, President of the IDD education and training firm IntellectAbility, says, "Since people with intellectual and developmental disabilities are living longer, we have to shift to ensure we're addressing all the factors that affect individuals as they get older. Supporters need to learn to recognize how chronic conditions like dementia might appear differently in a person with IDD."

According to the Association on Aging with Developmental Disabilities, the average lifespan of a person with IDD is approximately 70 years old – fairly close to the average American's projected lifespan of 77 years.[2] But little is known about how these individuals' lives change over time.

As with anyone else, it's important for a person with IDD to continue living on their own terms. That includes maintaining health and maximizing function, as well as reducing the impact of chronic diseases.[3] But those with IDD may have difficulty understanding their own need for greater support and care, while also struggling to communicate with others about that need. In many cases, problems are underestimated as supporters fail to recognize symptoms of age-related health issues.[4]

Dr. Seth Keller, Past President of the American Academy of Developmental Medicine & Dentistry, co-President of the National Task Group on Intellectual Disabilities and Dementia Practices, and Chair Adult IDD Section of the American Academy of Neurology, says, "You must know the individual's activities and abilities and see if there are any changes. Supporters must collect detailed information on how, when, and under what circumstances the changes are occurring. But don't jump to conclusions – it might be normal aging or changes in social environments and the person with IDD is just reacting to that. Or, it could be a social decline, not a physical one. Supporters must recognize these factors, and that's where training comes into play."

RECOGNIZING SIGNS OF AGE-RELATED ILLNESS IN PEOPLE WITH IDD

Unfortunately, people with IDD often show signs of earlier medical, functional, and psychosocial changes compared to those without IDD.[5] With those changes comes a variety of symptoms which may be mistaken for behavioral changes in a person with IDD, especially if that person doesn't use words to communicate. Signs of age-related illness might include:

- *Distancing themselves from others*
- *Increased fear*
- *Loss of interest in daily activities*

But people with IDD are also at higher risk for cognitive conditions like dementia or Alzheimer's. Signs of these diseases might include:[3]

- *Aggressiveness*
- *Hoarding*
- *Late-onset seizures*
- *Personality changes*
- *Sleep disturbances*
- *Forgetfulness*
- *Incontinence*
- *Loss of skills*
- *Wandering*
- *Verbal outbursts*

It can be extremely difficult to recognize these problems as symptoms of a disease, especially if a supporter hasn't had sufficient training. Supporters include family members, paid staff such as direct support professionals, and can also include anyone in the medical field, such as doctors and nurses who help a person with IDD achieve a better quality of life. IntellectAbility's Health Risk Screening Tool is designed to identify risk factors for conditions that worsen with aging. Also, training in person-centered support can help supporters become more aware of possible age-related symptoms they may encounter in a person with IDD.

Mrs. Pamela Merkle, Executive Director of the Association on Aging with Developmental Disabilities, says, "Some disability behaviors can be mistaken for dementia. It is imperative that the clinician look at the medical factors first and rule out physical changes. As for the supporters, they have to trust their gut when it comes to changes. Aging happens to everyone; one has to look at the social as well as the physical before making any decisions."

Aging in individuals with IDD is the same as in any other person. But certain factors can make it difficult to recognize the signs of aging, especially if the person with IDD doesn't use words to communicate. For people with IDD who live independently, they may or may not grasp that they have a health issue. That's why any supporter must be educated and trained to seek help whenever even the smallest issues are noticed. As it is now, many supporters misinterpret the symptoms a person with IDD shows, leading to potential misdiagnosis and unnecessary or improper treatment.

Dr. Keller says, "Parents and other supporters need to be aggressive in their healthcare and not wait until the individual with IDD is older. They should establish a medical foundation early so that the person can age well."

To build an effective medical foundation, healthcare professionals must first recognize the value of a person's life, regardless of their level of disability. They must strive to provide the same level of preventative care that's offered to people without IDD. That includes bolstering a person's sense of purpose. Part of the person-centered approach to care for people with IDD, Dr. Escudé notes, includes involving them in activities they deem valuable to their own lives. Supporters may include a person in social activities and events which help connect those individuals with the community. Ultimately, this boosts a person's quality of life. Those activities should continue even if a primary supporter isn't up to the task anymore.

Another factor to take into consideration is that just as the individual with IDD is aging, so too is the supporter. Often, the supporter – especially if it's a parent – will predecease the individual with IDD. Mrs. Merkle says, "One thing that cannot happen after the loss of a supporter is to isolate the individual with IDD. That can lead to depression, regression, and even suicide." Society can help prevent these issues by continuing to involve people with IDD in activities they enjoy with others in their community.

Aging is simply a fact of life, and everyone eventually experiences health issues, but it's often worse for people with IDD. However, thorough training can help ensure that medical professionals and other supporters can recognize signs of age-related illness. That way, problems can be addressed sooner so the person isn't impacted over the long run.

"We need to treat people with disabilities the same as everyone else and remove the stigma that's associated with this group. We need to remove any and all fears of interacting with people with IDD to help create communities in which all members are valued for who they are," Dr. Escudé says. •

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ABOUT INTELLECTABILITY

IntellectAbility
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IntellectAbility provides tools and training to agencies, governmental entities and supporters of people with intellectual and developmental disabilities to foster early recognition and mitigation of health risks thereby improving health and wellness. IntellectAbility also provides numerous health-related and person-centered service trainings for supporters of people with IDD. Learn more at **https://replacingrisk.com**

CONGENITAL HEART DISEASE IN DOWN SYNDROME

STRAIGHT FROM THE HE♥RT

BY DOREEN BESTOLARIDES, RN

The cicadas chirped outside the classroom in rural Northeast Ohio. The nursing instructor proctoring the Pediatrics test said, "Don't worry too much about that question on 'Tetralogy of Fallot' because you will never see it in your lifetime. These children typically die."

That was a profound statement, given the fact that I studied my brains out preparing for this exam and, more important, the mournful reflection of that statement.

Fast forward 10 years, when the real-life test began, and the proverbial cicada chirping visual surrounded me. I was now happily married and, following two painful miscarriages, was now early in the third trimester of my third pregnancy. As fate would have it, I went into labor during my shift working as a critical care nurse. Emergently, the staff paged the obstetrician who required convincing that he really did have a patient in the unit, that was me, the unit First Line Supervisor.

My son's premature birth was not entirely distressing because, on that particular day, it was my father's birthday. My father had a malignant metastatic brain tumor and our son was to be his namesake, "Danny," so that date would remain meaningful. Following an uneventful labor, there was a delay in seeing our newborn. As a nurse, I was able to hear and decipher some of the hospital staff's chatter in the hallway. As a new parent, I was terrified. Not only were we informed that our son had some physical characteristics of Down syndrome but also had a dangerous heart murmur. He was having episodic periods of cyanosis, or turning blue, in the nursery. Following a myriad of diagnostic testing, came the second diagnosis… Tetralogy of Fallot. The essence of my soul skipped a beat.

HEART AND SOUL: Danny at home; The transition to adulthood for people with Down syndrome and CHD is an important factor to consider to promote overall wellness, prevention of complication and timely access to life saving or palliative treatments.

Tetralogy of Fallot (TOF) is a complex congenital heart defect named after the French physician Etienne-Louis Arthur Fallot, who published the description in 1888. It manifests as four abnormalities: ventricular septal defect (VSD), right ventricular outflow tract (RVOT) stenosis or narrowing, enlarged right ventricle (lower chamber of right side of heart) and overriding aorta (aorta is the main artery that carries blood away from the heart to the rest of the body and in TOF, it lies directly over the VSD). The consequence is resulting blue skin color and mucous membranes due to lack of oxygen. Difficulty breathing and feeding are early problems. My son would require very brief, small feedings and had episodes of "TET spells" developing blue skin and lips caused by rapid drops of oxygen in the blood. The only life-saving intervention was intra cardiac repair to correct the structural defects. Because the heart is both mechanical and electrical, heart irregularities or arrhythmias may occur later, from scar tissue. Timing of surgery is dependent on symptoms and supplemental oxygen is of limited value, as the primary abnormality is decreased pulmonary (pertaining to the lungs) blood flow.

The challenge of primary significance began with securing a cardiology specialist and the timing of surgical intervention. Like most rural hospitals, advanced medical care may be several hours and hundreds of miles away. Our situation was no exception. An unexpected challenge was responding to a remark by a "healthcare professional" inquiring why I would consider surgery on "a retarded child." Really? No congratulations on my new baby? It occurred to me that those very perceptions and attitudes were the antiquated foundation, regarding people with developmental disabilities and complex medical needs.

Congenital Heart Disease (CHD), once fatal in childhood, is now dramatically improved in ability to repair defects. Understanding of cardiac health and implications in Down syndrome is a requirement for strategizing optimum screening to coordinate person and family centered objectives with the goals for lifelong care manage-

PHOTOS PROVIDED BY DOREEN BESTOLARIDES

ment. Continuous health monitoring and functional status, for those with CHD is imperative. Some families are not provided adequate teaching, including to continue cardiac follow up throughout the lifespan. Despite a background in cardiac care, there were limited to no resources regarding CHD and travel to the nearest CHD specialist was a grueling two hours away. The TET spells became more frequent and more severe up to 2 ½ years old, when surgery was then emergent.

WALKING THE WALK: Danny was a proud participant in 2021's NDSS New York City Buddy Walk; This November, Danny will be 33 years old. He enjoys socializing and going out to breakfast with cousins and "is the happiest guy I know."

Down syndrome occurs when an individual has a full or partial copy of chromosome 21. There are 47 chromosomes in each cell instead of 46. Down syndrome is a major cause of CHD. 65% of heart defects are atrio ventricular septal defects. The additional genetic material alters the course of development. In the general population, mutations in 6-8 different genes are required to produce a heart defect. Characteristic heart defects derive from the abnormal development of the endocardial cushions (two areas of thickening that eventually develop the wall of the heart that separates the 4 chambers).

The common heart defects in Down syndrome are Endocardial cushion defect, A-V septal defect, ventricular septal defect, Tetralogy of Fallot, and others.

The biology of the lungs in Down syndrome are significant due to the smaller amount of the lung's functional unit, called alveoli, where gas exchange takes place between air in the lungs and the blood in the tiny capillaries of the lungs. These changes are important to the understanding of cardiopulmonary issues, respiratory tract infection, aspiration, and immunity. Genetically, the influence of Trisomy 21 on the immune system may impact the risk for viral and bacterial infections and cardiopulmonary function. Differences include a narrow upper respiratory tract, smaller trachea, hypotonia, and lung vascular issues.

UNDERSTANDING OF CARDIAC HEALTH AND IMPLICATIONS IN DOWN SYNDROME IS A REQUIREMENT FOR STRATEGIZING OPTIMUM SCREENING TO COORDINATE PERSON AND FAMILY CENTERED OBJECTIVES WITH THE GOALS FOR LIFELONG CARE MANAGEMENT.

According to the 2018 American Heart Association scientific journal *CIRCULATION,* patients with CHD are not cured of their disease after successful treatment in childhood. Almost all patients with Adult Congenital Heart Disease will have sequela of either their native (original) CHD or it's surgical repair or palliation, although these sequelae can take decades to manifest.

CHD requires long-term monitoring, regular cardiology follow-up, understanding of consequence for a particular defect or repair and endocarditis prophylaxis. Bacterial Endocarditis is a serious and sometimes fatal bloodstream infection, affecting the heart's inner lining and often involving the heart valves. It can occur with common daily activities (tooth brushing/flossing/ chewing food, etc.), poor dentition and prior endocarditis.

People with CHD are at high risk for developing bacterial endocarditis. Symptoms include fever, chills, unexplained rashes, nailbed hemorrhages, painful sores, muscle aches, fatigue and possible red spots on palms/feet. Management includes recognizing signs of symptoms and prompt medical care. Heart valve vegetations can cause emboli (blood clot), damage heart valves and require open heart surgery. Lifelong care includes carrying a descriptive card, ongoing follow up with an Adult Congenital Disease Cardiologist, advocating to obtain blood culture samples BEFORE antibiotics, and providing prophylactic antibiotics prior to dental or invasive procedures. These guidelines are outlined by the American Heart Association/American College of Cardiology evidence-based management of adults with CHD.

One year following our son Danny's correction of TOF, he developed septic shock, multisystem failure with poor cardiac function, and an enlarged liver that compressed his right ventricle. The physician noted "it is unfortunate that he received so many antibiotics prior to hospitalization, because it has clouded the picture for us." Subsequently, multiple blood clots impaired the function of his spleen and he spent one month in Intensive Care at a tertiary medical center.

Fortunately, he recovered and spent many years catching up with things like learning to walk and eventually going to school.

In 2016, at age 27, he developed increased respiratory infections and fatigue. As a result of his TOF repair as a child, he had developed severe pulmonary regurgitation, severe RV dilation and "challenging anatomy."

Cardiac conferences were held between two medical centers. Evolving technology became a promising option for Percutaneous Interventional Cardiology, as an alternative to Open Heart Surgery, although medically feasible decisions are criteria driven. less invasive hybrid Cath lab procedure was promising, the Transcatheter Pulmonary Valve Replacement (TPVR) for our son was unsuccessful as his pulmonary valve sizing was suboptimal for adaptability of the necessary equipment. These procedures are not without risk and long-term data is evolving. The first transcatheter pulmonary valve in humans was in the year 2000. Now, transcatheter valve procedures are becoming more readily available in hospitals with Interventional Cardiology programs and the technology is rapidly improving.

> DANNY'S INCREDIBLE JOURNEY HAS ENCOURAGED ME TO DO BETTER. EVERYONE HAS A STORY. WE ARE ALL HERE FOR A SPECIAL PURPOSE.

The transition to adulthood for people with Down syndrome and CHD is an important factor to consider to promote overall wellness, prevention of complication and timely access to life saving or palliative treatments. Improved understanding of how gene expression affects cardiac function, improved health screenings and access to care are hallmark for improving the lives of people with CHD. Partnering with families and health teams is essential for promotion of inclusive equitable care for this vulnerable population. Working with health professionals to help with understanding and accommodation, will improve the clinical experience of enduring necessary screening tools as EKG's, Echocardiograms, Cardiac CT scans, lab work, etc.

CHD was recognized and became a subspecialty for Physician Board Certification in 2016. Sharing experiences, knowledge and resources becomes our strongest asset when advocating for our children. Coordinating and working side by side with an interprofessional health team ensures safety, quality and best practices.

Last year, we celebrated Danny's 30th Heart Anniversary since his initial cardiac repair. This November, Danny will be 33 years old. He enjoys listening to the Beach Boys and Styx, collecting Toy Story characters and folding dish towels. He also enjoys socializing and going out to breakfast with cousins and is the happiest guy I know. Danny still has severe pulmonary regurgitation and is currently without symptoms of heart failure.

Danny's incredible journey has encouraged me to do better. Everyone has a story. We are all here for a special purpose. Either by evolving to it, or something we are driven by.

From my heart to yours, Happy Heart Month! •

ABOUT THE AUTHOR:

Doreen Bestolarides R.N. is a parent and professional advocate with over three decades of hospital nursing experience, with a focus in critical care. She has dedicated the direction of her nursing career, by developing a nursing role, to better serve hospitalized patients with developmental disabilities. She has continued that advocacy in her personal life to not only be a resource and educator in her own community, but to pursue her vision on the national stage through organizations such as DDNA (Developmental Disabilities Nurses Association) on the Practice Committee, defining nursing practice standards; the AADMD; and serving as Board member for ADHC (Alliance for Disability in Healthcare Education). She is the 2021 recipient of the AADMD Family Advocacy Award. She retired from the hospital in 2020. For questions, call 209-470-8287.

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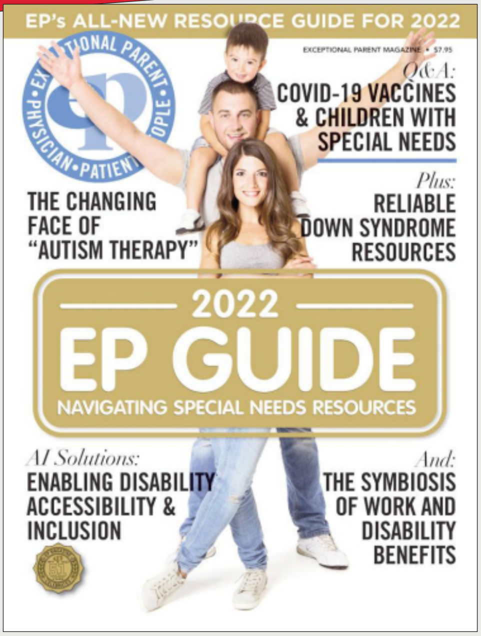

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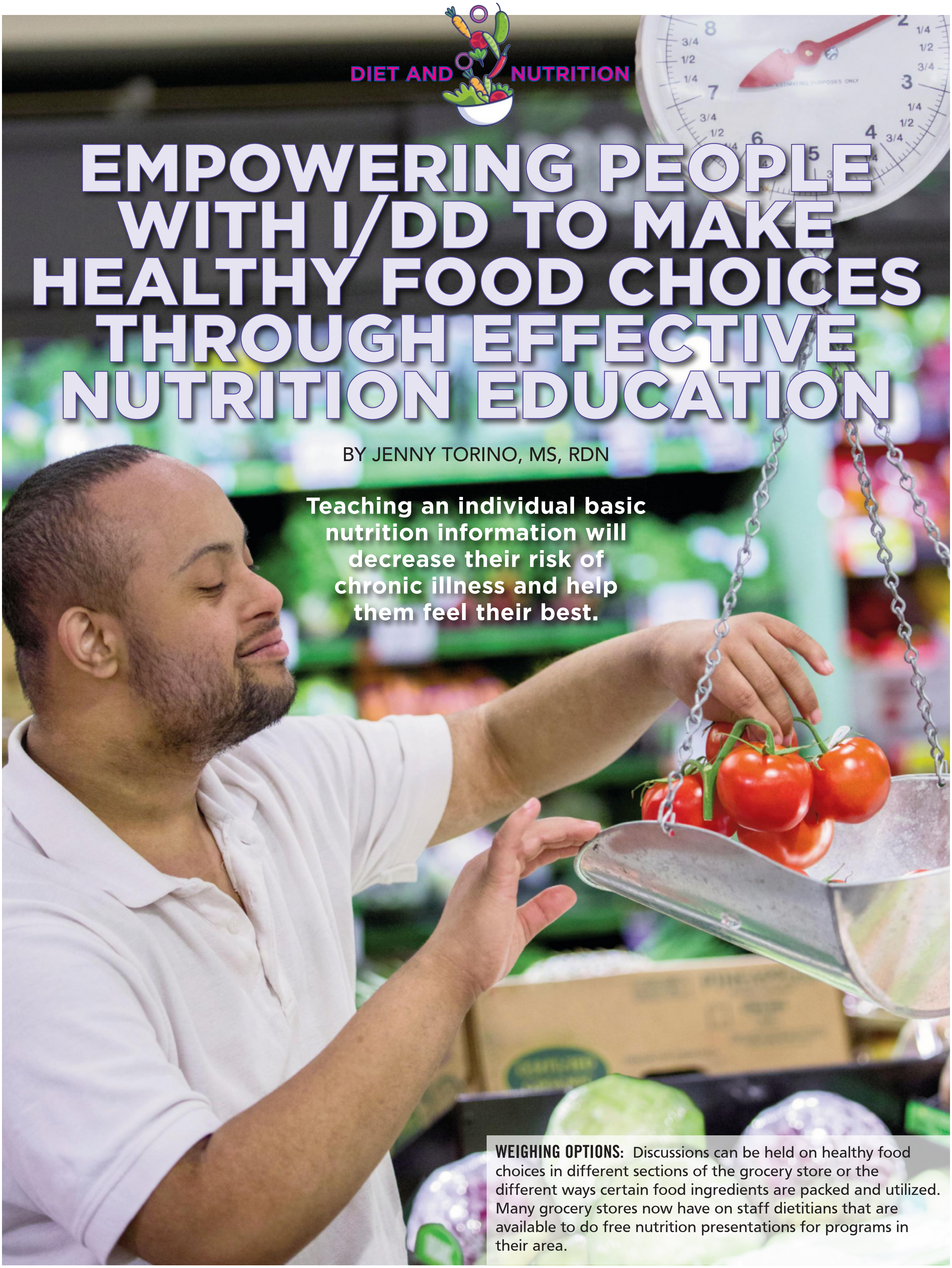
EP MAGAZINE: THE JOURNAL FOR SPECIAL NEEDS FAMILIES AND PROFESSIONALS

DIET AND NUTRITION

EMPOWERING PEOPLE WITH I/DD TO MAKE HEALTHY FOOD CHOICES THROUGH EFFECTIVE NUTRITION EDUCATION

BY JENNY TORINO, MS, RDN

Teaching an individual basic nutrition information will decrease their risk of chronic illness and help them feel their best.



WEIGHING OPTIONS: Discussions can be held on healthy food choices in different sections of the grocery store or the different ways certain food ingredients are packed and utilized. Many grocery stores now have on staff dietitians that are available to do free nutrition presentations for programs in their area.

When provided with nutrition education, individuals with I/DD can learn to reduce their risk of chronic diseases, fuel their bodies with essential nutrients and become empowered to make their own healthy choices.

Ellyn Satter, Registered Dietitian and well-known authority on child feeding states in her "Division of Responsibility in Feeding" that parents are responsible for the "what, where and when" of feeding. They are responsible for choosing what foods are offered, when they are offered and where the food is eaten. Children are responsible for how much of the food is eaten and whether the food is eaten.[1] As children grow up, they learn to be responsible for choosing what to eat. A common issue in the adult I/DD community is balancing an individual's food preferences with food choices that are best for their health needs, which may not coincide. Fortunately, we do not have to choose between healthy foods a person is unhappy with or conceding to ice cream for dinner.

Providing nutrition education for people with I/DD that is easily communicated, memorable and most important, fun, are keys to effective learning. Nutrition activities can be done at home with family or in congregate settings. Replacing wordy handouts with colorful picture references, keeping nutrition messages brief, revisiting topics often and building on prior concepts make nutrition information easier to remember. Rather than providing guidance from a distance, nutrition education becomes exciting with hands-on activities like cooking and games that motivate individuals to take care of themselves and reinforces nutrition recommendations. These types of activities should be tailored for the age level and modified for any specialized diets and feeding instructions given to you by your health professional.

Research has shown that adding pictures to written or spoken health education materials increases the students' attention, comprehension, recall and adherence to health recommendations. Pictures are especially helpful for those with differing literacy.[2]

Creating handouts with pictures of healthy foods from a favorite local convenience store, restaurant or grocery can help individuals recognize healthy options available in their familiar environment. Handouts highlighting food choices from local stores allow choices to be made ahead of time and can prevent frustration or challenging behaviors as new foods and eating habits are introduced. If someone has difficulty incorporating fruits or vegetables into their diet, a pictorial handout can help encourage them to work toward the recommended amount per day.

Enjoyable participatory exercises relying on pictures include slide show grocery store tours, displaying pictures of local restaurants and menus, and watching the evolution of a food starting with where it is grown, then packaged and cooked. Group discussions can be held on healthy food choices in different sections of the grocery store, what the best menu items are from local restaurants and the different ways certain food ingredients are packed and utilized. These more complicated activities may be suggestions for a day program or may inspire similar home activities. Many grocery stores now have on staff dietitians that are available to do free nutrition presentations for programs in their area.


HEALTHY HABITS: A common issue in the adult I/DD community is balancing an individual's food preferences with food choices that are best for their health needs, which may not coincide.

Keeping nutrition messaging simple is a key to retention and adherence in all populations. Using Myplate or the "plate method" helps individuals understand a balanced diet to provide themselves proper proportions of fruits, vegetables, grains, dairy and protein throughout the day". Myplate, the current food guide published by USDA's Center for Nutrition Policy and Promotion, provides a printable graphic demonstrating a balanced plate comprised of approximately 20% protein, 30% grain, 20% fruit and 30% vegetables with a serving of dairy (or fortified non-dairy alternative) on the side. Myplate.gov includes nutrition recommendations for every stage of life, making it a rich resource for all age groups. Browsing the food group gallery, individuals can learn which foods fit in the main food groups. Using blank Myplate templates, individuals can draw, write or paste pictures of the foods they like in the correct area of the plate for each food group. When an individual favors or avoids certain food groups on their exercise sheets, that can be noted and can help guide nutrition goals toward a balanced diet.[3]

Additional resources that have been very useful in this setting are Myplate catch phrases such as "Make Half your Plate Fruits and Vegetables", "Think About Your Drink" or "Try Whole Grains." These sayings help individuals remember to avoid sugary beverages or to try whole-grain bread or pasta instead of the white flour varieties. [3]

For individuals that have specific and sometimes limited diets due to sensory preferences or anxiety with changes in routine, exposure to a new food in a fun way can help increase the likelihood of trying new foods. Myplate.gov offers Grocery Store Bingo Cards where a player can search the aisles looking for specific healthy foods.[3] Additionally, online templates allow for creating custom bingo cards using individualized bingo squares with nutrition goals such as "Had a Fruit for Snack" or "No Sweets Today".

Filling out the bingo card throughout the week can get a Healthy Eating Bingo! In areas with accessible farms, individuals might develop a connection to foods from a visit to a nearby farmers' market to see the varieties of fruits and vegetables or to a pick-your-own farm. Outings and trips can increase exposure and help build positive associations to new and healthy foods. For someone who has never before tried a strawberry, a trip to see where the food grows and handling that food is the first step toward trying it.

RIGHT APPETITE: Research has shown that adding pictures to written or spoken health education materials increases the students' comprehension. This poster is based on the USDA's MyPlate recommendations.

"Taste Tests" are another way to increase exposure to foods and allow individuals to describe their experience of the food. Taste tests can be set up for different types of apples or pears picked from an orchard or from a grocery-store trip. Individuals can be asked to describe the difference in taste (tart, sweet, bitter), texture (crunchy, smooth, mushy) and take notes next to each type. Originally intended for children, the USDA offers a "Kids Food Critic" handout that can be adapted for all ages and groups where they can draw a food they are tasting, rate it by visual appeal, smell, taste and texture, and then give it a total score.[3] For those with sensory preferences, strategizing with a feeding therapist first is beneficial.

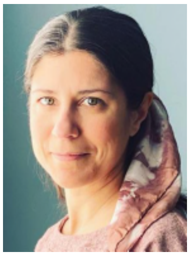
When there are no contraindications, including an individual in meal preparation is fundamental. Among youths, helping to prepare meals is associated with healthier eating behaviors, and helping at home with meal preparation has been demonstrated to be associated with improved overall diet quality, eating more fruits and vegetables and potentially with consuming more grains, meat and meat alternatives and milk and milk alternatives.[4] For individuals where a hot oven or handling a knife is not feasible, they might choose recipes, gather ingredients and kitchen tools, wash vegetables, measure and stir ingredients and help set the table. Introducing an individual to a kitchen starts with safety and sanitation, where hand washing and the dangers of knives and kitchen equipment are reinforced.

Finding healthy recipes to prepare and sharing why the recipes were chosen will help fortify nutrition concepts. There may be stories or books related to a major ingredient in the recipe to read aloud or share beforehand. Along with meal preparation, being involved with meal planning can help individuals develop self-efficacy and confidence in making healthy food choices. Individuals can plan a dinner and make sure the meal is balanced with a protein, vegetable, fruit, and grain or starchy vegetable. They can aid in planning the grocery shopping list and by making sure there are enough vegetables to serve for the week's dinners. Lastly, tending to a small vegetable garden or growing some herbs on the windowsill to use in home-cooked recipes can be fulfilling for a family or housemates living in a group residence. As they become acclimated to inclusion, there are endless ways individuals can participate in food related activities.

Trying and handling different foods can be very difficult for some children with I/DD or autism, especially for those that have Sensory Processing Disorder. While an individual may grow out of limited eating, some individuals maintain a restricted palate through adulthood. Individuals may favor certain textures or temperatures over others, so introducing new foods or recipes within those parameters can increase acceptance (ex. crunchy, creamy, cold, etc). Avoiding too many new textures at once and loud kitchen equipment can also be helpful.

Given the heavy load shouldered by caregivers, finding time for nutrition activities can be difficult, but even planning one nutrition activity per month around one important and practical nutrition goal can make a difference. Seek advice and resources from your healthcare team, including a Registered Dietitian. When time is limited and accessing visual and print resources is not an option, you may still request them from a Registered Dietitian or Feeding Therapist. Teaching an individual basic nutrition information will decrease their risk of chronic illness and help them feel their best. With clear nutrition messages imparted through enjoyable activities appropriate for one's age and individual needs, we can respectfully provide those in the I/DD community the knowledge to make healthy choices for themselves. •

ABOUT THE AUTHOR:



Jenny Torino is a Registered Dietitian with over 15 years experience in the field. She is currently working with individuals with I/DD at the ARC in Sussex County, NJ. She has also held positions as an outpatient dietitian at the VA Medical Center and a private nutrition practice in Providence, Rhode Island. She initially started her career at GMHC, the nation's first HIV/AIDS service organization in New York City. She holds her Masters Degree in Clinical Nutrition from New York University.

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POSTER IMAGE COURTESY MYPLATE.GOV

Eating healthy can be fun!

LET'S MOVE

Let's move isn't just noble; it's a necessity.

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The set up for lifelong nutrition and activity habits begins in our homes. The answers will be found by parents who seek to find what works for themselves and their family.

REASONS FOR THE RISE IN CHILDHOOD OBESITY

BY MARY PITTAWAY, MA, RDN

For a variety of reasons, children and adults with special needs are more likely to be overweight or obese than their neurotypical counterparts. This commentary is intended to inform families on the extent of the obesity problem for children and adults, its causes, possible solutions and the risks it poses to children's health and wellbeing if not addressed.

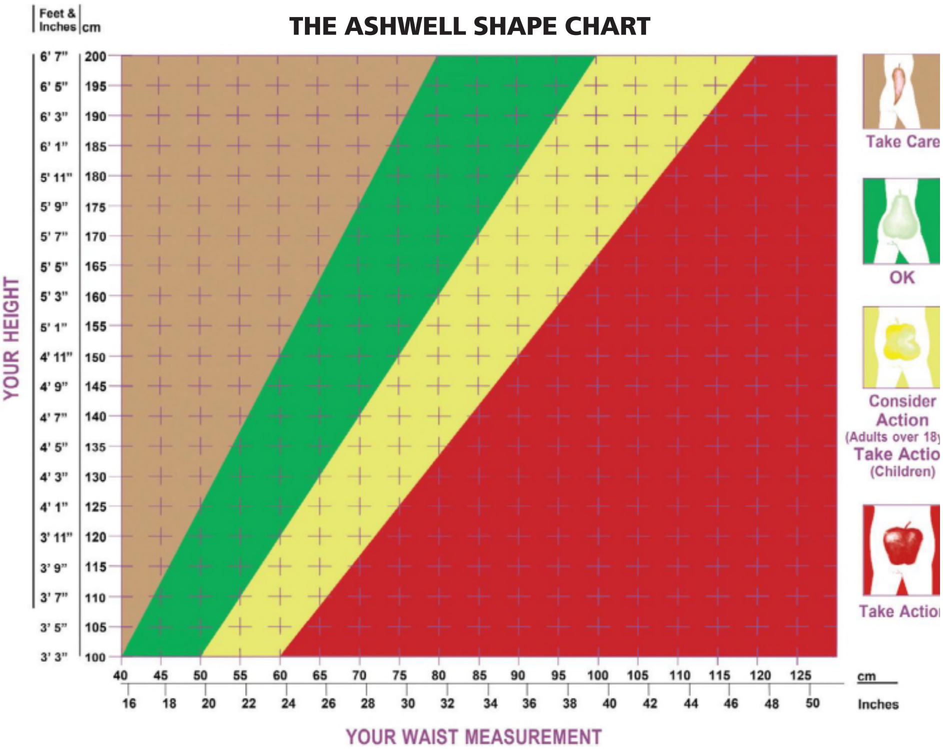
When parents and caregivers are empowered with obesity prevention tools, resources, and solutions, they are better equipped to help their children to become and stay fit and healthy. In this article, you'll find tips on how to monitor your child's weight using a tool that reveals the impact their current weight has on their overall health. This includes suggestions on home environment changes that can have a significant impact on the weight and health of your family members, including your child with special needs.

- The increasing trend in obesity prevalence since the early 1980s poses a significant population health burden throughout the world. Many, if not most children with special needs face multiple challenges when it comes to maintaining a healthy weight. According to the Centers for Disease Control and Prevention (CDC), 20% of children 10 through 17 years of age who have special healthcare needs are obese compared with 15% of children of the same ages without special healthcare needs. Children and adults with mobility limitations and intellectual or learning disabilities are at greatest risk for obesity.
- As a parent, it's important to recognize the impact a healthy food and activity environment in your home will have for your whole family, and especially for your child. We have learned more about the unique risks that obesity presents to our children and realize how essential it is to address the causes to alter the trajectory to certain chronic diseases associated with obesity.
- The set up for lifelong nutrition and activity habits begins in our homes. The answers will be found by parents who seek to find what works for themselves and their family. Thirteen percent of U.S. families have a child with a disability, yet children with disabilities are seldom included in the discussions about solutions. We know what a challenge it is for parents to help their children maintain a healthy weight. How can parents ensure their family makes healthy food choices and adequate opportunities for physical activity to replace sedentary pursuits? How can families create opportunities for more routine movement that's fun, affordable and safe?

People with disabilities can find it more difficult to eat healthy, control their weight and be physically active. This might be due to:

- *A lack of healthy and affordable food choices and the over abundance of low-cost nutrient poor foods, that are high in fat, sugar, and salt.*
- *Physical and mobility limitations that can reduce a person's ability to exercise.*
- *A lack of resources and social support from family, friends, neighbors, and community members.*
- *A lack of accessible environments, for example, sidewalks, parks, and programs that support healthy nutrition and exercise.*
- *Difficulty with chewing or swallowing food, or its taste or texture.*
- *Medications that can contribute to weight gain, weight loss, and changes in appetite.*
- *A lack of energy and/or pain.*
- *And for some, genetics.*

Obesity affects different people in different ways and increases the risk for other health conditions among people with and without disabilities. We know that there continue to be fewer chances for physical activity, because sedentary hobbies are more prevalent than ever.



SHAPE OF THINGS: The Ashwell Shape Chart allows health professionals and/or their patients to match their waist circumference against their height and to see into which category they fall. Learn more at www.ashwell.uk.com/shapechart.htm

So, what influence do parents play? Although research shows a link between parent and child weight, not all children of overweight parents are overweight themselves. The child inherits its genetic makeup, but parents also influence through parenting skills. In fact, parents may be able to protect their children from the impact of larger, environmental factors on whether a child becomes overweight.

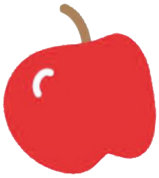
Recent reports show that over 39% of adults in the world are overweight or obese and for many, problems with weight began as children and continue as they age. We have several tools to use to interpret a child or adult's weight, including BMI, waist circumference, waist-to-hip ratio and DXA, a low dose x-ray process that measures body fat, including visceral fat that grows around organs.

A new tool, the waist-to-height ratio (WHtR) has been introduced, to help parents monitor theirs and their children's waist size compared to height, and the risk of several chronic diseases represented in health disparities of children and adults with disabilities. Some of these non-communicable diseases are linked to and can be predicted by looking at person's waist size compared to their height. These include diabetes, hypertension, heart disease, non-alcoholic fatty liver disease and even cognition problems like early onset dementia. The WHtR most accurately predicts both the percent of body fat, and visceral adipose tissue.

Visceral fat collects around organs, including the heart, liver, pancreas, arteries, and intestines and it is dangerous. It stimulates the release of proteins and hormones that cause inflammation which can damage tissue and impair organ function. For example, when it collects around and in the pancreas, the cells which store and release insulin so sugar can get to your cells are damaged, and it impairs how the body breaks down sugars.

Some people may have a “healthy” BMI of less than 25, but may not be fit, because BMI does not account for muscle mass. Some people with a BMI over 25 can be fit and healthy. The truth about a person’s risk of chronic disease is more accurately determined by their WHtR than their BMI. Studies show that central obesity or belly fat, is associated with higher mortality rates, even in individuals with normal BMI scores.

What is a healthy waist size for children? The answer depends on their height! Their waist should be no more than half their height. This is for both boys and girls, all ethnic groups and ages. And as luck would have it, it works the same for adults as well!



How to measure the waist: Measure waist and height accurately, because even small errors can cause the ratio to be inaccurate. When measuring waist and height, if possible, bring all family members into the activity. No need to “call anyone out” if their ratio is above .5. The measurement is appropriate for ages two and older. The beauty of starting to look at WHtR with younger children is that as they grow taller, if waist size remains, their ratio goes down.

- *Wrap a flexible tape measure around the waist slightly above the navel. Keep the tape measure level with the floor, exhale, and measure.*
- *The height measurement: Remove shoes, stand straight with three points of contact including back of head, heels and seat touching the wall. Put a box or book (right angle), on person’s head and where item touches top of the head, mark the wall.*
- *Divide the height in inches by the waist in inches. For example, if a person is 48 inches tall and his waist is 27 inches, 27 divided by 48 gives a ratio of .56. Ideally his waist will be 24 inches.*

Excessive abdominal fat or a WHtR over .5 is linked with higher risk for type 2 diabetes, elevated cholesterol or triglycerides, high blood pressure, coronary artery disease and other health conditions.

SCALING DOWN : HEALTHY WEIGHT STRATEGIES

Here are some great resources for parents interested in looking at healthy weight strategies for their children with special needs.

ABILITY PATH

Finding Balance Obesity and Children with Special Needs

An online resource and social community for parents and professionals serving the needs of adults and children with disabilities.

https://abilitypath.org/wp-content/uploads/2015/11/obesity-report.pdf

SPECIAL OLYMPICS

How to measure your own waist and height

https://media.specialolympics.org/resources/health/disciplines/health-promotion/virtual/Waist-Height-Measurement-Guide-Imperial.pdf

BIOED: BAYLOR COLLEGE OF MEDICINE

Make body measurements fun for yourself and your children

www.bioedonline.org/BioEd/cache/file/7E2446DB-EDF2-E213-50FE881FE130862F.pdf

IGAMEMOM

Fun Body Measurements with a piece of string

https://igamemom.com/fun-body-measurement-activities-with-a-piece-of-string

If a person’s WHtR is higher than .5, take heart! Being physically active, eating well, and watching portion sizes can positively impact waist size and overall health. Discuss your or your child’s health risks and goals with your doctor.

A HEALTHY APPROACH : ADULT WAIST TO HEIGHT RATIO RESOURCES AND READINGS

NIH NATIONAL LIBRARY OF MEDICINE

Waist-to-height ratio is more predictive of years of life lost than body mass index

https://pubmed.ncbi.nlm.nih.gov/25198730

Waist-to-height ratio is a better screening tool than waist circumference and BMI for adult cardiometabolic risk factors: systematic review and meta-analysis

https://pubmed.ncbi.nlm.nih.gov/22106927

A systematic review of waist-to-height ratio as a screening tool for the prediction of cardiovascular disease and diabetes: 0·5 could be a suitable global boundary value

https://pubmed.ncbi.nlm.nih.gov/20819243

CENTER ON TECHNOLOGY AND DISABILITY

A proposal for a primary screening tool: Keep your waist circumference to less than half your height

https://bmcmedicine.biomedcentral.com/articles/10.1186/s12916-014-0207-1

ASHWELL ASSOCIATES

The Ashwell Shape Chart

www.ashwell.uk.com/shapechart.htm

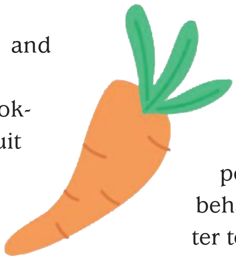
NATIONAL DEAF CENTER

Evaluation of the impact of abdominal obesity on glucose and lipid metabolism disorders in adults with Down syndrome

www.sciencedirect.com/science/article/abs/pii/S089142221400314X

Studies show that parents who engage in healthier eating and activity habits are more likely to have children who mimic these behaviors as they grow into adulthood. So, to get our children to develop healthier eating and activity behaviors, parents must first engage in these behaviors themselves.

When the balance of food intake and physical activity is disrupted, children gain excess weight and once children become overweight, their ability to self-regulate food intake may be altered and additional regulation or monitoring of food selection and quantities eaten may be needed.



Parents can shape their child's food preferences and eating behaviors by making sure healthier options are readily available. For example, remove chips, cookies and candy from the cupboards and have fresh fruit or cut up vegetable sticks readily available and visible so that when children are hungry for a snack, their only option is a healthy one. The same process works to decrease sedentary time.

Studies show that children with a TV in their bedroom spend an extra 1.5 hours per day watching TV than children who don't. Removing the TV from the bedroom reduces screen time and frees up time for more physical activity. Parents who are physically active and who include their children in these activities, can inspire a love of physical activity, games, being outdoors and play with others. Involving your child in Special Olympics can provide ample physical activity and healthy nutrition opportunities. And by adjusting the home environment, parents can shape their child's behaviors, reduce temptations, and create a health-inducing space where good habits are formed for life.

However, certain behaviors can create negative effects. Encouraging children to clean their plate, whether they are hungry or full, teaches them to ignore their internal satiety cues leading to overeating and loss of self-regulatory ability regarding food intake. Prompting or encouraging children to eat may result in increased eating time and caloric intake. Allowing children to internally regulate their intake and stop eating when they are full may be beneficial. Once children become overweight, their ability to self-regulate intake may be altered and additional regulation or monitoring of how much and what they eat may be necessary.

Equally detrimental is criticizing a child's weight, body shape and food choices. Afterall, when the environment supports health, and when parents and siblings practice healthy behaviors, everyone benefits. Instead of commenting, it's far better to role model health food and activity choices and stock your kitchen with healthy foods and beverages, making the healthy choice the easiest choice for everyone in your family.•

ABOUT THE AUTHOR:

Mary Pittaway has worked in public health nutrition for over 40 years. As a public health nutritionist, she's managed senior nutrition programs, WIC, community gardens, vitamin D, osteoporosis prevention, breastfeeding education for health care providers, obesity and diabetes prevention and nutrition programs for people with intellectual and developmental disabilities. She serves as a Global Clinical Advisor for Health Promotion with Special Olympics International and teaches nutrition at the University of Montana. She can be reached at mpitt59802@aol.com

ESTABLISHING HABITS : PEDIATRIC WAIST TO HEIGHT RATIO RESOURCES AND READINGS

NIH

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Waist-to-height ratio as a risk marker for metabolic syndrome in childhood. A meta-analysis

https://pubmed.ncbi.nlm.nih.gov/29700992

Body mass index classification misses to identify children with an elevated waist-to-height ratio at 5 years of age

https://pubmed.ncbi.nlm.nih.gov/30287892

An exploratory study of the association between physical activity, cardiovascular fitness and body size in children with Down syndrome

https://pubmed.ncbi.nlm.nih.gov/26366976

National Center for Biotechnology Information
NCBI

NATIONAL CENTER FOR BIOTECHNOLOGY INFORMATION

Waist-to-height ratio index or the prediction of overweight in children

www.ncbi.nlm.nih.gov/pmc/articles/PMC5849367

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AMERICAN ACADEMY OF PEDIATRICS

Recent Trends in Waist Circumference and Waist-Height Ratio Among US Children and Adolescents

https://pediatrics.aappublications.org/content/118/5/e1390

Cardiometabolic Risk and Body Composition in Youth With Down Syndrome

https://publications.aap.org/pediatrics/article/144/2/e20190137/38477/Cardiometabolic-Risk-and-Body-Composition-in-Youth

SPRINGER NATURE

SPRINGER NATURE

Screening using Body Mass Index alone may miss every second preschooler with excess abdominal fat

www.springer.com/gb/about-springer/media/research-news/all-english-research-news/screening-using-body-mass-index-alone-may-miss-every-second-preschooler-with-excess-stomach-fat/16131944

SAGE journals

SAGE JOURNALS

Are there anthropometric and body composition differences between children with autism spectrum disorder and children with typical development?

https://journals.sagepub.com/doi/abs/10.1177/1362361320987724

"Brody, and most of his peers are not striving to be an athlete, nor do they want another therapy. They desire a relationship, a challenge, and an opportunity to do what others their age do."

THE MISUNDERSTANDING OF EXERCISE FOR PEOPLE WITH AUTISM

BY DAVID GESLAK, ACSM EP-C, CSCS

After a parent discovers their child has autism, they dedicate themselves to following the early intervention (EI) plan. While their child may be getting the required services in EI or from their school, many parents do not stop there. In their mission to enhance their child's opportunities and quality of life, they exhaust all possibilities, beyond doctors and/or therapists.

PHOTOS PROVIDED BY DAVID GESLAK, ACSM EP-C, CSCS

This was the case with Brody's paents who read about the benefits of exercise for those with autism. They recognized that their son was not getting enough and wanted to add more physical activity to his schedule.

I first met Brody at his home when he was eight years old, when I went there as a personal trainer to give him a physical fitness assessment. As I entered through the front door, Brody walked toward me, made brief eye contact, and kept walking past. I thoughtfully followed him as he tip-toed around the dining room table and I said, "Hi Brody."

I was taken aback by his response, "no more doctors."

In my many years working with those with autism spectrum disorder (ASD) I was accustomed to hearing "no exercise," or "I don't want to exercise," but never heard anyone say, "no more doctors."

I went there to teach Brody, but in fact he taught me. I have come to understand that due to all the new breakthroughs in research, therapies, and programs, Brody and his peers have what I would call "therapy fatigue." Hearing those three simple words changed my approach for delivering exercise to this community, and how I educate parents, exercise professionals, therapists, and higher education. Exercise needs to be positioned differently because exercise is not *therapy*. Exercise is part of a healthy lifestyle, the same thing that their parents, the professionals who serve them, and what everyone else does (hopefully).

> "Imagine if you went to work and your manager was right next to you, commenting on every move you make for six hours a day, five days a week. My guess is you too may be prompted to scream, hit that person or yourself, or cry. It makes complete sense why Brody would blurt out, "no more doctors."

For all the right reasons, professionals are assessing, observing, critiquing, box-checking, and following the students' every move. Brody, for example, would go through a full day of school with a one-to-one paraeducator, come home for a "break" (e.g., 30-minutes for a snack), and then start three more hours of therapy sessions. Hence, therapy fatigue.

Imagine if you went to work and your manager was *right* next to you, commenting on every move you make for six hours a day, five days a week. My guess is you too may be prompted to scream, hit that person or yourself, or cry. It makes complete sense why Brody would blurt out, "no more doctors."

10-MINUTES TO EXERCISE SUCCESS

As professionals and parents, we are all looking to meet our clients' or children's goals as quickly as possible. The *wrong* goals and expectations when teaching exercise will be counterproductive. Many people think of a quality workout as 60-minutes of high-intensity exertion that ends in pools of sweat. This approach will backfire for those with ASD and certainly will not introduce exercise as a lifetime activity.

The *goal* is to get through the exercise session in an enjoyable way. As long as you get them through the session, you have won. When starting, be like the tortoise not the hare.

A 2017 research study from Rutgers University concluded that 10 minutes of low- to moderate-intensity exercise produces significant and large reductions in stereotypical behavior (i.e., echolalia and hand flapping) in those with ASD for the following 60 minutes.[11] Additionally, exercise is identified as one of the 27 evidence-based practices for those with autism, as an intervention involving increases in physical exertion as a means of reducing problem behaviors or increasing appropriate behavior while increasing physical fitness and motor skills.[16] While we know the function of stereotypic or repetitive behaviors can vary, exercise is a key component in a multifaceted approach to reducing stereotypical behaviors, when appropriate.

10-minutes is an achievable starting goal for both the child and parent/professional. So is the low-to-moderate intensity level. Introducing exercise at a low intensity for a realistic timeframe (for your schedule and theirs) is the pathway to success. As further evidence in the National Survey of Autism Treatment Effectiveness, autism parents rated exercise as the #1 treatment for those with autism.[1] The benefits and power of exercise are too great to be ignored.

AWARENESS RAISES MORE QUESTIONS, EDUCATION PROVIDES MORE ANSWERS

A population-based study indicates that U.S. adolescents with learning and behavioral developmental disabilities are 60% more likely to become obese.[15] Another study found that 31.8% of adolescents with autism were obese. While gross motor and movement-based activities are often part of physical therapy (PT) and occupational therapy (OT), and many children are participating in physical or adapted physical education, this is still not enough physical activity.

DOWNWARD DOG: One way to introduce exercise is through yoga. Pairing the movements with words like "dog," "cat," and "table" can enhance vocabulary by making connections with the targeted words used.

What a parent of a newly diagnosed child may not realize is that PT & OT end when goals are met or children "age out." Also, these services are not designed to meet children and adults' daily or weekly physical activity requirements. I want to be clear, exercise *does not* and *should not* replace OT or PT. These are critical therapies that exercise professionals do not have expertise in. But exercise serves its own purpose, and should not be lumped in with PT, OT, *or even* physical education (PE) and adapted physical education (APE).

The Every Student Succeeds Act[4] and the Individuals with Disabilities Education Act [7] support students with autism and all disabilities participation in physical education in schools. Unfortunately, many students with disabilities do not receive appropriate PE services or the full benefits from PE. This was the primary reason Brody's mom called me.

There is a lack of understanding of how to effectively deliver exercise for those with autism in communities worldwide, in our schools, and ironically, in PE and APE. Only 14 states in the United States require an advanced certification for physical educators teaching students with disabilities. That leaves the other 36 states not requiring any specialized training in their undergraduate PE teacher education preparation.

Undergraduate PE programs meet the Society of Health and Physical Educators (SHAPE America) state standards for PE licensure by requiring students to only take *one* class in APE.[12] When that class is passed, the teacher is deemed "certified" to instruct *all* students with disabilities. With only one course in APE, new PE/APE teachers are woefully unprepared to lead a classroom of students with a variety of disabilities.

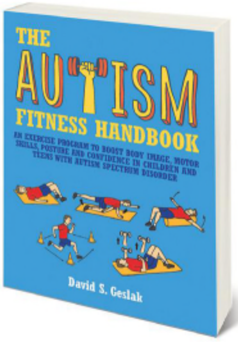
PHYSICAL EDUCATION, OR SPORT EDUCATION?

While PE can be a great way for some with autism to get physical activity, many of these programs are focused on sports, not individualized exercise. Programs focused on sport will likely set students up for failure.

Sports can be difficult because they involve social communication and interaction, both of which are persistent deficits directly related to ASD. Also, many of the unstructured sports (e.g., basketball, soccer) taught in PE/APE are taking place in the most un-sensory friendly environment in the entire school… the gym! The social and communication demands associated with sports may cause significant effort and anxiety for individuals with ASD as they consciously calculate what is socially intuitive for others (2). In an environment with kids running, jumping, screaming, echoing of sounds, and objects being thrown, kicked, or hit it's no wonder why many of those with ASD are left wandering and wondering in PE – if they get PE at all.

Even with all the dedicated and tireless research that has shown exercise has a positive impact on autism beyond the gym, it's a shock (no, it's actually sad and frustrating) that exercise is not getting the attention it deserves by more schools. Supporting research for the autism community shows that exercise can improve focus, on-task behavior, language development, and reduce maladaptive or stereotypical behaviors.[5, 9, 11, 13, 14] In a study published in *Psychology in the Schools,* the authors examined the impact of antecedent physical activity on academic engagement time among third grade boys with autism. The authors concluded "participation in a physical activity intervention contributed to overall increased academic engagement for high-functioning students diagnosed with an ASD".[9] Furthermore, a meta-analysis of 16 studies suggested that on average, exercise interventions led to a 37% improvement in symptoms of autism, specifically behavioral and academic improvement.[13]

Legislation has been passed (for years!) that those with ASD and other disabilities are entitled to specialized physical education in the schools. Everyone needs to work together to use the resources available to provide the proven benefits of exercise to this deserving population.



Title: **The Autism Fitness Handbook**

Author: **David S. Geslak**

Publisher: **Exercise Connection**
Publication Date**: April 2011**
Paperback: **62 pages**
ISBN-13: **978-0615470573**
Available at: amazon.com and
www.barnesandnoble.com

WORTH THE WEIGHT: Coach Dave guides Brody to maximize his lifting exercises. Weight training can tone muscle, improve posture, reduce tension in the neck and shoulders, and calm the nervous system.

SEE THE DIFFERENCE – VISUALS WORK!

When talking with parents to learn about their children, I always ask "does your son/daughter use visuals?" A common response from many parents is, "No, my child can talk." I understand that some parents may confuse visuals, or visual supports, with PECS (Picture Exchange Communication System) which is commonly used with individuals who are nonverbal or have limited communication. When asking this question, I am not referring to just PECS.

Successfully engaging a person with autism in *any* new activity - especially exercise - will take patience, creativity, and the use of evidence-based teaching practices (EBPs). One effective method to teach those with autism are visual supports (e.g., photos, visual schedules, video models, social narratives, modeling). Visual supports add structure, routine, and sequence that many children with autism require to carry out their daily activities.[10] When implemented correctly, visual supports allow students with autism the freedom to engage in life, regardless of impairment.[6]

Visual supports and other evidence-based practices (e.g., technology-aided instruction, reinforcement, and peer-mediated instruction) are successfully used in special education classrooms to teach academic and functional skills. When you use these same strategies to teach exercise, they will be familiar and effective.

When I first began teaching exercise, there were limited paper-based exercise visuals (e.g., jumping jacks, walk or run) or sport visuals. The ones that did exist fell short of communicating effectively to my students. For example, when the objective was to have my students kick a soccer ball to each other, the best visual I could find showed half a leg touching a soccer ball. Anyone who understands autism knows that they need the whole picture. I quickly realized there was a need for exercise visuals that would successfully communicate instruction and empower individuals to reach their full potential.

To best help the individuals, and the professionals or parents teaching them, I brought together a multidisciplinary team of professionals (i.e., special education teachers, physical therapist, and speech-language pathologist). Together, we built a variety of high-quality, inclusive visual systems. The paper-based Visual Exercise System allows parents and professionals to create visual, structured, and functional exercise sessions for individual & group programs, yoga, sports, and many other activities. These color-coded systems bring a consistency that the children and students are familiar with and provides images

EXERCISE SUCCESS | 3 STEPS

1. USE PICTURES

Many with ASD, if not most, benefit from visual supports. They can be especially helpful when you start incorporating exercise (or any new task) into your child's routine. The pictures teach and show them what is expected.

2. ESTABLISH STRUCTURE

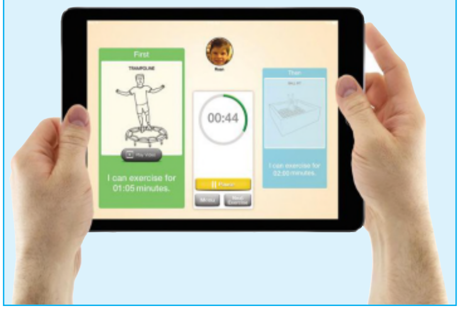
Creating structure and routine can be a powerful reinforcement for autistic individuals. Develop structure by staying consistent with exercises, scheduling, and timing. Visual supports will also help to establish structure. Pick a day, a time, and get started. You may begin once a week and then gradually increase to two-to-three times per week as you discover what works best for your child.

3. APPLY IN CROSS CURRICULUM

Exercise is a lifestyle change or a lifestyle addition. Educate and share the research and many benefits with your child's teachers and therapists. Exercise should not be limited to only physical education; it can be used a sensory break as well.

• • •

THERE'S AN APP FOR THAT: Supported in seven research studies, Exercise Buddy leverages technology to empower those with autism and other disabilities to exercise at home, in the gym, or in the classroom.



that effectively communicate a person doing exercises and sports.

To leverage the benefits of technology-aided instruction (16), we created Exercise Buddy, an inclusive visual exercise app, available on tablet devices that embeds six evidence-based practices to empower parents and professionals to teach exercise. Supported in seven independent research studies, one study completed by a BCBA-D professor from Ball State found that, “Exercise Buddy, in conjunction with a system of least prompts and reinforcement, taught participants to acquire physical activity skills at home and generalize the skills at local community fitness sites.”[3]

As the saying goes, “a picture is worth a thousand words” but in the case of those with autism, or other disabilities, a picture is worth more than a thousand words. Adding visuals to support verbal instruction can be the catalyst for engaging your children or students to make the exercise connection.

To better equip fitness and special education professionals with best practices for teaching inclusive exercise, we created the Autism Exercise Specialist Certificate, in partnership with the American College of Sports Medicine (ACSM). Also supported in research, a study on the ACSM/Exercise Connection Autism Exercise Specialist Certificate’s Online Modules found that the frequency at which participants reported using evidence-based practices increased significantly from pretest to posttest (3.26 ± 0.59 to 3.40 ± 0.59; Cohen $d = 0.15$; $p = .031$). Moreover, participants perceived self–efficacy in using evidence-based practices significantly improved from pretest to posttest (2.78 ± 0.76 to 3.20 ± 0.76; Cohen $d = 0.40$; $p < 0.001$).[18]

I am happy to report that there are now thousands of professionals and parents who have been educated and better equipped to make a profound impact – one child at a time.

PERSISTENCE VS. PERFECTION

I have spent that last 17 years working with, *and learning from,* individuals with ASD, their families, and transferring that knowledge to exercise and special education professionals. Through this time, I have found the one common denominator of people who have been successful when introducing exercise to this community, no matter their age or ability level: Persistence, not perfection.

While perfection is the goal that is often strived for, the goal should *really* be to enjoy exercise so they can make it part of their routine and experience the lifelong benefits. You (we) just need to keep your children moving.

There is in fact a miracle workout routine for your child or students, but it has to be uncovered by you and your child over time. Start slowly with your child or students. Engage them in a few exercises for a short period of time. It may only be one exercise on a Tuesday before school. Or it could be five minutes spent exercising before they go to bed. Get down on the ground (or jump up) with them. Using visuals, giving positive reinforcement, and incorporating breaks will result in steady progress. This “pull approach,” as I might call it, is in stark contrast to the “push approach” that many fitness professionals use successfully with their other clients.

Exercising with your child, and them seeing you do the work, provides a whole new perspective for them that will lead to exercise success. When I was training Brody, I would leave his sessions with sweat dripping from *my* forehead. As progress is made, celebrate each “win”, and build on it by adding another exercise, or a few more repetitions or minutes.

Today Brody is 18 years old and continues to exercise. I asked his mother to sum up what exercise has done for Brody and the family; here is what she said, “Exercise provided a backdrop to age-appropriate regulation, communication, a release from stress, and weight loss. It crosses back and forth from school to home allowing him to feel superior in one particular setting when most times he feels out of the loop or disconnected. And now in gym class, he rises to the occasion.”

Brody, and most of his peers are not striving to be an athlete, nor do they want another therapy. They desire a relationship, a challenge, and an opportunity to do what others their age do. According to many parents of those with autism, exercise is not just one more thing, it’s *the* thing. Again, autism parents rated exercise the #1 treatment.[1] Exercise builds confidence, enhances quality of life, and can result in many untold opportunities. Mic drop! (Now pick it up and repeat 10 times…) •

ABOUT THE AUTHOR:

David Geslak, the founder of Exercise Connection, has pioneered award-winning and research- supported visual exercise tools and programs to improve the lives of those with autism and other disabilities. David began his career as an Assistant Strength Coach for the University of Iowa Football Program. After leaving, he opened a gym where he worked with his first client with autism that changed his career path. To understand how those with autism learn best, he became a paraeducator and eventually the Fitness Coordinator at an autism school. He is now a published author, writes journal articles, and is a renowned presenter on autism and exercise. His commitment and methodology to bringing exercise to those with autism has been enthusiastically embraced by parents, professionals, higher education, and the autism community around the world. David is an ACSM Certified Exercise Physiologist, NSCA Certified Strength and Conditioning Specialist and has a Bachelor’s Degree in Health Promotion from the University of Iowa.

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For families of children in the spectrum, mealtimes can sometimes be a demanding endeavor. Learn about common mealtime challenges and ways to address them so that you can enjoy the best part of family meals — each other.

MEALTIMES FOR CHILDREN LIVING WITH ASD

BY HEATHER SEID, MS, RDN, CPS, CNSC, CLC AND JANE ZIEGLER, DCN, RDN, LDN

You have probably seen the "ideal" family meal on television at least once or twice. Relaxed parents pass around balanced meals, while hungry children, who always say please and thank you, eat mounds of vegetables and whole grains without complaint.

The scene shows a table washed in a warm glow of smiles and pleasantries. If you have seen this image, it probably won't surprise you that there are many benefits when families sit down to enjoy meals together.[1] Positive influences begin as early as the toddler and preschool years and they extend into adulthood.[1] Families that have structured meals may also have children with lower body mass indexes (BMI), decreased rates of overweight, and healthy dietary and eating patterns.[2] Adolescents who eat three or more meals per week with their caregivers are less likely to have disordered eating or substance abuse issues.[1,2] Talking during meals can improve communication skills, strengthen the family dynamic, and improve children's self-esteem.[1]

"My son only ate foods that were yellow, brown, and white: chicken nuggets, french fries, mac and cheese, vanilla cookies.

The only green thing he would eat was mint chocolate chip ice cream."

However, the media has neglected to show a far more typical family mealtime. A realistic portrayal is a parent acting as a short-order cook, food flung onto the floor, children crying, and a general feeling of chaos looming. Mealtimes are hard work for all parents, and they can be especially challenging for families and children living with autism spectrum disorder (ASD). ASD is a complex neurodevelopmental disorder characterized by social deficits and repetitive patterns of behaviors.[3] It is estimated that up to 89% of children with ASD experience some challenging mealtime behavior.[4] Common issues include food selectivity, fear of new foods (also called neophobia), and disruptive behaviors. Meal challenges can begin early in life and extend through adolescents and adulthood.[4]

Children with ASD may have increased sensitivities to certain foods.[5] For example, foods that are crunchy, brightly colored, or too hot/cold may be difficult to process from a sensory perspective.[5] To combat uncomfortable sensations, children may prefer a limited number of foods that they feel safe eating.[5]

> *"From the time he was 18 months, my son only ate foods that were yellow, brown, and white: chicken nuggets, french fries, mac and cheese, vanilla cookies. He ate anything in that carbohydrate category. The only green thing he would eat was mint chocolate chip ice cream. If I made green vegetables, like a salad, he would vomit. If I cut lettuce in front of him, he would vomit just from looking at it. He was so overwhelmed by the sight or smell of fruits and vegetables that he couldn't be around us if we were cooking or eating them."* – A.M. about her son R.M. who is diagnosed with ASD.

FOOD FOR THOUGHT: The "ideal" family meal is one where you and your family feel calm and relaxed, and your child consumes a variety of foods. Hopefully, by making a few small changes, you can create a mealtime that you and your family look forward to.

COMING TO THE TABLE : CREATING A MEALTIME YOUR FAMILY CAN LOOK FORWARD TO

While meal challenges exist for all parents, they can certainly be difficult to manage for children within the ASD community. However, there are some things caregivers can do to make strides towards happier and healthier meals.

ENLIST SUPPORT

First, if you are a parent or caregiver of a child with ASD, you know that you are the absolute expert in your child. You can sense when something is amiss, even when it's invisible to others. You know your child backward and forwards, inside and out; you can do this. Yet, you do not have to do this alone. Enlist the help of experts! Registered dietitians are uniquely qualified to assess your child's nutritional status and recommend various strategies to address dietary concerns. Dietitians can also help navigate special diets like gluten or dairy free. They will work with you to mitigate nutritional risks and explore foods you can try. Occupational and feeding therapists are also valuable allies for helping you create a physically comfortable eating environment and bring in any adaptative equipment if necessary.

Before you make any mealtime changes, it is essential to rule out any physical problems interfering with your child's ability to eat. Dental decay, chewing and swallowing difficulties, constipation, irritable bowel syndrome, and acid reflux are common issues that may make eating unpleasant for your child. Common medications prescribed for children with ASD may affect appetite and cause stomach upset as well. Once any physical problems have been addressed, consider evaluating the meal environment.

ASSESS THE MEAL ENVIRONMENT

Children and caregivers may experience heightened stress and anxiety around meals. Try relaxing into mealtimes by spending a few minutes deep breathing or meditating. Going for a quick walk around the neighborhood may help ease uncomfortable feelings and set the stage for a calmer environment. Occupational therapist Jenny L. Clark, ORT/L, suggests talking your child through belly breathing with a beanbag animal *(outlined below)*.

It is vital to build a routine around meals to help decrease fears and implement healthy behaviors. Try to eat meals at the same table and have everyone in the same seat. Minimize distractions such as pets, TV, or other background disturbances.

If meals are currently very challenging, start by sitting together at the table as a family (without food), even if it's for just a few minutes. Make sure your child can sit at the table comfortably. If your child slouches, wiggles, or expresses discomfort, consider seeing if you can improve their seating with rolled towels, a booster, or footstools.

BELLY BREATHING WITH BEANBAG ANIMAL

"Have children lie on the floor and place a small beanbag animal on their stomach. Cue the children: 'Breathe in slowly through your nose and feel the stuffed animal rise, breathe out slowly through your mouth and then feel the animal lower.' Repeat at least 3 times. Play quiet music for increased relaxation."[16]

– *Jenny Clark, ORT/L*

Food selectivity means that an individual has a small repertoire of foods that they agree to eat.[6,7] These foods are often eaten multiple times throughout the day.[6,7] Food selectivity can be challenging because it reduces the variety of foods and puts children at risk for nutritional deficiencies.[6,7] Children with ASD are more likely to have significantly lower calcium, protein, and fiber intake than neurotypical children.[8] Additionally, food selectivity behaviors often favor high calorie, sugar, and fat foods (e.g., pudding, candy, juice), which may increase the risk of overweight and obesity.[6,9] In fact, children with ASD are 40% more likely to develop obesity than neurotypical children.[5] They also have an increased risk of developing heart disease and Type 2 diabetes.[5,6,9-13] Food selectivity goes hand-in-hand with 'neophobia'or fear of trying new and different foods.[5] Children with ASD may actively avoid trying novel foods, and they may become upset when new foods appear on their plate or if their favorite foods are presented in unfamiliar ways.[7] Caregivers frequently report preparing special foods or separate meals to accommodate their child's preferences.[7]

Children with ASD may also exhibit disruptive behaviors at or around mealtimes. Challenging behaviors may be a result of increased anxiety, and may include frequently leaving the table, throwing food or silverware, tantrums, crying, and food refusal.[14]

> *"I learned that going into meals, my son isn't able to sit at the table for the whole meal, he won't eat the same foods that I eat, or have excellent manners. But, I started to ask myself, what is my absolute 'yes' for him? What does he have to do? I told him, 'You have to sit in your chair and you have to eat 2/3 of your meal.' Finding what was an absolute yes on my end helped establish the minimum. Once he met the minimum, we bumped it up."*
>
> – A.M. about her son R.M. who is diagnosed with ASD.

Mealtime disruptions may ultimately decrease the healthful benefits of family meals, and research has shown, unsurprisingly, that caregivers report increased stress and anxiety around eating.[14,15] Parents may also shift their attention from the whole family to their child with autism, thus limiting the benefits of mealtimes to their other children.[15] However, there are some things caregivers can do to make strides towards happier and healthier meals *(see above)*.

The "ideal" family meal is one where you and your family feel calm and relaxed, and your child consumes a variety of foods. Meals won't look "perfect" or TV-ready, and it won't always be easy. Still, hopefully, by making a few small changes, you can create a mealtime that you and your family look forward to.

> *"I have developed a deeper understanding and appreciation for milestones. These tiny wins over time helped us make progress with food. As he got older, my son became much more tolerant. It was gradual shift, but looking back he has made great progress!"*
>
> – A.M. about her son R.M. who is diagnosed with ASD. •

Special thanks to A.M. for generously sharing her time to discuss her son's journey with ASD.

Ideally, children should have their feet on the floor or support and sit up without slouching (within the constructs of their physical abilities).

As children become comfortable sitting together, gradually introduce the concept of eating at the table. Try to stick to set times for eating as much as possible. Aim for three meals and one snack per day, with no more than 2-4 hours between meals depending on your child's age *(note: determine the ideal number of meals/snacks per day with your dietitian).* If a child experiences hunger between meals, this provides a learning experience to tune into their bodies. By establishing set times for eating, children can learn to accept food at the appropriate times, and they will come to anticipate their daily routines.

Be a role model! Meals are a powerful time to model ideal behaviors. So, parents, eat a varied diet and demonstrate how you would like your child to behave.

ADDRESSING FOOD SELECTIVITY

Children's food selectivity comes from a place of fear. It is essential to recognize that new foods are very anxiety-provoking and a source of discomfort for many children with ASD.

Gradual exposure may help improve acceptance of new foods and ultimately improve nutritional intake. If a child is fearful of oranges, start by having the child look at an orange from across the room. Over time, move the orange closer and have them touch and play with it. As their comfort increases, show them an orange in different ways; cut into chunks, slices, and orange juice.

Try food-chaining! Food-chaining is an approach where you introduce new foods to your child while building on previously accepted and successful foods. Dietitian Jenny Friedman, RD, has developed helpful visuals if you need ideas transitioning to new foods. *(check her out at www.jennyfriedmannutrition.com).*[17]

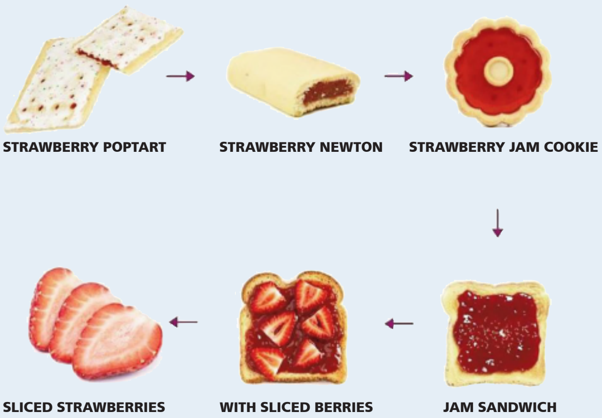
Expand on already accepted foods. If your child accepts McDonald's french fries, try substituting oven-baked fries, then work towards transitioning to zucchini fries. You can also try swapping foods with similar textures (e.g., swap yogurt for pudding).

Focus on the food not the behavior.

– Jenny Freidman

POPTART TO STRAWBERRIES: LEARNING TO ENJOY FRUIT

Food chaining is a way to get your selective eater to try new foods. It takes into account the sensory properties of foods that your child likes and builds on his/her preferences. Essentially, it's a tool that helps you identify which new foods your child is most likely to eat. The chain is created by making gradual changes to the accepted food.



MEALTIME MATTERS : A RECAP

Enlist Support: Find a dietician: **www.eatingright.org/find-a-nutrition-expert**
Meal Environment: Ease into meals with an anxiey lowering activity • Sit at the same table, consider assigning seats • Establish set meal times • Model ideal behavior.
Food Selectivity: Understand fear of new foods is similar to fear of spiders or heights • Try exposure therapy • Consider food chaining to move children away from less nutritionally desirable foods.

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DIET AND NUTRITION

A FOCUS ON FEEDING, CHEWING AND TEETHING

BY DAVID A. TESINI DMD, MS, FDS RCSEd

Feeding and chewing behaviors are important conditioners for proper development of the face and jaws. The progression of oro-facial development from infancy through childhood affects the skills of chewing, drinking, swallowing, speech and breathing.

Eruption of the teeth occur in a specific progression and timed sequence consistent with food progressions from liquids to pureed to solids. For Children with Special Health Care Needs (CSHCN), development of the necessary skills are often burdened by sensory and tactile delays. It is important to know that over-the-counter products can be both helpful and harmful. This article will give you that general understanding of the related science and practical knowledge needed to advocate for your child's needs.

A LITTLE SCIENCE TO GET US STARTED

Human feeding is dependent on an integrated sequence of events requiring the coordination of over 20 muscles to move food and saliva in the mouth, from the first chew to the swallow. Children's oral motor development begins with the mouth working as a total unit, but as the child matures, the movement of jaws, the tongue and lips function as separate but coordinated entities. There is a progression over time with corresponding development of the jaw joint (TMJ) which adds jaw stability needed to chew foods varying in firmness, size and texture. More recent research added to the understanding that early perceptual and discriminatory abilities also develop between infancy and early toddlerhood.

ONCE BITTEN: Learning to bite and chew food is challenging for Children with Special Health Care Needs, and most difficult for those with sensory integration type disorders.

It has been demonstrated that the oro-motor developmental stages of the child jaw movement, masticatory muscle functions, (i.e., feeding functions, tongue functions and eruption of the teeth) has an influence on what textures are accepted or rejected. Simply put, the child knows what types of food she can eat and what types she cannot. Infants start out with only liquids and at four to six months, the diet is complemented with the first solid foods, which are semi-liquid (e.g., pureed fruits or vegetables). At around six months, teeth will develop and the lateral/more advanced movement of chewing begins. By this stage, infants have experienced different textures and learn to like textures that can be easily manipulated by their tongue, lips and gums. These preferences are determined by their prior experience with texture variations.

In fact, over the first two years of a child's life, the most marked period of increasing oral skill occurs between the age of six and 10 months for transition to more solid textures. Further increases in chewing efficiency continue up to 24-36 months. This corresponds directly with the "teething stage" (the eruption of teeth and the downward and forward growth of the mandible). The chronological link between chewing and teething thereby has been established.

What the science teaches us is that, as the child matures, the movement of jaws, the tongue and lips function as separate, but coordinated entities. Jaw movement, masticatory muscle functions, i.e., feeding functions, tongue functions and eruption of the teeth, have an influence on what textures are accepted or rejected. The child must strengthen their muscles and coordination skills in order to progress along the feeding and speech path. During the most critical time of oral development (age 6-24 months) the child's muscles/joints/ tongue learn to handle and coordinate the eating of complex solids. This corresponds directly with the eruption of teeth. Simply put, most children know what types of food she can eat and what types she cannot.

But for Children with Special Health Care Needs (CSHCN), learning to bite and chew food is challenging and, specifically, most difficult for those with sensory integration type disorders. Learning to bite and chew is dependent on the sensory properties of the food (rheology) and the feeling of that food in the mouth, both at the first bite, second bite and progressive chewing. Palate size and shape, tongue function, soft tissue concerns such as lip and tongue frenum attachments, mouth breathing, and yes, even teething, to the "art of chewing."

PROCESSED FOOD, CHEWING AND DRINKING FROM A CUP

There are health benefits of chewing. Chewing stimulates oral myofunctional development. Crooked teeth affect chewing and chewing affects crooked teeth. Chewing is integrated with breathing, sucking and affects the whole development of the cranio-facial-respiratory system. So, what do we do when our child has cognitive and sensory delays that present as difficulties in chewing – and we revert to soft proceed foods as a "safety measure," and spouted sippy cups as a carpet-saving strategy? Both are compounding difficulties, and both are delaying their feeding and drinking skill maturation.

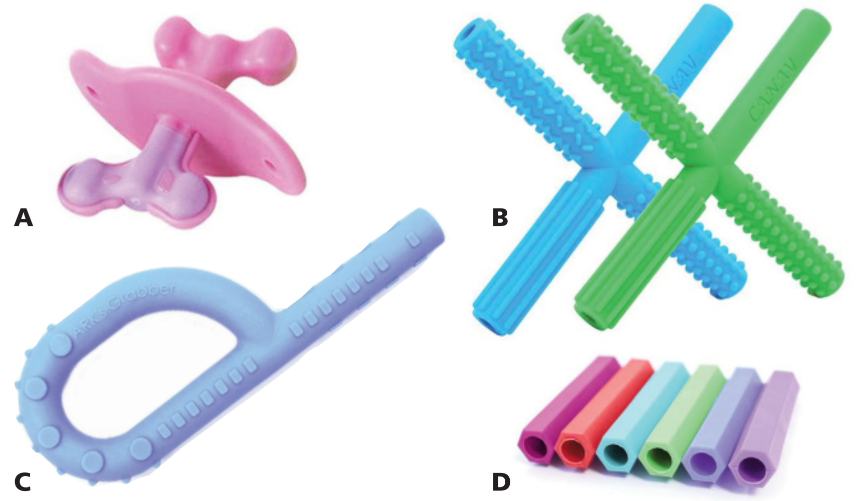
CHEWERS, TEETHERS AND ADJUNCTIVE CHEW APPLIANCES

Oral motor chew tools and specifically designed teethers are an excellent way to provide oral stimulation, exercise the mouth muscles, build oral tone, and practice biting/chewing skills.

So back to rheology. Specifically, resistance, sensory input, size shape texture, consistency placement and oro-motor skills for creation of a bolus to prepare for the swallow are critical parameters in food progression. Oh yes, again… let's not forget the role of the teeth (10 teeth chew better than six, and 20 teeth chew better than 12).

- *Aceli' Trainer teether with a varied response to biting (patent pending). The teether can replicate and coordinate this natural progression. The teether can achieve the various textures, firmness, and compressibility of different foodstuffs. Through textures, design features and teether response, the teether can replicate and coordinate the child's natural feeding and speech progression. Training the child with the teether can accelerate transitions between feeding stages and help develop control required for speech.*
- *ARK Grabber for speech and oral motor development texture aversions drinking, feeding and chewing.*

CHEW ON THIS : SPECIFICALLY DESIGNED TEETHERS



CHEWER BEWARE: Chewther aids can be both helpful and harmful; *(A)* Aceli' Teethers from Toothprints PC; *(B)* Canay Hollow chew tubes *(C)* ARK Grabber chew *(D)* ARK pencil tip chew; Chewable toothpicks or extra hard pencil toppers may cause oral trauma if a child falls, or the chew aid becomes driven to the back of the throat from an impact.

A WORD OF CAUTION

Chew aids, or perhaps better called "Chewther toys," should be selected specific for the age and development of the infant, toddler of child. Designs such as the ARK chewable toothpicks, or extra hard pencil toppers, as well as the Canay straight hollow tubes, may cause oral trauma (impalement injuries) if a child falls, or the chew aid becomes driven to the back of the throat from an impact. Devices that limit the depth of the chewther or teether when placed in the child's mouth (often called a safety shield), such as the Gifty Hollow teether tube, are best advised for children with unsteady gate, newly walking toddler, or those with poor hand -eye coordination. Also, there have been reports of pieces of these textured chewthers breaking off, and it has cause for concern of the parents. Any problems or injuries with "Chew aids" of any kind or brand, please let me know at tesini22@gmail.com and I am happy to follow up with the company for you.

As with all teethers, pacifiers, chew aids or toys, parents should supervise the use, regularly inspect and replace the product if the item shows signs of cracking, wear or tear.

FINAL WORD

Pediatric dentists and speech and language pathologists are good resources able to evaluate oral anatomy and oro-myofunction during speech, feeding and breathing. They will be able to offer a diagnosis and direct parents to treatment options. •

ABOUT THE AUTHOR:

David A. Tesini DMD, MS, FDS RCSEd, is a retired pediatric dentist with ongoing positions and an Associate Clinical Professor at Tufts University School of Dental Medicine, and President of Toothprints PC, a baby product design company. He was past president of the Academy of Dentistry for Persons with Disabilities (ADPD) and parliamentarian/trustee of the American Academy of Pediatric Dentistry (AAPD). He was a co-founder of Project Stretch: Dentistry Reaching out to Children, a non-profit organization providing free care to impoverished children around the world. He and his wife Bernadette enjoy spending time at the family vineyard in Italy producing their award-winning Prosecco Venti22due.

BEST OF EP: FEB 2019

DIET AND NUTRITION

ADHD and a WHOLE FOOD PLANT-BASED DIET

What role does nutrition play for children with ADHD? This is a controversial subject and, because we often have an emotional attachment to food, we are reluctant to look at this as an adjunct treatment. The studies that have been done do not provide consistent results. It is suggested, however, that the "Western" way of eating (the Standard American Diet) plays a role and this is especially true for boys.

BY TERI YUNUS

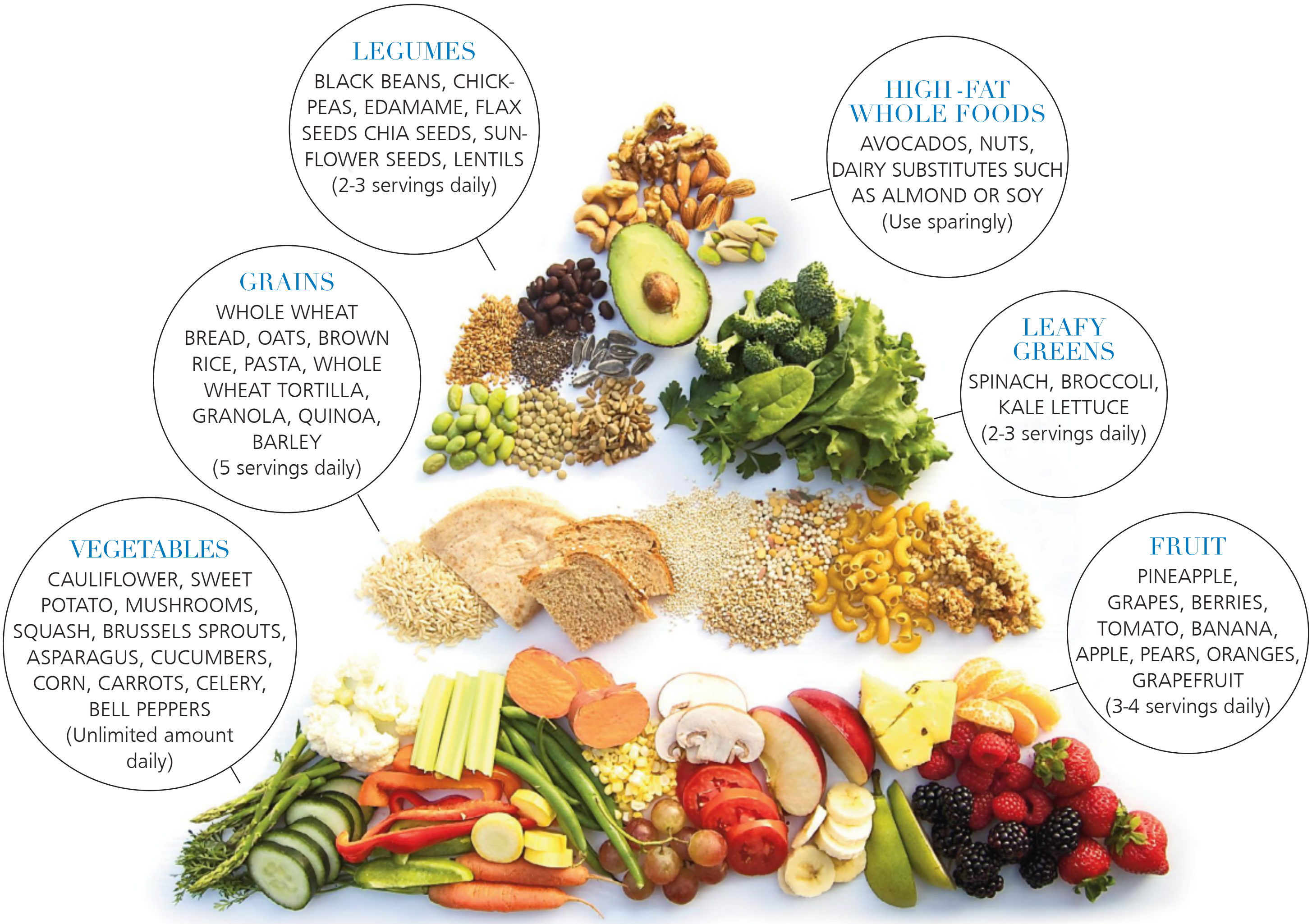
When my son's preschool teacher called me and said that my three-year-old was so fidgety he kept falling off his chair, I felt like this was another level of challenge for this little one. He had been in the program for deaf children just a few weeks when I got the call. In the 1980s, attention disorders were becoming more prominent and teachers were often at their wit's end with how to manage these kids.

At that time, I was a single mom with three little boys and two jobs and convenience was top priority for me. My boys ate Fruit Loops and Cap'n Crunch, Spaghetti O's, boxed macaroni and cheese, along with lunchmeat and canned tuna. My youngest son was born deaf (to the best of our knowledge) and was a very picky eater. He was offered fruits and vegetables and was so tactically defensive that he gagged on anything with texture. He would only tolerate soft foods. Bologna and pancakes became his favorites.

By age four, my son was being prescribed stimulants to control his hyperactive tendencies. This was over 30 years ago, and I remember it as being stressful for my son, who was the most loving little boy, and our entire family. His symptoms became center stage and that environment was hard on all of us. The double disability demanded a lot of attention and the entire family felt it. The medications required multiple doctor visits for adjustments and we tried them all. None of these drugs gave him significant relief and the investment in managing this disorder was an added stressor.

Attention deficit hyperactivity disorder (ADHD) affects approximately 11% of US children aged 4-17. The Centers for Disease Control estimates that 2.7 million children in the U.S. are currently taking medication for ADHD. The disorder can disrupt cognitive, academic, behavioral, emotional and social functioning. It may be associated with other conditions, such as learning disabilities, anxiety, depression and conduct disorders. The cause is unknown and thought to be a combination of genetic and environmental factors. It is characterized by inattention and impulsivity and may present as disorganization, forgetfulness, poor concentration, academic underachievement, inability to follow instructions or finish tasks, risky activities without consideration of consequences, disruptive behavior, interrupting others, impatience. Hyperactivity can be seen as fidgeting, difficulty remaining seated, inability to remain quiet, or restlessness.

The disorder is seen more frequently in boys and there seems to be a genetic propensity among siblings with the disorder. Early lead exposure is one of the environmental risk factors known.



GREAT PYRAMID: A whole food plant-based diet is based on whole foods that have minimal to no processing. Beans, legumes, vegetables, whole grains, fruit, nuts and seeds provide the macro and micronutrients that promote health. These foods also contain hundreds of naturally-occurring phytonutrients that may protect against cancer, heart disease, osteoporosis, and other chronic health conditions.

There are diagnostic criteria that must be met prior to diagnosis as not all children with these symptoms have the disorder.

Standard management for ADHD often focuses on pharmacologic treatments with stimulants and other prescription medications. These drugs can be helpful in many cases but the side effect profile for most of the treatments can be problematic. Behavioral interventions are often recommended as the initial treatment for children with ADHD and are often used in combinations with medications. We know that physical activity is critical for growth and development and may help reduce the symptoms for kids with ADHD.

What role does nutrition play for children with ADHD? This is a controversial subject and, because we often have an emotional attachment to food, we are reluctant to look at this as an adjunct treatment. The studies that have been done do not provide consistent results. It is suggested, however, that the "Western" way of eating (the Standard American Diet) plays a role and this is especially true for boys. High intakes of sugar, salt, fat with minimal consumption of whole grains, fruits, and vegetables may be an associated risk of ADHD.

Some of the nutritional factors that are currently under study include artificial food colorings and common allergens. It is likely that artificial food colorings play a role in the development of symptoms in some with ADHD. Some children with ADHD may also be sensitive to foods such as milk, chocolate, eggs, soy, wheat, corn and legumes, along with salicylate-containing foods such as grapes, tomatoes and oranges. Inadequate vitamin and mineral intake may play a role in ADHD. Iron, copper, zinc, magnesium and calcium deficiencies are common in those with ADHD and it is theorized that this may affect the central nervous system. Nutrient poor meals and snacks are implicated as contributory for those with ADHD. Those with ADHD may also have lower levels of omega-3 fatty acids and higher levels of omega-6 that may lead to inflammation and oxidative stress.

They say hindsight is 20/20 and looking back, I would have done things much differently if I knew then what I know now. As parents, we do the best we can with the information and experience we have. This is the motivation for this article. There is information that you may not be aware of and your family may be struggling like mine did. Most of us turn to our doctors for nutritional advice, not knowing that physicians get little to no nutritional education. No medical professional ever talked to me about diet when I was seeking treatment for my son's ADHD. What I know now came many years later.

Most of us believe that we are eating and feeding our children a healthy diet. It is difficult to know what a healthy diet is given all the conflicting information we are exposed to on a daily basis. The food industry promotes food products not based on health, but based on sales and demand. Food that is advertised is typically highly processed. These items lack adequate nutrients yet taste so amazing we go back for more (earning the industry more dollars). Highly processed foods often contain artificial food colorings, flavorings, and preservatives and do not have the micronutrients that are essential for good health. Fast foods and foods high in sugar, salt and fat light up all the dopamine receptors in the brain and can be soothing to those with attention disorders.

What we know is that there is little good science consistently connecting diet with ADHD. We know that there is concern about food additives, preservatives and flavorings, along with other toxins and chemicals found in our food supply. We know that most children with ADHD eat the Standard American Diet (SAD). This way of eating is associated with multiple disease processes and not optimal for health. We know that most children do not eat the recommended amount of vegetables, fruits, beans and whole grains. We know that the gut microbiome plays an important role in overall health and may be strongly associated with ADHD. We know that children lead more sedentary lives than their parents did. Lack of physical activity has a role in ADHD. We know that environmental exposures to toxins has been linked to ADHD.

One treatment that may help in all these areas is a whole food plant-based (WFPB) diet. This style of eating is based on whole foods that have minimal to no processing. Beans, legumes, vegetables, whole grains, fruit, nuts and seeds are the foods that provide the macro and micronutrients that promote health. Dr. Michael Greger, nutritional expert, researcher and founder of www.nutritionfacts.org states these foods contain not only the essential vitamins and minerals, but also hundreds of naturally-occurring phytonutrients that may protect against cancer, heart disease, osteoporosis, and other chronic health conditions.

Meat has become the "main dish" in the SAD and many people wonder what plant-based eaters actually eat. A WFPB diet does not need to be complicated. There are recipes available online to satisfy the needs of most families. There are soups, casseroles, salads, side dishes, pasta dishes, comfort foods, amazing desserts, and so much more. Some WFPB eaters are starch based, others based on greens and beans. The possibilities are endless.

ROUNDING INTO SHAPE: Diet may be that added tool that can make a difference with your child today and in his future. Eating a whole food plant-based diet can help prevent obesity, diabetes, high blood pressure, cancer, heart disease and many other chronic illnesses. Setting our children up for the best adult life is part of our jobs as parents.

Foods that are excluded from this way of eating include added oils, added sugar, all animal products including meat (includes chicken and turkey), fish, dairy (yes, cheese, too) and eggs along with processed foods. These foods are often very high in saturated fat, trans fat, salt and other additives. "Junk" foods are also excluded from this lifestyle as they do not promote healing but can diminish our health. It is important to know that not all "health" foods are healthy.

Growing up, most of us heard repeatedly, "eat your vegetables"... many of us may use these words with our own children. Most of us know that vegetables are one of the healthiest foods we can eat. Many plant-based doctors and nutritionists agree that the more veggies we eat, the healthier we will be.

Foods common in the WFPB diet feed the gut microbiome (the good bacteria in our digestion tract). You may have heard the old adage, "you are what you eat"... this one, too, is very true. What we eat determines what gut bacteria are in our intestines and this plays an important role in our ability to fight disease and our overall well-being. Preliminary human studies have demonstrated the likelihood of a connection between the gut microbiota and ADHD and overall brain health. Eating a WFPB diet improves gut health and consequently reduces inflammation.

The bottom line is this... there is not ONE right way to treat this complex condition. Often, ADHD is best managed by multiple modalities. Medication is one, behavior therapy is another, diet may be that added tool that can make a difference with your child today and in his/her future. Eating a whole food plant-based diet can help prevent obesity, diabetes, high blood pressure, cancer, heart disease and many other chronic illnesses. Setting our children up for the best adult life is part of our jobs as parents. Your family may consider experimenting with adding more plant-based foods and reducing animal products to see what improvements may be seen. Using dietary intervention does not mean abandoning medications. Nutrients are compatible with drugs to a greater degree than the medications that are common to ADHD are compatible with other drugs.

Dr. Joel Fuhrman, Dr. Neal Barnard and Dr. Michael Greger offer information on what this lifestyle can do for your child and your family. These physicians, and others, are reputable and base their recommendations on the best research available. ADHD management can be easier when offering the healthiest foods. The bonus is that typical chronic illnesses that so many Americans are experiencing now can be prevented when the illness-causing foods are eliminated and replaced with the most nutritious options. Many cities and town have organized groups for plant-based eating support. If your town doesn't have one, consider working with other parents to create one in your community. You are not alone. Many parents are searching for better answers, just like you. •

ABOUT THE AUTHOR:

Teri Yunus is a Family Nurse Practitioner and Nationally Board-Certified Health & Wellness Coach with Health Up with Teri! She recently retired from her work as a nurse practitioner and devotes her time to coaching with emphasis on transitioning to a whole food plant-based lifestyle. She empowers her clients to take their power back and the results she sees with her clients is transformative! www.healthupwithteri.com Contact Teri at healthupwithteri@gmail.com

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Children photo - Designed by Pressfoto

Communication techniques for people with disabilities must be person-centered to be effective.

PERSON-CENTERED COMMUNICATION METHODOLOGIES

BY LAUREN AGORATUS, M.A.

It is beyond the scope of this piece to describe all the communication technologies available to individuals with special needs. Instead, the focus is on the "whole person," or wholistic approaches for communication to be authentic.

WHAT DO WE MEAN BY "AUTHENTIC COMMUNICATION"?

Augmentative/alternative communication can be low or high tech. Augmentative communication supplements speech and alternative communication replaces speech. Options can include American Sign Language (ASL), pointing/gestures, or communication boards using pointers, eye gaze, etc., or computer software. Person-centered communication can be aided or unaided, but it's important to note that inauthentic communication could result if a support person is misinterpreting the individual's communication or doing the communication themselves.

SPEAKING FREELY: Methodologies and interventions must be person-centered, strengths-based approaches to be effective and maximize communication and independence.

WHEN WOULD COMMUNICATION BE INAUTHENTIC?

The American Speech-Language-Hearing Association (ASHA) came out with a policy statement against what is known as "facilitated communication" or FC. The statement notes that this technique, although still being used in some environments, has been discredited. Scientifically, FC has not been validated and subsequent research indicates that the "facilitator is the author" rather than the individual with a disability. In fact, further studies showed actual harm to the person with disability and FC should not be considered as communication for them.[1] Another article, "Who Is Doing the Pointing When Communication Is Facilitated?"[2] calls FC pseudoscience and rebuts the notion that FC gives a voice to someone with a disability. FC does not result in self-expression, and is seen as a civil rights violation which has inadvertently led to sexual abuse and even murder. The extreme example of FC is used to demonstrate that unless caution is used in some types of aided communication, the genuine words of a person with a disability may not be heard.

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1. https://www.asha.org/policy/ps2018-00352
2. https://www.mcgill.ca/oss/article/pseudoscience/who-doing-pointing-when-communication-facilitated

TECHNOLOGIES THAT ENHANCE COMMUNICATION BASED ON DISABILITY

Although not speech-related, certain technologies can help people with certain disabilities to communicate, including:

Visual impairments: In addition to reading books, OrCam's MyEye (www.huffpost.com/entry/how-artificial-intelligence-is-helping-the-visually_b_58ed5c09e4b0145a227cb963) can help people with disabilities to recognize faces, as does Seeing AI.

Deaf and hearing impairments: For those that use Sign Language, Microsoft Translator translates the interpreter's spoken words and converts them into Sign Language. Also, SignAll can translate sign language into text as does KInTrans and GnoSys. For people who do not sign, Ava mobile app uses language processing to transcribe conversations in real-time.

Intellectual/Developmental/Learning Disabilities: For individuals with intellectual/developmental disabilities, Empower Me (www.brain-power.com/autism) uses smart glasses to help interpret emotions using a digital coach. A robot that helps children on the autism spectrum with social skills is QTrobot (luxai.com/qtrobot-for-autism) For students with Learning Disabilities, Speech to Text/Text to Speech help with reading and writing.

A SPECIAL NOTE ON SPEECH TO TEXT SERVICES (STTS)

NDC (National Deaf Center) on Post-Secondary Outcomes has a new resource page. This webpage explains the different speech-to-text services, transcripts, automatic speech recognition vs. STTS, and finding providers.

For more information on the technologies mentioned above, see "Artificial Intelligence: Intelligent Solutions Enabling Disability Accessibility and Inclusion" in the January 2021 issue of *EP* found at https://reader.mediawiremobile.com/epmagazine/issues/207657/viewer?page=23

RECOMMENDATIONS BASED ON REVIEW OF LITERATURE

It is estimated that 5 million individuals in the U.S. could benefit from AAC.[3] Evaluations can be done by Speech-Language Pathologists (SLPs), including for students in schools. Under the Individuals with Disabilities Education Act (IDEA), the evaluation must include consideration of assistive technology, and training the student/family on its use. ASHA has done extensive research in this area. Their website explains the roles/responsibilities of SLPs, high/low tech and aided vs. unaided communication, and different tools, including digitalized and synthesized speech. Considerations in school-based settings are given, including use for transition to adult life activities. ASHA also examines additional communication supports such as Braille, hearing aids/cochlear implants, teletype, text phones, etc. Communicative competence is defined as the ability of the individual with a disability to "to freely express ideas, thoughts, and feelings…"

Recommendations for treatment approaches and AAC strategies use include:

- ➡*Augmented input (communication partner pairs spoken words with symbols)*
- ➡*Behavioral interventions (teach desired behaviors)*
- ➡*Discrete Trial Training (behavioral approach using step-like method)*
- ➡*Milieu therapy (range of methods)*
- ➡*Incidental teaching (uses "behavioral procedures to teach elaborated language")*
- ➡*Time delay (fades the use of prompts)*
- ➡*Core vocabulary approach (uses core vocabulary of common words)*
- ➡*Functional Communication Skills Training (expressing wants)*
- ➡*Language Acquisition through Motor Planning (child initiated activity)*
- ➡*Mentoring Programs (paired with peer mentor)*
- ➡*Picture Exchange Communication System (based on applied behavioral analysis)*
- ➡*Total communication (speaking/signing or gestures/expressions simultaneously)*
- ➡*Video-based instruction (video modeling)*
- ➡*Visual prompting (use visual cues like pointing), includes visual schedules*

ASHA does *not* recommend the use of the previously-mentioned FC or the Rapid Prompting Method (aka Spelling to Communicate). All recommended techniques must have cultural and linguistic competence considerations.

Finally, AAC barriers are examined. For the purposes of this discussion, person-centered communication must serve the "needs of the individual and can be updated when these needs change." For example, a non-verbal student with autism may start using sign language. If the student becomes verbal through whatever methods used, then speech can focus on enunciation/pronunciation of words. Students with autism may later also need assistance with pragmatic speech, the practical aspects of speech such as responding appropriately, taking turns, etc.

Whichever methodologies and interventions are used with students with disabilities, they must be person-centered and strengths-based approaches to be effective and maximize communication and independence. •

ABOUT THE AUTHOR:

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.

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[3] https://www.asha.org/practice-portal/professional-issues/augmentative-and-alternative-communication

STRONG CONNECTIONS : AUTHENTIC COMMUNICATION AND PERSON-CENTERED METHODOLOGY RESOURCES

AMERICAN SPEECH-LANGUAGE-HEARING ASSOCIATION

AMERICAN SPEECH-HEARING-LANGUAGE ASSOCIATION
Augmentative and Alternative Communication
www.asha.org/practice-portal/professional-issues/augmentative-and-alternative-communication

CENTER FOR PARENT INFORMATION AND RESOURCES
Considering the Needs of Students Who are Deaf or Hard of Hearing
www.parentcenterhub.org/considering-hearingloss

Guidance from ED and DOJ on Effective Communication for Students with Disabilities
www.parentcenterhub.org/effective-communication-for-students-with-disabilities

CTD

CENTER ON TECHNOLOGY AND DISABILITY
www.ctdinstitute.org

fhi360
THE SCIENCE OF IMPROVING LIVES

FAMILY CENTER ON TECHNOLOGY AND DISABILITY
www.fhi360.org/projects/family-center-technology-and-disability%E2%80%93ii-fctd

NDC
National Deaf Center
on Postsecondary Outcomes

NATIONAL DEAF CENTER
Resource page on speech-to-text
www.fhi360.https://www.nationaldeafcenter.org/STTS

TASH

TASH COMMUNICATION FOR ALL CAMPAIGN
Multiple resources
www.fhi360.https://www.nationaldeafcenter.org/STTS

HELPING PREPARE YOUR BILINGUAL CHILD WITH DEVELOPMENTAL DELAYS FOR SCHOOL

BY ALMA L. CONTRERAS-VANEGAS PH.D., CORINNA VILLAR COLE, PH.D.

Every parent wants to prepare their child for the first day of school, but what if the child is born at 25 weeks (about five-and-a-half months) gestation with developmental delays?

As a first-time mother, I welcomed my new role, but as I delivered my daughter Kiwi (pseudonym), I was unexpectedly inducted into two different worlds. The world of first-time parents and the world of parenting a child with disabilities.

As a former bilingual schoolteacher and current bilingual teacher educator at a university, I knew I wanted to raise bilingual children, but despite my experience with bilingualism, I started to question this decision for my child with developmental delays. After a speech pathologist and a vision specialist suggested that I reconsider my decision to raise Kiwi bilingually, I conducted some research of my own which demonstrated that bilingualism was beneficial, no matter what type of disability a child had. As a result of this quest, my husband and I decided to teach her English and Spanish. Kiwi's grandparents were her caregivers and spoke Spanish with her. Therefore, to communicate her basic needs, it was important for Kiwi to learn the language of her grandparents. Even though her therapists and doctors spoke English, the professionals responsible for her care supported our efforts of raising a bilingual child.

DRAWING CONCLUSIONS: "I conducted some research which demonstrated that bilingualism was beneficial, no matter what type of disability a child had. Even though her therapists and doctors spoke English, the professionals responsible for her care supported our efforts of raising a bilingual child."

BE POSITIVE

When Kiwi turned three years old, she started the Preschool Program for Children with Disabilities (PPCD). Before beginning PPCD, special education examiners administered Kiwi many assessments that highlighted her struggles and deficits. As the examiners completed her paperwork, they pointed out that Kiwi's case was extremely complicated. As her mother, I focus on her potential – how intelligent she is and how I am going to prepare her for school. I did not want others to concentrate on her deficits; therefore, my bilingual educator training helped me as I set out to teach Kiwi the colors, shapes, and numbers before entering PPCD.

Kiwi has cerebral palsy and was non-verbal until the summer she turned 5 years old; therefore, working with her and trying to teach her proved to be particularly challenging. First, I had to find colorful and easy-to-grab toys and objects that would interest her and motivate her to reach out for them. I started introducing them one item at a time. I would place a familiar item in front of her and would ask her to point or to pick up that item. Once I knew that she had made the connection with one object, I would introduce the next one. After that, I would review both items and continue to add more, always making sure that she had correctly identified the color, shape, or number of items. This technique of starting with easy items and increasing the difficulty as the child successfully masters the task is called scaffolding and it works well with children who are verbal and nonverbal.

INTERVIEW TEACHERS

Before Kiwi entered school, my husband and I had a choice between two schools—a bilingual campus outside our school zone and an all-English campus in our school zone. After interviewing the teacher in the bilingual campus, we learned that she was not bilingual, but her assistant was. Furthermore, this teacher did not seem well prepared as she had not studied Kiwi's records before our meeting. When we met the other teacher who was in our school zone (all-English campus), she had studied Kiwi's folder and seemed very well prepared to answer all our questions. Even though we had planned and hoped for a bilingual school setting for our daughter, we decided to choose the all-English campus with the teacher that seemed most prepared. Finally, we decided that I would continue speaking Spanish at home with Kiwi, and my husband would begin speaking English at home; thereby, providing her with a connection between the home and school languages.

> "I AM PLEASED TO SAY THAT WE HAVE BEEN EXTREMELY HAPPY WITH KIWI'S EDUCATION, AND I HAVE DEVELOPED CLOSE RELATIONSHIPS WITH HER TEACHERS.
>
> EVERY CHILD NEEDS A COLLABORATIVE TEAM TO HELP THEM REACH THEIR GOALS WHILE KEEPING THEIR BEST INTEREST IN MIND."

When Kiwi was ready for kindergarten, my husband and I were faced with another decision involving which school she would attend. The school she attended for PPCD did not offer the life skills special education program, which is designed to provide specialized support for children with special needs. Therefore, we needed to choose between a dual-language school (same as before) or a school that was all English; both schools were not in our school zone. Once again, my husband and I made an appointment to meet the teachers that would instruct our daughter.

The current PPCD teacher arranged a meeting between us and the potential new kindergarten teacher from the all-English school. This meeting was extremely successful, and it revealed how kind and understanding this new teacher was. He not only answered all our questions but was interested in knowing about Kiwi. We brought Kiwi's five-month-old younger sister to our visit with the new teacher and as the meeting progressed, she became unhappy and restless and, without losing a beat, the teacher scooped her up and entertained her as we continued our meeting. Both my husband and I were extremely impressed and pleased with how this potential new teacher showed his kindness and patience. Despite our gratifying experience with the potential new teacher, we continued to investigate the dual language program for Kiwi and arranged a visit to meet the teacher at the school that could provide bilingual education to our daughter.

I was excited to meet the teacher at the dual-language school and hoped for a successful conclusion this time. However, as the meeting started, the teacher informed us that she had a previous engagement in 15 minutes; therefore, she seemed pressed for time and continually looked at the clock on the wall behind us. She also indicated that she was not bilingual even though her aid spoke Spanish. Both my husband and I continued to ask her about suggestions on how to better support our daughter, and she responded with generalities without focusing on our daughter's specific needs. After the meeting ended, I was disappointed because I had built my expectations for this option to work out. My husband and I once again concluded that the best placement for Kiwi would be an all-English school and that we would continue to promote and speak Spanish at home.

I am pleased to say that we have been extremely happy with Kiwi's education, and I have developed close relationships with her teachers. As we plan for Kiwi's future, our goal is to help design her individualized education plan (IEP) and work very closely with her life skills teacher and all her therapists. Every child needs a collaborative team to help them reach their goals while keeping their best interest in mind.

CONTINUE TO CHALLENGE YOUR CHILD

Kiwi is now eight years old, and I continue to speak Spanish to her at home. She prefers to speak English, but easily translates from Spanish to English and understands everything that is said to her in either language. She continues to attend an all-English school with encouragement from her teachers who support her bilingualism. Kiwi absolutely loves school and enjoys learning. She especially loves her reading time and can read on a screen that enlarges the font. She can type with a keyboard and play educational games on her tablet and computer. Although she prefers to read in English, she has memorized books in Spanish.

Today, our daughter continues to show growth despite any challenges she may have. If parents play an active role in their children's lives and education, obstacles can be managed. •

ABOUT THE AUTHORS:

Alma L. Contreras-Vanegas Ph.D., is an associate professor at Sam Houston State University in the department of the School of Teaching and Learning (SOTL). There she teaches courses that prepare future educators concerning bilingual education, second language acquisition, and English language learners. Alma's doctorate is from Texas A&M University in Educational Psychology with an emphasis in bilingual education. Her research interests include Bilingual/ESL/Dual Language Education, Hispanic Gifted Identification, and bilingual children in Special Education.
Corinna Villar Cole, Ph.D., Associate Professor/Coordinator of the Bilingual (Spanish) Educational Diagnostician Graduate Certificate at Sam Houston State University (SHSU). She is Director of Appraisal and Diversity of the Garrett Center (GC) at SHSU. For over 30 years, Dr. Cole has been an enthusiastic advocate and trainer of parents of children with disabilities. Texas Educational Diagnosticians' Association (TEDA) past president, university advisor for Hou-Met, TEDA Chapter, and director of the Bilingual Assessment Leadership Group (BALG).

WHO IS MY NEIGHBOR?

BY CARL K. LANGE, M.D.

Advocacy. It's a great word, a powerful word with a plethora of implications. And although the implications of the word may be widespread, the definition can only draw me in one direction. An advocate is an intercessor; one who pleads for or on the behalf of another. The "other" most often being one who could not otherwise speak for themselves.

IMAGE COURTESY KUNSTHISTORISCHES MUSEUM, VIENNA

ROAD TO JERICHO: Francesco Bassano "The Good Samaritan," c. 1575; The Samaritan, upon encountering the disabled man, washed his wounds, bandaged them, carried the man on his donkey to a nearby inn and paid for the innkeeper to care for him until he returned.

Exceptional Parent Magazine has been pleading on behalf of a population, who, through no fault or even option of their own, is incapable. They have been accomplishing this galactic task for 50 years, more recently under the leadership of Editor-in-Chief Dr. Richard Rader. For those who cannot express the following sentiment for themselves, I advocate for them with a resounding "thank you" *Exceptional Parent Magazine*, and thank you, Dr. Rader.

Before we bask in the successes of the past 50 years, I'm certain that *Exceptional Parent Magazine* will be first in line to acknowledge that the task is not yet complete. That is, of course, until the day all genetic defects and disabilities no longer exist. A state of being which some attribute to one of the benefits of Heaven. But, until then, along with Exceptional Parent Magazine, Dr. Rader and all of the parents of those who have been blessed with a special needs family member, and me, we press on.

In the New Testament, Jesus related a remarkable story of a special needs person and offered a prescription for how we are to behave :

On one occasion an expert in the law stood up to test Jesus. "Teacher," he asked, "what must I do to inherit eternal life?"

"What is written in the Law?" Jesus replied. "How do you read it?"

He answered, "'Love the Lord your God with all your heart and with all your soul and with all your strength and with all your mind'; and, 'Love your neighbor as yourself.'"

THE METAPHORICAL "ROAD" IS LONG.

~

WHICH IS A GOOD THING, BECAUSE IT AFFORDS US EVEN MORE OPPORTUNITIES TO BE GOOD NEIGHBORS.

"You have answered correctly," Jesus replied. "Do this and you will live."

But he wanted to justify himself, so he asked Jesus, "And who is my neighbor?"

As the parable progresses, Jesus relates the story of a Jewish man, who while traveling alone on a desolate road between Jerusalem and Jericho, was beaten, robbed and left for dead. The disabled man was then encountered by three different passersby who happened to intersect with him on the road. A Jewish priest, a Levite and a Samaritan. First a brief lesson in first century Palestinian culture. Samaritans and Jews hated each other and were very unlikely to come to each other's aid. The priest and the Levite were from the same culture as the disabled man. The Samaritan was not.

In contrast to the Samaritan, who would have been considered a heathen to both men, the priest and Levite were considered to be righteous, upstanding pillars of society. They knew and taught the Scripture. When both men saw the disabled man lying on the road, they both crossed to the other side. The Samaritan, however, upon encountering the man washed his wounds, bandaged them, carried the man on his donkey to a nearby inn and paid for the innkeeper to care for him until he returned. Jesus then asked the expert in the law, "Which one of these three men was a neighbor?"

The learned man said, "The one who showed mercy."

Jesus responded, "Go and do likewise."

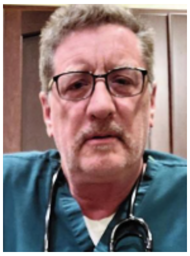
These words were spoken 2000 years ago. The question for us today is how in the world did we ever get this far as a civilized people "crossing over to the other side of the road?"

The metaphor for the man on the road comes in many shapes, sizes, ages and genders. The man in the road sometimes has an IQ of 160, and more often, much less than that. He may wear a suit and tie or even tattered, dirty clothing. He, many times, has two legs but sometimes one or none. Communicative skills? Who knows? I've heard the man on the road, in a very articulate manner say, "Can you please help me?" As an emergency room physician, who often has the honor and privilege to care for special needs patients, many times gets no more than a squeak, drool or scream. I simply translate that into a "Can you please help me?"

The metaphorical "road" is long. Which is a good thing, because it affords us even more opportunities to be good neighbors.

The road is long. Don't cross to the other side. •

ABOUT THE AUTHOR:



Dr. Carl Lange is an Emergency Medicine physician practicing in Pittsburgh, Pennsylvania. He is Board Certified by the American Board of Surgery and works with University of Pittsburgh Physicians at The University of Pittsburgh Medical Center.

A BIGGER PURPOSE

BY CARL K. LANGE, M.D.

You've heard the story before, but please indulge me. It serves a bigger purpose. The young music aficionado from the farmlands of Iowa just got off a bus at the Port Authority Terminal in New York City. He walked around Manhattan for quite a while before asking someone who looked like a native New Yorker for directions to his destination. He approached a salty old man, who clutched his bagel in one hand and a paper Greek diner coffee cup in the other.

"Excuse me sir. How do you get to Carnegie Hall?" asked the young man.

"Practice, my son, practice." the old man replied.

Such was the advice of Andres Fassi to his daughter, Maria, as she experienced an extraordinary metamorphosis from a middling golfer to one of the rising stars on the Ladies Professional Golf Tour. Originally from Pachuca, Mexico, 50 miles northeast of Mexico City, she was the third child born to Andres and Fabiana Fassi. From the start, Maria seemed genetically programmed to excel in both golf and life in general. Her parents were both physical education teachers intimately involved in both amateur and professional sports. Maria had three brothers, one who is a professional soccer player. The Fassis also had a close relationship with golfing legend, Lorena Ochoa, another Mexican professional golfer who served as yet another role model for Maria. Sports was in her blood, but in an endearing way. Her parents cultivated a loving home environment where sports were woven into their daily family activities. Maria played golf as a child with her brothers, and by her own admission, was not very good. Andres Fassi was a father who encouraged, not demanded excellence in his children. In her words she explained to me, "Excellence was not mandatory, but my father taught me how to work towards it. He gave me the tools for success." Maria was emboldened to pour her very best efforts into whatever endeavor she undertook. At the age of seven, she fell in love with the game of golf. It was here that her father's tutelage in striving for excel-

A DRIVE FOR INCLUSION: After her first year on the professional tour, Maria was forced to concede to the fact that something else had been tugging at her soul.

THE LOVE OF THE GAME: Maria with her cousin Josefina *(left)*; Josefina went to all of Maria's tournaments and developed an affection for the game, but trying to find someone who was willing to teach her how to play golf was nearly impossible.

lence took root and the lampoon in the opening paragraph of this story starts to make sense.

The seven-year mark was a tipping point in the life of Maria Fassi. She admits that it was at this stage in her life where she consciously began, in her words, to "organize the steps that would allow me to achieve my dream of playing on the LPGA Tour." Practice she did. Utilizing the tools for success endowed to her by Andres Fassi, Maria progressed at an amazingly dizzy pace toward her goals and dream of playing golf at a professional level. After performing exceptionally well at the junior level, she was recruited by multiple colleges to play for their team. A fellow Mexican golfer encouraged her to accept the full scholarship offered to her by the University of Arkansas. She went on to win multiple tournaments while in college in addition to the highest honor in Mexican amateur golf in 2015, 2016 and 2018. Her dream was finally realized when Maria Fassi turned professional and earned her LPGA Tour Card in May of 2019.

After her first year on the professional tour, Maria was forced to concede to the fact that something else had been tugging at her soul. She recalled that, going all the way back to her childhood, there were friends in her immediate circle who did not "look or act like the rest of us." She recounted that they were just part of her life and incorporating special needs kids into their daily activities required no specific extra efforts. This all changed when Maria's cousin Josefina Gomez wanted to learn how to play golf. What the majority of society considers "abnormal," the special needs community deems unique, with a strong emphasis on the "special" in special needs. Josephina is deaf, mute and is challenged with a form of intellectual disability. Maria and Josephina were inseparable. She went to all of Maria's tournaments and began to develop an affection for the game while watching her cousin play. It was around this time that two more dreams evolved. Josephina wanted to learn the game of golf. Trying to find someone who was willing to teach her how to play golf, according to Maria, was nearly impossible. "This is messed up," she shared with me during our chat. The seeds of her benevolence began to take root and materialized in the form of The Maria Fassi Foundation and her golf clinics called "Fassi's Friends".

Maria loved playing golf and as a natural born competitor, she loved pursuing the victory. Watching Josephina struggle to achieve her goal brought her to the realization that she longed "to play for something bigger than herself." The passion in her demeanor was palpable when she related, "I realized that I needed a greater purpose and something bigger than the game itself to play for." Sprung from this passion was "Fassi's Friends".

In March of 2021, The Maria Fassi Foundation officially became a nonprofit benevolent organization. Fassi's Friends provides not only a place where special needs kids could learn how to play golf, but a safe place for them to congregate, socialize and just act like kids. Her five- week golf clinic, as Maria states, "is designed to teach the basics of the game of golf to special needs students in much the same way any other student would be taught."

By holding charity events, soliciting donations from people who understand the importance of such an organization, and partnering with The First Tee, she is able to provide a golf education to special needs children, as well as the less privileged at no cost. The impact of such generosity is not merely experienced by the student. When Josephina Gomez began to play golf on the local courses, her motivation and drive were contagious. Others in the community were inspired to say to themselves, "I can do this." More dreams were realized because of Josephina, Maria and Fassi's Friends. Maria is fond of articulating that in addition to kids just having plain fun, Fassi's Friends offers therapy through sports and competition.

The pleasure of getting to spend two hours with this remarkable young woman was all mine. Her zeal for the cause of the special needs community was beyond inspirational. Her closing words to me encapsulated who she truly is, "Fassi's Friends is not simply to make me feel better, it is a cause I sincerely care about." •

ABOUT FASSI'S FRIENDS

THE
MFASSI
FOUNDATION

Fassi's Friends is a golf clinic for disabled and full-bodied kids to come together and learn the game of golf. The Maria Fassi Foundation's goal is to create inclusion for kids of all abilities to come together to learn and grow the game of golf through Fassi's Friends. To donate, please reach out to olivia@fassisfriends.com or call 214-801-4419

ABOUT THE AUTHOR:

Dr. Carl Lange is an Emergency Medicine physician practicing in Pittsburgh, Pennsylvania. He is Board Certified by the American Board of Surgery and works with University of Pittsburgh Physicians at The University of Pittsburgh Medical Center.

SPECIAL NEEDS MOM BURNOUT TIPS

BY HINA KALHORO

As a Life Coach, I have a lot of clients that experience burnout from taking care of their children with special needs, developmental delays, or serious illnesses that require an extensive amount of attention and care. These moms are constantly focused on the care of their children and consequently forget the importance of self-care.

What does self-care even mean, you might wonder? This includes taking care of your health and well-being, not only physically, but mentally as well. Neglecting self-care will eventually lead to a “mom burnout”. It can become difficult to function in a healthy and productive manner with depleted energy. Remember, some time is better than no time at all, even if you get a few minutes all to yourself. It can be complete bliss. So, to all the special need moms out there: start with an active commitment to dedicating some self-care time daily or weekly in your schedule.

Let’s do it! First, make a list of activities you enjoy. This could be anything that alleviates your stress and uplifts your mood. Second, look at your current schedule and find small open time slots you have available.

The key is to start small. Let’s say you have 20 minutes of free time between appointments and meetings. Use that time slot available to go jogging around the neighborhood (or anything on your desired list). This is a good way to add self-care in your schedule and once it’s on the calendar, you will most likely be inclined to complete it.

It’s easy to get preoccupied with work, household chores, cleaning, kids, or family. However, recognizing the importance of self-care not only replenishes your energy, but also gives you a form of control that empowers you. The following are some more ideas to squeeze in some self-care in your daily schedule. Keep in mind, just a few minutes of self-care daily can have many lasting benefits. •

ABOUT THE AUTHOR:

Hina Kalhoro is a Life Coach and loves to work specifically with moms of special needs children to avoid burnout through self-care. She resides in Orange County, California and is a mother of two children. She loves to advocate for children with special needs and provide support for moms to stay resilient and strong!.

ME TIME: AVOIDING BURNOUT

- Grab a coffee
- Get a massage/ facial/pedicure/ manicure
- Cook your favorite food
- Go out for a meal
- Watch your favorite movie or TV show
- Listen to your favorite music that uplifts your mood
- Meet with friends to catch up, or meet up virtually through Zoom or Facetime. Talking is still more interactive than texting!
- Read a few pages of your favorite book
- Exercise or meditate

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FROM OUR FAMILIES... TO YOUR FAMILIES

MILITARY SECTION

SIT UP AND TAKE NOTICE: All children of active-duty, Guard and reserve service members can take advantage of Boys & Girls Clubs programs like Mission: Youth Outreach, where they experience high-quality programming and caring mentors.

BOYS & GIRLS CLUBS OF AMERICA: 30 YEARS OF MILITARY PARTNERSHIP

Help your children meet new people, try new things and have fun with the Boys & Girls Clubs of America.

Since 1991, the military services have worked with the Boys & Girls Clubs of America (www.bgca.org/about-us/military) to provide children between ages of 6 and 18 access to Boys & Girls Clubs or Boys & Girls Club-affiliated youth centers in all 50 states and 16 countries worldwide. Whether you are active duty, reserves or National Guard, Boys & Girls Clubs offers free memberships to traditional clubs for geographically dispersed military. Through Mission: Youth Outreach, your child can be involved with high-quality programming (www.bgca.org/programs/all-programs) and caring mentors. Additional fees may apply for Boys & Girls Clubs as well as programs offered at installation youth centers.

The clubs and affiliated youth centers provide:

- *A solid support network that offers a sense of belonging*
- *Ongoing relationships with caring adults*
- *A safe and healthy environment to develop lifelong skills*

ON INSTALLATION

Installation youth centers worldwide are affiliated with the Boys & Girls Clubs of America. In addition to their own unique programming, youth centers offer many of the same programs as traditional Boys & Girls Clubs and are available to more than 450,000 military children. This continuity of programming, such as the Youth of the Year (www.militaryonesource.mil/products/military-youth-of-the-year-fact-sheet-296) and Keystone Clubs (www.bgca.org/programs/character-leadership/keystone) for leadership development, help youth make smooth transitions from installation to installation. Your children and teens can participate in national events and volunteer on the installation or in the surrounding community — in the same clubs and activities — regardless of installation.

OFF INSTALLATION

Families located off installation can also participate in the fun. Active-duty, National Guard and reserve children can attend a local Boys & Girls Club (www.bgca.org/get-involved/find-a-club) for free. That means your children have the same opportunities as on-installation families, with the same benefits and a chance to partake in entertaining, character-building programs.

PROGRAMS

Typical Boys & Girls Clubs (www.bgca.org/about-us/local-clubs) have an arts and crafts area, gymnasium, library, game room and multipurpose room. Some clubs have swimming pools, computer learning centers, camps and outdoor play areas, too. All clubs are staffed by trained professionals. No matter where military youth participate, Boys & Girls Clubs offers specific programs just for them:

- **Education and workforce readiness programs** (www.bgca.org/programs) help children develop goals for the future by providing career exploration and unique educational opportunities. These programs include Summer Brain Gain (www.bgca.org/programs/education/summer-brain-gain), Computer Science Pathway (www.bgca.org/programs/education/computer-science-pathway) and the MyFuture (www.bgca.org/programs/my-future) digital literacy program.
- **Character and leadership programs** (www.bgca.org/programs/character-leadership) offer opportunities for planning and decision-making to help youth become responsible, caring citizens and develop leadership skills to foster a new generation of leaders. Programs include Torch Club (www.bgca.org/programs/character-leadership/torch-club), the Million Members, Million Hours of Service program (www.bgca.org/programs/character-leadership/million-members) and the Keystone Clubs (www.bgca.org/programs/character-leadership/keystone).
- **Health and wellness programs** (www.bgca.org/programs/health-wellness) encourage children to engage in healthy, active lifestyles that nurture their well-being and to set personal goals to improve overall well-being. Programs like SMART Moves (www.bgca.org/programs/health-wellness/smart-moves), Healthy Habits (www.bgca.org/programs/health-wellness/healthy-habits) and Passport to Manhood (www.bgca.org/programs/health-wellness/passport-2-manhood) help develop responsibility, make good choices and engage in healthy relationships.
- **The arts programs** (www.bgca.org/programs/the-arts) provide positive outlets for creative self-expression and help youth foster creativity and develop skills in visual, performing and literary arts. Studies in music, drama and fine arts promote critical thinking, self-discipline, self-esteem, self-confidence and teamwork.
- **Sports and recreation programs** (www.bgca.org/programs/sports-recreation) provide quality, structured sports programming designed to increase opportunities for fitness and positive use of leisure time, build interpersonal skills and reduce stress. Children and teens enjoy golf, baseball and other general fitness programs.

If you are wondering about other unique opportunities through Boys & Girls Clubs, take a look at the Youth of the Year annual event (www.militaryonesource.mil/products/military-youth-of-the-year-fact-sheet-296). Since its beginning in 1947, this leadership program has evolved into a leadership develop program that highlights outstanding military youth who exemplify academic success, strong character and dedication to service – becoming the leaders of tomorrow.

HOW TO PARTICIPATE

All children of active-duty, Guard and reserve service members can take advantage of Boys & Girls Clubs programs. Families living on installation may visit their local military youth center to participate in Boys & Girls Clubs-affiliated programs.

All children of geographically dispersed active-duty, Guard and reserve service members can visit the Boys & Girls Clubs Military Partnership website (www.bgca.org/about-us/military) to search for a club to join near you. Through this partnership, children who do not live near installations may be eligible to receive free membership to their local Boys & Girls Club. Additional fees may apply for transportation, field trips and other supplemental activities. To learn more about free membership through Mission: Youth Outreach, call 404-487-5355 or visit www.bgca.org/about-us/military●

– Military OneSource

DE-STRESS AND RELAX WITH CHILL DRILLS BY MILITARY ONESOURCE

Sometimes the best way to move forward is to pause for a moment to refresh and recharge. Chill Drills by Military OneSource allows you to do that by lowering your stress level wherever you are, whenever you need.

Chill Drills is a collection of simple audio mindfulness exercises to relax the body and mind. The Department of Defense developed these relaxation exercises for the military community and are free to service members and their families via the mobile app or the Military OneSource website.

YOU KNOW THE DRILL: Install the Chill Drills by Military OneSource app on your mobile device, and one touch can take you to expert stress-relieving techniques.

ABOUT CHILL DRILLS BY MILITARY ONESOURCE

Chill Drills by Military OneSource is presented by Heidi J. Bauer, MSW, LCSW, a therapist who works with service members and their families. She developed these guided drills to help create calm by slowing the heart rate, lowering blood pressure and reducing the level of stress hormone in the body.

While each drill was designed to help calm your mind and relax your body, some target common challenges, including back pain, negative thoughts and sleeplessness. Practice your favorite drills regularly to lower your baseline stress level and be better prepared to deal with pressure in the future. The six Chill Drills segments are:

- **Overview.** A brief overview of Chill Drills to help you get ready to relax. www.militaryonesource.mil/products/chill-drills-overview-55
- **Chill Drills 1**: Tuning In. A progressive muscle relaxation exercise to reverse the symptoms of stress. www.militaryonesource.mil/products/chill-drills-1-tuning-in-50
- **Chill Drills 2:** Releasing Stress. A calming drill to rid your mind of negative thoughts by focusing on different parts of your body. www.militaryonesource.mil/products/chill-drills-2-releasing-stress-61
- **Chill Drills 3:** Easing Back Pain. A drill to help you become pain-free by targeting and releasing tension in your neck, shoulders and back. www.militaryonesource.mil/products/chill-drills-3-easing-back-pain-62
- **Chill Drills 4:** Getting to Sleep. A relaxation exercise to listen to in bed to help you fall asleep and improve the quality of your rest. www.militaryonesource.mil/products/chill-drills-4-getting-to-sleep-60
- **Chill Drills 5:** Music to Chill By. A calming soundtrack to help you fall asleep. www.militaryonesource.mil/products/chill-drills-5-music-to-chill-by-63

WHERE TO FIND CHILL DRILLS BY MILITARY ONESOURCE

Chill Drills by Military OneSource is available on Google Play and the App Store. Install the app on your mobile device where one touch can take you to expert stress-relieving techniques, anytime, no internet access needed. You can also listen to Chill Drills on the Military OneSource website, or order a playaway portable media player (www.militaryonesource.mil/products/chill-drills-playaway-158) through the website.

The Chill Drills app is available through Military OneSource, a Department of Defense-funded program that connects the military community to the resources they need to be well, mission-ready and thrive in MilLife, from relocation planning and tax services to confidential, non-medical counseling and spouse employment. Service members and the families of active duty, National Guard and reserve (regardless of activation status), Coast Guard members when activated for the Navy, DOD expeditionary civilians, and survivors are eligible for Military OneSource services, which are available worldwide 24 hours a day, seven days a week, free to the user.•

– Military OneSource

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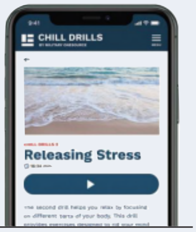

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SMITH

PUZZLES & CAMO SHELLY HUHTANEN

Feelings

Typical emotions people identify as feeling are happy, sad, or angry, but if we are able to dig deeper to identify more specifically what we are feeling, we can begin to explore why and how it affects us and our relationships.

Andy Williams' 1970s song "Feelings" plays in my head as I think about what I've been experiencing this holiday into the beginning of this year, 2022. I understood Jim Gaffigan on CBS Sunday Morning when he stated that he was still trying to wrap his mind around the fact that the year is 2022. Jim and I have something in common. We both have a child graduating high school this year. He describes the moment in kindergarten when, as a parent, you hear, "Here is our class of 2022!" I giggle when I think of that moment at Fort Hood, TX when Hayden started kindergarten at Grace Lutheran. Broden, Hayden's brother, was only three years old at the time, working on potty training. Jim is right. The year 2022 was so far into the future. Weren't we supposed to be transporting ourselves around in flying cars like the Jetsons by 2020?

TEARDROPS ROLLING DOWN: "As I hold my oldest child tighter and experience panic attacks at the idea of him going to college seven hours away from me, I celebrate my son with autism's achievements of becoming more self-sufficient."

Knowing that this Christmas was going to be the last Christmas with both of my children living at home, I continued to try to live in the moment, hoping not to forget any experience, no matter how small. Hayden continued to roll his eyes when I would say, "This will be the last Christmas dinner with you living at home with us," or "This will be the last time you walk downstairs to see what Santa brought you before you go to college." To set the tone, Andy Williams should have been in our living room singing his song "Feelings" as I reminded Hayden of how my heart was bleeding this past holiday.

I've been having more conversations with moms who are either dealing with similar experiences as I am right now or who have experienced it before and who have made it to the other side somewhat still intact. Spoiler alert, apparently, parenting doesn't get any easier when they get older, typical, or with special needs. I'm so glad no one told me this when Hayden was in kindergarten while Broden was still in potty training.

Ignorance is bliss. The more I think about it, I should have worked on some yoga and stayed limber this year, since I will be stretching to try and meet each of my child's needs for growth as one prepares to leave the house and move to college while my youngest is still learning to independently take a shower at 15 years old. Time and time again I'm coming back to the same theme raising my two boys, one who is typical and one who has severe autism. Both are in my world, but seem to be on such different paths as they develop.

As I hold my oldest child tighter and experience panic attacks at the idea of him going to college seven hours away from me, I celebrate my son with autism's achievements of becoming more self-sufficient. I tell Hayden to be slow to anger and think before he speaks, but celebrate when Broden yells, "No!" when he doesn't want to go outside and go for a walk. Christmas evening, Broden didn't like the blanket and pillow we bought him for his room so he dragged them downstairs and threw them on the couch. He then stomped up the stairs. I smiled and thought, "I love how he took the initiative to control his environment! This is progress."

If my typical son would have done that, I would have lectured him about how he needed to be sensitive to my feelings and a simple, "I don't care for this blanket," would have sufficed. My boys are so different, which means the way I interact with them is different. My two boys continue to be on their own paths. Their paths are unique in their own way and I need to recognize that I can't control either of them. I find myself in two different worlds in the same room at the same time.

Brene Brown's new book, Atlas of the Heart was published just for me. Well, this is what I'd like to think each morning as I'm reading it as I drink my coffee. The essence of Brene's new book is that through her research, she uncovered the realization that there are many emotions that people feel, but are unable to identify. Typical emotions people identify as feeling are happy, sad, or angry, but if we are able to dig deeper to identify more specifically what we are feeling, we can begin to explore why and how it affects us and our relationships.

This concept that Brene explored in her new book was revolutionary for me as I enter into this year of transition for my family. I needed to really identify what I was feeling and explore what it is like for me as a mom, wife, friend and daughter raising two boys in two worlds, adventuring out into the world on such different paths. As I nudge Broden to be more independent and practice self-advocacy, I realize that I want this for Hayden as well, but I feel fear. I know that Broden will always need me. I will always have a large presence in his life, but will Hayden eventually stop needing me? If so, I will have to be prepared to accept it. I want Hayden to be independent, and self-confident, but as his mom, I still want him to need me. This is a feeling I will need to continue to explore and eventually find a way to express to Hayden. I want to encourage his independence, but I also want to encourage us to stay connected. I need Hayden to know that staying connected does not jeopardize his independence as a young man as long as he defines his boundaries and I am held accountable to those boundaries.

> "I know that Broden will always need me. I will always have a large presence in his life, but will Hayden eventually stop needing me? If so, I will have to be prepared to accept it."

I will continue to learn from Brene and take the time to try and identify more carefully what I am feeling in the hopes of using that information to steer me on to a path where I can be a supportive mom to both of my boys, no matter where they are on their journey. While living in two worlds, my goal is to continue to stretch, bend and grow while having one hand touching Hayden for connection and one hand on Broden's elbow, encouraging him to communicate and self-advocate for himself. •

PUZZLES & CAMO

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

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